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The Surgeon General's  
Workshop on

[Pt. 1]  
1991

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# INCREASING ORGAN DONATION

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BACKGROUND PAPERS

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Washington, D.C.  
July 8-10, 1991

U.S. DEPARTMENT OF  
HEALTH & HUMAN SERVICES  
Public Health Service

## **ACKNOWLEDGEMENTS**

The Surgeon General's Workshop on Organ Donation was supported by the Division of Organ Transplantation, Bureau of Health Resources Development, Health Resources and Services Administration.

Veretta W. Blake was a much valued consultant to the Division of Organ Transplantation, bringing courage and inspiration to the many lives she touched. Her contribution to the planning and conduct of this workshop was invaluable. Ms. Blake died on January 5, 1992. She will remain an inspiration to her colleagues and friends and she will be dearly missed.

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## **FOREWORD**

The July 1991 Surgeon General's Workshop on Increasing Organ Donation was a response to the critical need for a comprehensive effort to save the lives of thousands of Americans waiting for donor organs to become available. While many concerned individuals and organizations have implemented numerous efforts to increase donation, the need for donor organs continues to exceed their availability. Seven expert panels of workshop participants focused their collective energies and knowledge to propose recommendations and strategies for resolving this perplexing dilemma.

The background papers in this volume, written by some of the leading experts in the field of transplantation, were prepared specifically for the workshop. Collectively the authors have presented state-of-the-art information on numerous topics that affect donation. Recommendations and proceedings of the workshop are presented in a companion document.

It is my sincere hope that the efforts of these authors, the workshop participants, and the activities of all those in the transplantation field who are fighting for this important cause will soon begin to show the positive results that are so vitally needed.

Antonia C. Novello, M.D., M.P.H.  
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## **Abbreviations**

<b>AATB</b>	<b>American Association of Tissue Banks</b>
<b>ABTC</b>	<b>American Board of Transplant Coordinators</b>
<b>ACT</b>	<b>American Council on Transplantation</b>
<b>AHA</b>	<b>American Hospital Association</b>
<b>AOPO</b>	<b>Association for Organ Procurement Organizations</b>
<b>ASHI</b>	<b>American Society for Histocompatibility and Immunogenetics</b>
<b>ASTP</b>	<b>American Society for Transplant Physicians</b>
<b>ASTS</b>	<b>American Society for Transplant Surgeons</b>
<b>CDC</b>	<b>Center for Disease Control</b>
<b>DHHS</b>	<b>Department of Health and Human Services</b>
<b>DOT</b>	<b>Division of Organ Transplantation</b>
<b>EBAA</b>	<b>Eye Bank Association of America</b>
<b>ESRD</b>	<b>End Stage Renal Disease</b>
<b>HCFA</b>	<b>Health Care Financing Administration</b>
<b>HHS</b>	<b>Health and Human Services (Department of)</b>
<b>HIV</b>	<b>Human Immunodeficiency Virus</b>

<b>HRSA</b>	<b>Health Resources and Services Administration</b>
<b>IHS</b>	<b>Indian Health Service</b>
<b>MOTTEP</b>	<b>Minority Organ/Tissue Transplant Education Center</b>
<b>MHC</b>	<b>Major Histocompatibility Complex</b>
<b>NATCO</b>	<b>North American Transplant Coordinators Organization</b>
<b>NIH</b>	<b>National Institutes of Health</b>
<b>NKF</b>	<b>National Kidney Foundation</b>
<b>OPO</b>	<b>Organ Procurement Organization</b>
<b>OPTN</b>	<b>Organ Procurement and Transplantation Network</b>
<b>PHS</b>	<b>Public Health Service</b>
<b>RFC</b>	<b>Request for Contract</b>
<b>RFP</b>	<b>Request for Proposal</b>
<b>SEOPF</b>	<b>South-Eastern Organ Procurement Foundation</b>
<b>TRIO</b>	<b>Transplant Recipients International Organization</b>
<b>UNOS</b>	<b>United Network for Organ Sharing</b>
<b>USRDS</b>	<b>United States Renal Data System</b>

# **SURGEON GENERAL'S WORKSHOP ON INCREASING ORGAN DONATION**

## **INTRODUCTION**

### **Historical Perspective on Organ Transplantation and Donation**

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Successful organ transplantation is one of the many medical miracles that have occurred in our extraordinary century. The dream is ancient. The well-known story of Cosmos and Damian, the martyred twin physicians who replaced the gangrenous limb of a white sacristan with that of a dead Moor, is visually recorded by many artists. However, it was not until the 1900s that scientifically documented attempts at organ replacement were made, and not until the last half of this century that success was achieved.

Although there was much faltering along the way, continuous advances in surgical technique, preservation, immunosuppression, and control of infectious diseases have now made success routine, so much so that the demand for human organs far exceeds the supply. This shortage has prompted a resurgence in xenotransplantation research (1), an avenue with the potential to lead us full circle. The first recorded organ transplants in humans (during the first quarter of the century) were from animal sources (2). All failed immediately. With a few exceptions (3), so did subsequent transplants from human donors until the landmark identical twin cases carried out at the Brigham Hospital in Boston during the mid-1950s by Murray, Harrison, Merrill, and associates (4).

Cadaver kidney transplants, however, continued to fail, as did most nonidentical twin related donor transplants, until the introduction of chemical immunosuppression in the 1960s (5). When azathioprine and steroids were used together, reversal of rejection episodes and long-term graft function became possible (6), feeding the stream that grew into the torrent we see today.

The sequential introduction of more effective immunosuppressants (polyclonal antilymphocyte preparations in the late 1960s and 1970s (7,8), and cyclosporine (9,10,11) and monoclonal antibodies (12) in the 1980s) were associated with

continuous improvement of results. By the early 1970s, well organized transplant teams were in place in several institutions, reimbursement for kidney transplants was assured by Medicare, and liver and heart transplants were beginning to be successful through the pioneering efforts of Starzl, Calne, Barnard, Shumway, and others (13-16).

In the 1980s extra-renal organ transplantation came into its own, with a success rate similar to that of cadaveric kidney transplants (17). By 1990, pancreas transplant results were also similar to that of the other organs (18).

The number of candidates for transplants of all organs dictates long and sometimes futile waits. Xenotransplantation has not yet become clinically applicable. There is a shortage of donors from closely related species (where success can be achieved in animals), while preformed natural antibodies against the more abundant but distantly related species remain an impenetrable barrier. Although these problems may be solvable and warrant vigorous investigational efforts, it is almost certain that during the next decade clinical transplants will still require human organs. Therefore, vigorous efforts are needed to increase their supply.

The history of organ donation is complex. As mentioned, the first successful kidney transplants were from living related donors. Although generally accepted as a legitimate act of altruism in the United States, there is still controversy over, and discomfort with, violating the medical imperative "primum non nocere" -- first do no harm (referring to the donor, of course). Variations in the prevalence of this attitude are reflected by the different rates that living related donor transplants are performed throughout the country. Historically, living related donors were successful because a fresh, undamaged kidney that would function immediately was available, and the close genetic matches mitigated against rejection during a time when the immuno-suppressive armamentarium was less than it is today. Nevertheless, it was apparent early on that it would be necessary to transplant cadaver kidneys to meet the needs of patients with end stage renal disease.

Many of the first cadaver organs were procured from individuals who were unable to come off the pump during open heart surgery, and the kidneys were removed during circulatory and respiratory support. The use of respiratory support systems for individuals with brain damage ultimately led to the concept and definition of "brain death." Formalizing criteria for brain death was necessary both to manage this tragic situation and to allow removal of organs for transplantation in the presence of circulatory and respiratory support. The publication of the Harvard Brain Death Criteria in the late 1960s (19), passage of legislation on the Uniform Anatomical Gift Act, evolution of relations between transplant centers and a network of hospitals and neurosurgeons who would identify brain dead cadaver donors, and employment of nurses designated specifically to coordinate the donation process, resulted in the process by which procurement of cadaver organs

became a standard procedure throughout the country by the early 1970s. Ad hoc sharing arrangements were made, organ procurement foundations (e.g., the Southeast Organ Procurement Foundation) and organ banks (e.g., Midwest) emerged. By the 1980s, about 2000-3000 brain dead cadavers per year were utilized for organ transplantation.

The passage of the National Organ Transplant Act in the mid-1980s led to the creation of the United Network for Organ Sharing (UNOS), standardizing and formalizing organ procurement agencies throughout the country. Most of them served more than one transplant center. There was hope that this kind of organization would, by itself, lead to an increase in organ donation, a hope which unfortunately was not fulfilled. About 4000 donors per year have been registered with UNOS from their inception (1986) through the end of the 1980s. Studies by Bart, et al (20) in the early 1980s indicated that the potential for organ donation greatly exceeded actual achievement. In two areas of the United States that he surveyed, only one in six brain dead cadavers were used. Whether the figure is similar today is not yet known, but new studies are under way. Some cadavers used in 1980 might not be used today, e.g., those with histories placing them at risk for HIV. Tests for HIV or hepatitis C were not available in 1980 but they are today, leading to further (and appropriate) exclusions. Thus, the proportion of cadavers that would be classified as suitable today may differ from the number judged suitable at the time of the Bart study. What is certain is that the number of cadavers used for donation is substantially less than the potential, and the need to increase cadaver organ donation is pressing. The potential to increase living related donation also exists. Strategies to increase donation are intertwined with ethical, financial, racial, demographic, and other considerations. It is to discuss and explore these issues that the Surgeon General's Workshop is convened.

Over the years many conferences have been held on the many issues involved in organ donation. The first was sponsored by the CIBA Foundation in 1965 (21). The extraordinary document that emerged from that conference contains discussions touching on virtually all the issues that are still of concern to us now, including living donation and the concept of brain death (the term being first used at this conference) in cadavers that allows organs to be removed while still under respiratory support. The issues raised then continue to be debated and many examples of such debates can be cited (22,23).

The most recent conferences specifically devoted to donor issues include one held in Munich in December 1990, entitled "Commerce, Ethics and Justice in Transplantation." Another, sponsored by the National Kidney Foundation (NKF) in February 1991 was entitled "Controversies in Organ Donation." The latter was designated as a consensus conference and, after intense discussion, issued statements on living donation, financial incentives, presumed consent, and minority donation. (All participants in the Surgeon General's Workshop should be familiar

with the consensus statements from the NKF Conference.)<sup>\*</sup> In this instance, "consensus" does not imply complete agreement on all the issues raised, but rather gives an indication of the evolved thinking of experts over the last 25 years.

However, in general, everyone agrees that efforts are needed to increase the supply of human organs. Difference of opinion involves only the means, not the ends.

The purpose of this introduction is not to expand on the background papers for the workshop, since the papers themselves were designed to be comprehensive. The first set of papers all address the issue of how to increase donation by focusing on the individual. Campaigns that reach the general public are needed. In the final analysis, it is education that will lead to positive attitudes toward organ donation. Educational efforts must be tailored toward the various socio-economic and cultural groups that exist in this country. This will be particularly important for increasing donations among racial groups who are disproportionately affected by the diseases for which transplantation is the optimal therapy. For example, blacks comprise only 12 percent of the total United States population, but they constitute 30 percent of patients on dialysis waiting for a kidney transplant. There has been much publicity about the fact that blacks have received less than 30 percent of cadaver donor kidneys (24). This is, at least in part, attributable to the fact that kidneys are distributed according to HLA matching; 92 percent of cadaver kidneys procured in the United States have come from non-black donors, making a match less likely. Efforts to increase donation among blacks are being made, but we clearly cannot expect organ donations greater than their proportion in the population. Distribution of organs must be made equitable without having a negative impact on transplant results. Ultimately the goal should be to improve anti-rejection strategies so that HLA matching becomes less important. Distribution could then be on a basis other than the chance inheritance of certain HLA antigens.

The second set of papers discusses how to increase donation by focusing on the health care environment. Besides regulatory issues, education of our professional groups is also needed. Impediments to donation do not always spring from the attitudes of the families of potential donors, but from environments where donation is not even discussed. Professional attitudes can make a difference.

A third set of papers discusses donor criteria. The criteria for being a donor have become more stringent - and appropriately so - with regard to assuring against transmission of diseases such as HIV or hepatitis C. On the other hand, criteria for being a donor could be more liberal in regard to factors such as age. Arbitrarily

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<sup>\*</sup>Available on request from The National Kidney Foundation, Inc., 30 East 33rd Street, New York, NY 10016; (800) 622-9010.

chosen exclusion criteria need to be examined scientifically. The very important issue of using non-heart beating cadaver donors is also addressed. Most deaths occur with the cessation of heart beat. Can the logistical aspects be solved to make these cadavers also sources of organs? These considerations involve legal and ethical issues. Presumed consent might be necessary for use of non-heart beating donation to be possible.

Finally, the use of living unrelated as well as related donors is discussed. Some of us feel that the use of living donors is justified only if the results are superior to those of cadaver donors, while others think that the use of living donors is justified if the results are at least equal, as long as there is a shortage of cadaver donors. Not using living donors is to deny someone a transplant, and why should the results have to be superior to justify their use? Thus, the debate goes on.

In summary, this workshop brings together all the groups and disciplines that are necessary to make transplantation the highly successful enterprise it is today. The challenge now is to expand the enterprise through increased donations, so that all who could benefit from transplantation will benefit.

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# **MOTIVATING THE PUBLIC: APPLICATION OF LESSONS LEARNED TO INCREASING ORGAN DONATION**

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## **INTRODUCTION**

The understanding of how to influence individual behaviors and societal norms has increased dramatically over the past 20 years. Social and health change agencies, marketers, and political image makers now use far more sophisticated techniques and technologies. As a result, strategies designed to influence, or "manipulate," are increasingly successful. And competition for the public's attention and interest is fierce. The opportunity exists for the organ donor community to take advantage of these advances in techniques and technologies.

Although the issue of organ donation is unique in many ways, there are some factors inherent to educating and motivating the public that transcend the subject matter. Some of these have emerged from behavioral, communication, and educational research. Others have arisen through trial and failure--lessons learned through Federal and other programs designed to produce behavioral change. The behavioral intent of these programs ranges from the relatively simple (immunization), to complex and difficult (breaking nicotine addiction). Others require individuals to confront their own vulnerability to disease and death (wearing condoms to prevent AIDS; seeking early detection of dreaded cancers). Beyond a lack of awareness and needed skills, many of these programs also have had to confront issues of denial, distaste, cultural taboos, and breaking with closely held traditions. There are many examples to prove that such change is difficult; there also is evidence that change is possible.

The purpose of this paper is to provide background information and to identify issues related to the potential value of educational campaigns to increase organ donation. This paper consists of four sections: the implications of selected theories, models, and disciplines for organ donation programs; recommendations emerging from analytic studies of mass media and other communication programs and community-based research; selected case studies demonstrating different approaches to motivating behavior change, and lessons learned from these programs; and recommendations for the design of a program to increase individual and social support of organ donation.

## **THE APPLICATION OF MODELS, THEORIES, AND DISCIPLINES TO MOTIVATING ORGAN DONATION**

Programs designed to promote behavior change are based on a number of models, theories, and disciplines. Behavioral change models and theories outline the complex process of individual change; diffusion theories explain how change moves through society. Other models examine the factors that ease or block this process.

For example, trial of a new behavior, such as family discussion and acceptance of organ donation intentions, follows awareness, understanding, interest, acceptance, personalization, and decision making related to the issue (1). The behavior change begins with awareness and requires that an individual proceed through this series of stages that culminates in behavior trial and change. Strategies to motivate behavior change must address each of these stages in turn, as the individual progresses toward the behavioral goal.

Public awareness of organ donation, which is very high (2), and favorable attitudes toward donation, also widespread (3,4), are only the beginning. Public response to the need for donated organs is still minimal. In 1987, Gallup reported that only 20 percent of those aware of organ transplants (84 percent of adults) had completed an organ donor card (2). For an individual to take positive action, he or she must become interested in organ donation, be convinced not only of its value but also of personal relevance, and know what to do about it. According to several studies, the public is still ambivalent about organ donation (2,3,4).

For organ donations to increase, there must be a supportive environment, in addition to acceptance and action by individuals. No one acts in isolation. If a person chooses to act, there must be positive support for that action to "take." That requires a positive family response to raising the issue of prospective donation, family acquiescence at the time of donation, and health system support and utilization of the decision (1). Therefore, increasing organ donations will require strategies that extend beyond educating and motivating individuals. Concomitant strategies to assure that social support and health system support exist to reinforce individual decision making also are necessary (5).

A large body of literature examines the diffusion of innovations, and how these new ideas (innovations) affect individuals (their knowledge, attitudes, and behavior) and social systems. Diffusion studies (6) look at what happens to an innovation such as donating organs. Whether the innovation is accepted (the new behavior adopted) depends upon whether individuals perceive it as beneficial, see it as in accordance with their needs and values, find it easy or difficult to understand or adopt, try the behavior, and find peer acceptance of it (6).

Information about an innovation can be communicated in different ways: through the mass media; community routes (e.g., schools, employers, religious institutions); or through interpersonal contact (e.g., family, friends, teachers, health care providers). Different means of communication are appropriate at different stages of the adoption process. For example, the mass media reach broad audiences quickly, an effective way to introduce new information or influence public attitudes. Community routes may be more credible. And, at the point of trial, interpersonal discussions are more influential (6). This means that a combination of the use of mass media to increase public understanding and support of organ donation with the credibility of community programs and interpersonal communication to provide motivation, skills, and support, is more likely to increase public response to organ donation than the use of mass media alone.

Communication of all types plays a necessary but not necessarily sufficient role in producing societal change. Other factors such as community linkages, regulations, social support, and incentives have an effect on the rate of acceptance of innovation (7). Some of the factors that are influential in facilitating or blocking behavior changes include an individual's knowledge, attitudes, behavior, beliefs, and values that affect willingness to change; the structure of the environment (community) and an individual's situation that facilitates or presents obstacles to change; and the positive or negative effects of adopting the behavior (including social acceptance and support) (7). For organ donation, an example of a barrier is religious beliefs that may predispose an individual against donation. One structural ("environmental") barrier might be a lack of clear hospital policies about organ donation, or lack of health care provider knowledge of the policies. Convenient access to donor cards is one example of a factor that can facilitate a behavior change.

Research indicates certain predictable patterns lead to large scale behavior change. The behavior change moves through a population in "waves," as adoption occurs first among "innovators," then "early adopters."

A new behavior is first adopted by a small segment of the population (who are referred to as "innovators"), and then by "early adopters" (8). These two segments of the population are likely to be well educated, affluent, and keyed into emerging trends through the media and in other ways. They are the individuals who are most likely to be able to "afford" change, both psychologically and financially. Organ donation appears to be attracting this population segment: those most likely to donate are white, younger, more educated, and more affluent (2,4).

It is the subsequent adoption of new behaviors by the "early" and "late majority" that transforms the idea or behavior from an innovation to the social norm. Organ

donation has yet to reach this status. This middle, majority group tends to respond to interpersonal influences as much as or more than the mass media -- another indication that a combination of motivational strategies is called for at this point (6).

The remaining population segment, "late adopters," are those individuals who lag farthest behind in change. Often referred to as the "hard-to-reach" within the public health community, this group is more likely to be socially or economically disadvantaged, underserved and/or isolated (8). While many public health programs target this last, most difficult to influence group, organ donor efforts should first seek to persuade individuals who are more likely, rather than less likely, to participate.

Health education (8) and social marketing (9) both call for careful delineation of target audiences, and a thorough understanding of the individual and the community systems that either support or block change. Behavior change strategies must appeal to what the target audience perceives as needed, valued, and desired, and must be modified to be appropriate for different population groups. Building strategies on the intrinsic value of organ donation, or the "public good," is not likely to be perceived as personally relevant for most people.

Health education strategies follow a continuum that culminates in behavior change and reinforcement to perpetuate that change. Because health education programs target different population groups and a range of precursors to change, a planned mix of methods and strategies is employed. Intermediate strategies leading to a goal of behavior change address what must occur as prerequisites. For organ donation, as for many other behavior change issues, interactions between (at least) several people are required for the goal to be met. This suggests that there should be coordinated strategies that target the different groups that must act for change to occur. For example:

- the potential donor, because expressing one's desires to donate to family members, and signing a donor card, may increase the likelihood that a family member will later agree to the donation (2,3,4).
- bereaved family members, because donation depends, in most cases, on the action taken by a family member at the time of death.
- the health care provider, because the donation transaction depends upon the capacity of the system to respond.

Programs addressing each target group require very different activities, routes of communication, and messages.

Social marketing practice has been broadly adopted by health and social change agencies over the past 20 years. In addition to target audience segmentation, it advocates the use of market research, message (product) testing, identifying and addressing barriers and opportunities for change, planned communications, and the use of incentives and/or the demonstration of benefits to stimulate acceptance of behavior change (9). The focus for developing effective motivational strategies is on identifying and relating to the needs, wants, and values of the target population, rather than on the intrinsic values of the behavioral goal.

A recent turn-about in the commercial marketing field is "guerilla marketing" (10). Guerilla marketing takes into account the vast number of advertising messages bombarding consumers, especially through the mass media, and the proliferation of mass media choices that have become available to consumers in the past few years. This multitude of media choices has made reaching consumers through the mass media more of a challenge. Therefore, guerilla marketing offers a broad range of "new," creative, non-media opportunities to expose consumers to marketing messages, such as point-of-purchase (ads on grocery carts), promotion at events (health fairs), or at other sites (product sampling at malls). Many of these "nontraditional" methods have been the mainstay of nonprofit programs over the years, especially community-based programs with small budgets and no option to buy mass media time or space. Seasoned marketers recognize that there is intense competition for the public's attention, that message repetition through many media carries the best chance of breaking through the information "clutter," and for repetition to work, the message must be the same no matter the medium. These lessons are as important for increasing attention to organ donation as for other topics (9).

It also is useful to review how public relations influences public opinion about an organization, a program, or an issue. An informed, supportive public is the first step toward increasing the number of organ donors. Public relations strategies are designed to influence the public to support an issue, program, or organization. Its practitioners continually monitor public knowledge and attitudes, recognizing that public opinion is subject to continuing shifts, and that public perceptions of an issue are not automatically accurate, or supportive, even if an issue is intrinsically "good" (11). Public relations strategies that can influence public opinion include actively seeking, in a planned way, to attract positive attention for an issue such as organ donation, to build confidence in the sponsor (organization), to lend credibility to the issue, and to gain governmental cooperation, or influence policies and laws, as well as gain public support.

One final field, health communications, is founded on a combination of behavioral and communication sciences, health education and social marketing. Health communications, as practiced by U.S. Public Health Service (PHS) and other national agencies, extends beyond information dissemination to include a variety of

proactive strategies. Generally, these programs focus on what communications can contribute to broad health and social issues, including to:

- raise awareness
- increase knowledge
- influence attitudes
- demonstrate benefits of behavior change
- reinforce knowledge, attitudes, and behaviors
- demonstrate skills
- suggest an action
- increase support and or demand for services (12).

Because communications strategies alone usually are not sufficient to produce behavior change, these programs are frequently components of interventions that address other contributing factors. One example, the National High Blood Pressure Education Program, is included as one case study in this paper.

Several PHS agencies include "media advocacy" as one of several communication strategies. Media advocates focus on using the mass media as an arena for influencing social and public policy (13). Very often, media advocacy messages and strategies are designed to negate a nonsupportive or opposing force. Media advocacy can be used to promote a point of view, and frequently is used to counter alcohol and tobacco advertising and marketing. Media advocacy also can be used to identify and counter misleading information. This attention-getting, confrontational approach is generally paired with more positive public relations strategies that are designed to seek media cooperation, and to prevent, or lessen, negative media coverage, including misinformation.

Behavioral, communication, and other change theories and models, as well as relevant practices, provide guidance for increasing organ donation.

1. Public awareness of organ donation is clearly insufficient to produce an increase in donations. Knowledge, attitudes, interest, social support, and skills must be increased to motivate organ donation.
2. Behavior change is the final stage in a continuum that begins with awareness. To motivate behavior change, each stage in the process must be addressed. Affecting changes in knowledge and attitudes is a prerequisite to behavior change, but is not sufficient to cause change.
3. Effective motivation begins with the identification of each target group (e.g., individuals matching the profile of most likely donors) and designing strategies based upon that group's values, needs, and desires, rather than broader perceptions of organ donation as the "right thing to do."

4. Market research is necessary to understand what will motivate a specific population group, what barriers to organ donation must be addressed, and how best to reach a target group with an organ donor message.
5. Appeals based on research findings should be tested with the target audience to assure relevance to their perceptions, values, and interests.
6. Tracking the public's knowledge, attitudes, and behaviors also is needed to assess whether and what changes are occurring, and to permit modifications to motivational strategies as public views change.
7. For organ donation rates to increase, multiple target audiences (e.g., the potential donor, family members, health care providers) must be addressed, motivated, and provided with the skills and services needed.
8. Change strategies are needed to increase social support for organ donation and decrease institutional barriers. Strategies directed at individual behavioral change alone are insufficient to increase the supply of donated organs.
9. Planned strategies and consistent interaction with the mass media are needed to increase supportive media coverage and decrease negative images and misinformation, and reduce the attitudinal barriers that these create.
10. For organ donation to be repositioned from an "innovation" to a social norm, a combination of mass media, community, and interpersonal communication strategies is needed.

In practice, the application of these theories and models does appear to strengthen program effectiveness. The next section reviews how this application works.

## **CONCLUSIONS REGARDING THE DESIGN OF MOTIVATIONAL PROGRAMS FROM SELECTED STUDIES**

Summarized here are the findings from five selected analytic studies that cumulatively reviewed dozens of communication and/or motivational and behavior change programs focussing on a channel (mass media), or a topic (smoking, safety belts), or audience (youth). Several of these studies included extensive interviews with diverse experts. The conclusions reported here were commonly reached by most of these researchers. Each reported many additional findings not included here, but yielding a rich source of information for planning behavioral change programs (14,15,16,17,18). Also summarized are the findings from the landmark Stanford Three City Study (19).

## **The Role of the Mass Media**

Uses of the mass media (television, radio, newspapers, and magazines) include public service announcements (PSAs); news; message placement in entertainment programming and films; production of television programming; paid advertising; and publishing targeted magazines. Other options include newspaper supplements, editorials and letters to the editor, media-sponsored events, and call-in talk shows.

One author concludes that the "...mass media can play an important but limited role" (14). Among the functions that the mass media can serve is helping establish awareness and knowledge of an issue, or helping establish broader school and/or community-based programs (e.g., by raising public awareness of a program, helping to recruit volunteers, promoting materials and events, reinforcing educational messages, and generating support for changes in public policy). The mass media also can stimulate interpersonal discussion and information seeking behavior.

Therefore, these authors see mass media strategies as one component of broader programs designed to influence change. However, they point out that the use of the media is vital to introduce a new program, quickly raise awareness, knowledge, and interest among the population; coalesce organizational interest to expand community-based involvement; influence public attitudes and maintain public and leadership support, and reinforce interpersonal and community-based behavior change strategies.

## **Planning a Campaign**

A number of conclusions have been drawn about what makes a motivational campaign effective. These conclusions address issues of theoretical foundations for programs, planning and evaluation considerations, program context and program duration.

Programs that utilize the principles of behavior change are likely to be more effective, as are those that set realistic goals based on what a campaign can be expected to accomplish. A social marketing influence is present in these more successful campaigns, which focus on carefully selected target audiences and use market research in planning. In addition, these programs use other formative evaluation methods including materials pretesting with target audiences. Tracking and other evaluation methods also are used to monitor progress and demonstrate results.

One aspect of successful planning is the inclusion of key "power figures" and groups. Advantages to this approach include access to a broader resource base, a broader base of program support, and continued support. Including key leaders

and groups also is essential to assure consistency on the same topic; to address social, community, and institutional factors that interrelate to the success or failure of the campaign; and to access the expertise of professionals from many disciplines. Establishing linkages with community-based organizations, the health care delivery system, and governmental agencies also is an important contributor to success.

Timing is another key campaign planning factor, including timing program release to avoid conflicts with similar or competing events. These authors recommend planning for the long term, with intermediate objectives that contribute to an ultimate behavior change goal. They also note that it is not realistic to expect changes as a result of brief interventions.

### **Designating Target Audiences**

The era of designing campaigns for the general public is long past. Segmenting broader populations into narrower groups (target audiences) and basing program design on knowledge of these groups is now the norm. Target audiences most often are the individuals among whom the behavioral change is sought, but those who can influence the primary target group(s) also should be considered as targets. These "influence agents" might include parents, friends, employers, or physicians. Segmentation into groups solely by demographics is not considered to be as effective as also considering psychosocial variables. For organ donation, for example, people who are more materialistic appear to be more likely to consider their organs as central to their self image (3). Target audiences are prioritized according to their potential for affecting the issue, accessibility, likelihood of change, and ability to influence others.

Campaign objectives and strategies may vary for each group targeted. Communications routes may also differ, depending upon the lifestyles and habits of each targeted group.

### **Developing Motivational Messages**

A number of integral factors contribute to the effectiveness of a message, including credibility, appeal, personal relevance, and intent. Messages that are based on the target group's knowledge, attitudes, values, and behavior, that are tested, and that offer a direct benefit, are more likely to be effective.

Style and production quality are important for attracting attention to a message. Celebrities also can be helpful in attracting attention, but these authors caution that celebrities also may not be perceived as credible or relevant to the target group's personal experience, thereby detracting from message effectiveness.

Target audience perceptions about the credibility of a spokesperson or message sponsor affects message acceptance. People tend to trust sources similar to themselves, one reason why testimonials by individuals from the target group often are compelling.

In addition to testimonials, these authors review other kinds of message appeals. Rational appeals are most effective when used to respond to an acknowledged need, and with more sophisticated audiences. Emotional appeals are often more motivational, especially for individuals who have not acknowledged a need. Threats of harm (moderate fear appeals) can motivate; strong fear appeals can produce rejection of the message. Fear works best when the message includes a simple action that can alleviate the anxiety, when the target audience does not perceive themselves as vulnerable, and when the source of the message is very credible. However, the appropriate use of fear remains controversial and these authors generally caution against its use.

Rather, they urge the use of more positive appeals such as the rewards of taking an action as opposed to the consequences of not doing so. Emphasizing immediate, personal rewards and benefits is seen as more relevant to most people than more distant, intangible effects. For organ donation, some studies have suggested that patients may be more likely to donate when appeals are based on benefits to them, rather than to others (3). These authors also recommend the use of incentives that build on the existing motives, needs, and values of the target group.

There are two important criteria for messages to motivate: the message must be effective -- that is, be clear, comprehensible, appealing, relevant, and motivational to the target audience. And the target group must be exposed to the message.

### **Promoting the Campaign**

Repeated exposure to a message generally increases its effects with the targeted population. Exposure to a concentrated cluster of message repetitions appears to work better than dispersion over a longer period of time.

Different mass media (television, radio, newspapers, magazines) attract different audiences, with television attracting the broadest audience and radio tending to attract more specific kinds of listeners. The choice of media format (print or broadcast) and outlets should match the message purpose and the media habits of the target population. Different people have different media habits (such as preferences for television over radio, or prime time over afternoon viewing). Public service announcements (PSAs) alone generally are not effective in bringing about behavior change; they must be combined with other approaches. The authors recommend using multiple media outlets, in combination with promotion through

community, small group, and individual activities. The authors also recommend considering selected purchase of media time and space, developing an understanding of, and personal, ongoing relationships with the media. Localizing the issue to relate to the needs of the community also is viewed as important.

### **Other Findings**

Many of the campaigns reviewed by these authors were federally-sponsored. Others were sponsored by national nonprofit organizations, and still others were community-based. Several authors offered additional observations about Federal campaigns.

Many Federal programs with limited resources have chosen a highly visible, agenda-setting, nationwide, ongoing mass media program as the most appropriate contribution to an issue. This can be an effective strategy when the mass media campaign is backed by collaboration with other organizations better positioned to offer leadership and services within the community. An example of this approach is included as a case study in this paper (Office on Smoking and Health).

In other cases, Federal agencies have positioned a mass media campaign as a "quick fix" to a public health problem or response to an issue. Characteristics of these programs include insufficient planning; political pressure (to respond quickly, use specified messages, and/or to use a political figure in the campaign); unrealistic expectations (for example, behavior change) of mass media programs by leadership or policy makers; inadequate resources and short term commitments. These are characteristics that contribute to failure.

Other shortcomings of public service campaigns observed by these authors include a small number of PSAs, of uneven quality, and scattered exposure. They note that PSA campaigns can be effective given certain conditions, including effective messages, widespread usage, high saturation, and endurance.

### **Findings from Community-Based Research**

In addition to the findings from analytic studies, it is important to note the comparable findings from landmark community-based research. The Stanford Three Communities study, conducted in the 1970s, demonstrated that the use of the mass media could positively affect the health of a community, and that a combination of mass media, interpersonal contact and social support is even more effective. In one community, where only mass media was used to communicate how to reduce personal risks of cardiovascular disease, a 17 percent reduction in the targeted risk factors (smoking, blood cholesterol, blood pressure, and weight) was noted. In a second community a more intensive intervention was undertaken,

adding personal instruction about risk factor reduction and strategies to increase social support to mass media messages. In this community, a 30 percent reduction in cardiovascular risk factors was found in one subpopulation. In a third community where there was no program, measures of risk factors found a 6 percent increase (19).

Follow up community-based research and demonstration field trials have been sponsored by the National Heart, Lung, and Blood Institute for the past 10 years (the Stanford Five City Study, the Minnesota Heart Health Program, and the Pawtucket Heart Health Program). These programs blend principles from health promotion, psychology, community theory, and social marketing, and all are designed as behavior change models. Some of the multiple strategies used by these community programs that have broad applicability include the involvement of community leaders and organizations; use of incentives and environmental change strategies; health professional education use of programs easily adaptable to fit the interests and needs of a specific target group; the use of volunteers for community acceptance and cost effectiveness; and media partnerships with media outlets, business, and the medical/insurance community (20).

### **CASE STUDIES: APPLICATION OF LESSONS LEARNED**

To illustrate how the theories, models, and applied research findings summarized here have been incorporated into national programs, six case studies are described:

- The National High Blood Pressure Education Program -- which serves as a model for many other health behavior change programs.
- The National Eye Health Education Program -- a new program that is applying lessons learned from the high blood pressure model.
- The Office on Smoking and Health mass media program -- an example of effective use of limited educational resources.
- The National Highway Traffic Safety Administration (NHTSA) passenger safety programs -- a model that includes information, education, legislation, and enforcement strategies.
- The Healthy Mothers, Healthy Babies and Healthy Older People Coalitions -- two health promotion programs that chose coalition building as the primary focus.
- The National Blood Donor Experience -- a review of parallel issues with relevant lessons about what motivates donors.

## **A Long-Term Multifaceted Approach -- The National High Blood Pressure Education Program**

By 1972, results had accumulated from several clinical studies showing that reducing high blood pressure reduced the risk of cardiovascular disease. Congress passed the National Heart, Blood Vessel, Lung and Blood Act, which called for (among other things) providing risk reduction information for the public and health professionals (21).

As one result, the National High Blood Pressure Education Program (NHBPEP) was established as a cooperative program between the National Heart, Lung, and Blood Institute (NHLBI), one of the National Institutes of Health, and other national health-related organizations. A coordinating committee now consisting of representatives of more than 35 national voluntary, professional, and public health agencies was established. Nearly 20 years later, the program continues to follow a program development process based on consensus-building. The program includes three interrelated components -- a health care provider program, a mass media program, and community-based activity models.

For the mass media program, the target audiences and messages change as changes in knowledge, attitudes, and behavior occur. Messages and motivational strategies are based on communication research and extensive pretesting. Public service announcements and media programming are developed for community "tagging" (identification) and ongoing news media relations promote coverage to keep high blood pressure visible to the public (22). About \$900,000 is budgeted for the mass media components of all NHLBI programs each year, with NHLBI staff support of two professionals (23).

Almost 20 years after this program started, nearly everyone knows that high blood pressure increases the risk of heart disease (91 percent) and that it cannot be cured, but can be controlled by staying on treatment (92 percent). More important, the age-adjusted stroke mortality rate has declined by more than 52 percent since 1972 (22).

### **Replication of NHBPEP -- The National Eye Health Education Program**

The National Eye Health Education Program is an example of how the NHBPEP model is being applied to another health issue. The National Eye Institute is another of the National Institutes of Health. In fiscal year 1988 new language in the National Eye Institute's (NEI) appropriation from Congress called for a large-scale national public and health professional education program, and designated approximately \$1.5 million per year for this purpose (24).

In 1989, the Institute sponsored a national planning conference bringing together representatives from 35 public and private sector organizations to set priorities for information and education related to two designated eye health issues: diabetic eye disease and glaucoma. Conference participants recommended target audiences needs and priorities, as well as information and education strategies to meet these needs. These groups have since agreed to become part of the National Eye Health Education Program (NEHEP) Partnership to establish an ongoing, interactive relationship between the NEI and other organizations concerned with eye health (25).

The NEI coordinates the Partnership program, and facilitates communications between the Partnership members; develops and distributes mass media and other materials; and identifies program strategies and policies. The Program "belongs" to the NEHEP Partnership -- health professional associations, voluntary, health, civic, and other public sector organizations. These organizations provide endorsement, resources, and linkages to community-level health care providers and organizations to promote eye health messages. Drug companies, equipment manufacturers, and other corporations also are being invited to participate.

An advisory committee representing the Partnership members reviews all draft messages for accuracy and appropriateness, and a formal health communications model (26) is followed to plan, test, implement, and evaluate the program.

In early 1991, the NEHEP again sponsored a national conference to share the results of target audience research, to introduce plans for the release of results of a national public knowledge, attitudes, and behavior baseline survey cosponsored by one Partner (Lions Clubs International), and to seek endorsement for prototype materials for national mass media campaigns and health education programs with community support. Recommendations of the Partnership members are being incorporated into the program, and long range strategic planning has begun (24).

#### **Use of the Mass Media -- The Office on Smoking and Health**

The Office on Smoking and Health (OSH), Centers for Disease Control, serves as the focal point for Federal tobacco control activities. One significant function of the Office is the communication program, mandated by 1984 legislation. A staff of four is responsible for press relations, mass media campaign development, development of other educational materials, marketing and distribution, and public inquiry response; in addition, an advertising agency contract averages about \$700,000 per year (27).

A number of organizations have a long history and an established role in tobacco control. Therefore, the challenge to OSH was to carve out an appropriate, effective, and affordable communication function. Because no national agency

was committed to maintaining a relationship with the mass media on this topic, OSH chose this function.

Plans for new campaigns are reviewed by representatives of national agencies and organizations with an interest in tobacco control and State health departments. The Office frequently co-produces public service announcements (PSAs) and related materials for distribution by other national organizations or Federal agencies; materials are offered once a year to State health departments for distribution with their own credit lines.

OSH has a reputation for creative, high-quality PSAs. Together with a concerted PSA marketing program (including personal delivery to television stations in large media markets and follow-up telemarketing), OSH has been able to keep a fair share of the available PSA time, even with very strong competition from issues including drug abuse and AIDS (28).

Broadcast Advertisers Reports (BAR), a service that monitors the airing of commercials on television, estimates that between 1983 and 1987, when OSH released twelve television PSAs, these spots were shown more than 48,900 times, about one-third in prime time. This is comparable to an advertising expenditure of \$9 million, or about \$1.8 million per year. It is estimated that up to 64 percent of the total population in these markets was exposed to OSH antismoking PSAs in any month of a given year (28).

However, BAR reports also show that the amount of public service time available from stations is decreasing. OSH is turning to alternative strategies including reaching youth through classrooms, coaches, and gym boards (locker room advertising); placement in specialty magazines; and regional and community-level strategies including media advocacy. (Because of tobacco advertising in newspapers and magazines, opportunities for the promotion of antismoking messages through the print media are extremely limited.)

The Office selects three target audiences for the three waves of media materials released each year -- for example, youth (to prevent uptake of smoking), pregnant women and new parents (to encourage smoking cessation), and middle-aged smokers (also to encourage cessation). Within each of these broad demographic categories, more specific groups are targeted; for example, campaigns produced this year will focus on African Americans (29). New strategies will address building support for tobacco control within African American communities.

OSH routinely commissions market research to identify changes in tobacco-related habits, specific motivational appeals, and changes in media habits of the target audiences. Appeals and selection of media outlets are tailored to fit each target audience. All educational materials are pretested with target audiences. Market

research findings are summarized as principles to guide the development of messages and materials. For example, OSH follows these principles to target youth:

- the use of celebrities to appeal to teens is troublesome because of the risk of inappropriate behaviors on the part of the celebrities, and the very rapid shifts in celebrity popularity among teens; spokespersons who are perceived as "like me" are the most acceptable to adolescents.
- teens say that they want to be "scared," but message pretesting has demonstrated that they are more likely to respond to positive appeals.
- peer acceptance and peer approval are strong motivators.
- lighthearted appeals, animation, and humor must not appear juvenile or the messages will be rejected.
- appeals to adolescents vary according to the specific group targeted (e.g., as segmented by age, interest, ethnicity, gender, or "clique").
- teenagers can be very critical of appeals and production values they consider out-of-style -- often by the time mainstream America accepts a teenage fad or style, it is considered outmoded by its originators.
- production values must "stand up" to the strict and constantly shifting standards of teenagers who are accustomed to MTV.
- anti-smoking appeals must compete in the marketplace with tobacco advertising supported by millions of dollars in market research and purchased space. (27)

OSH has found that television stations are very eager to receive PSAs appropriate for children and teens which they can use in the non-prime time slots (e.g., afternoons and Saturday morning) when a large proportion of the viewing audience falls within this age range.

The Office on Smoking and Health, given limited resources to communicate and a national mandate, chose to concentrate primarily on the use of mass media. Because other health agencies and voluntary organizations have community-level outreach capabilities, OSH materials are often integrated into broader, local programs. OSH considers this strategy to be cost effective, but foresees a need to move away from a reliance on dwindling public service time in the future.

## **Coalition Building -- Healthy Mothers, Healthy Babies, and Healthy Older People**

Summarized here are two Public Health Service programs that emphasize coalition building as a primary strategy to educate the public about health. These programs offer a different model for program development from the NHBPEP model, based on the same behavior change and communication principles.

Participants at the Surgeon General's Workshop on Maternal and Infant Health held in December 1980 identified a need to form strong linkages between individuals and groups concerned about maternal and infant health in order to increase public awareness and support for policies and programs. A small planning group representing the Public Health Service and several national voluntary and health professional organizations met to outline strategies for establishing a coalition for this purpose. A planning conference was held to identify needs, coalition functions, and priorities; as a result of the conference, 35 national organizations -- governmental, voluntary, and health professional -- agreed to work together and the Healthy Mothers, Healthy Babies Coalition was begun (30).

From the beginning, it was apparent that there would be scant financial support for this effort; one strong motivation for coalescing was a need to increase support for maternal and infant policies, funding, and programs. Therefore, the functions of the Coalition (which, 10 years later, counts more than 90 national organizations as members) are to share information, identify issues that can be addressed by all or clusters of member organizations, and provide a network to facilitate organizational sharing and collaboration. Many of the national organizations involved have community or State-based chapters, and an early Coalition initiative fostered the formation of independent but related State-level coalitions. Almost all States now have such coalitions; each with a different structure and function.

The national coalition is informal; it was not incorporated until 1989. It was managed by the Public Health Service for the first 5 years, with an annual budget of \$75,000 supplemented by staff and funding support from several PHS agencies (identifying that participation would benefit their own programs). Since the mid-1980s the coalition has been maintained by a staff of two, housed within the American College of Obstetricians and Gynecologists and supported by a small Health Resources and Services Administration (HRSA) grant (through HRSA's Bureau of Maternal and Child Health) averaging about \$130,000 a year (31). No media activities are developed by the Coalition; instead, the materials and programs of its members are promoted (32).

The Healthy Older People program was sponsored from 1985 through 1989 by the Office for Disease Prevention and Health Promotion to encourage health promotion among older adults (33). During a 3-1/2 year campaign, approximately

\$1 million and two professional staff (part-time) were assigned to this program. A primary focus was the establishment of State-level coalitions to link the health and aging networks that have traditionally been funded and operated separately. Of the more than 40 States that participated in the health promotion program, which included both mass media and community activities, 35 developed Healthy Older People Coalitions. Each developed their own activities; some have continued past the end of the national campaign.

Lessons have been learned about coalition building from these efforts, including the importance of investing in the development of the coalition structure, and in coalition support. Support may include the development of mass media and other educational materials, or other activities that offer an incentive for widespread involvement.

Each of these coalitions was founded in cooperative priority-setting and planning, with the Public Health Service offering support and initial leadership. Also important were the establishment of minimum standards and guidelines, early agreement that credit and ownership would be shared, and agreement regarding the role of private sector support.

Important benefits have resulted from the investment in coalition building, including ongoing linkages between organizations, broad "ownership" of and sponsorship for programs, and leveraged resources, including broad use of volunteers to support program activities. Most significantly, these coalitions have provided a level of attention to and involvement in their issues, over a longer period of time, than could have resulted from Federal sponsorship alone.

#### **The Role of Legislation -- Safety Belt and Child Restraint Programs**

Fewer than 12 percent of drivers, and approximately 20 percent of children under age 5 were using safety restraints in motor vehicles in 1982 (34). The National Highway Traffic Safety Administration, U.S. Department of Transportation (DOT), estimated that approximately half of all highway fatalities could be prevented if all passengers were properly restrained, and called for a combination of public information, education, incentive, and use requirement programs to be implemented by a network of organizations to significantly increase the number of restraint users. Criteria for these efforts included specific audience targeting; comprehensive programs designed to reach large numbers of people; conducted over a substantial period of time (34).

Reasons and excuses given by the public for not wearing belts include inconvenience, discomfort, laziness, fear of entrapment, and forgetfulness. Factors believed to underlie these reasons include a perceived lack of vulnerability,

lack of understanding of the efficacy of use, misinformation, lack of established habit, and negative attitudes toward use (34).

In 1984, DOT recommended the passage of State laws mandating the use of restraints as the most cost effective measure. At the same time, DOT recognized that neither legislation nor increased usage would likely occur without public information, education, and incentive programs; the greatest attitudinal obstacle to legislation was identified as "intrusion into the family." Since 1985, all 50 States and the District of Columbia have enacted laws requiring that young children ride in safety seats or belts. The combined effects of these laws, law enforcement, and public education has resulted in a child safety seat use rate of 84 percent (1990) (35).

By 1990, overall safety belt use had risen to 49 percent. Safety belt use in cities with belt use laws was 52 percent; in cities without laws, 36 percent. The safety belt usage rates in States with laws in effect ranges from 33 to 80 percent. This variation reflects factors such as differences in public attitudes, enforcement practices, legal provisions (penalties), and the availability of public information/education programs (35). The Department has set a national goal to reach 70 percent safety belt usage by 1992 (35).

To reach this goal, NHTSA has developed a comprehensive program including media messages, educational and incentive efforts with other organizations, encouragement of organizational use policies, and research, development, and evaluation. The types of national-level organizations involved have included education, health, medical, civic, safety, and media. NHTSA also works through State offices of highway safety, providing technical assistance and materials. In turn, these State offices develop networks within their States (35).

Program components include a public service mass media campaign of long duration, promotional events such as an annual "Buckle Up America!" week, collaboration with national organizations, coordination through State highway departments, and intensive efforts to support organization and activities at the community level.

At the community level, involvement of law enforcement agencies is strongly promoted both to enforce laws, and to conduct educational activities. Involvement of a wide range of others within the community is encouraged, including school administrators and teachers, physicians, judges, legislators and other public officials, parents, employers, media, tavern and restaurant owners, pharmacists, and attorneys. Many communities develop committees or task forces representing these sectors. Recommended strategies for community-based programs include using a mix of public information and mass media, education and incentive programs, with requirement policies or law enforcement. Principles underlying

community efforts include identifying, integrating, and coordinating the roles and resources of all community sectors. Public information, education, enforcement, and prosecution should be interdependent parts of an operating community system addressing the issue; establishing programs that are comprehensive, coordinated, and sustained are necessary to assure a lasting effect. Social norms must change to ensure long-range success. Such change can be accomplished through a comprehensive community-wide approach over a long period of time (36).

The NHTSA program demonstrates the value of including policy change strategies in programs that ultimately aim for behavior change by individuals. This program also shows that no one strategy, including laws that mandate behavior, can guarantee that change will occur.

### **Understanding the Public -- Blood Donors and Their Motivations**

The National Research Council (NRC) recently completed a review of the U.S. blood supply, as one part of a larger study to look at the effects of HIV/AIDS on our society (37). Summarized here are findings from that report, related to who donates blood, motivation and barriers to donation, and special efforts to recruit minority donors. This case study is presented to demonstrate the value of identifying and conducting research to understand potential donors. Although there are obvious differences between blood and organ donation, some of the donor motivations and barriers identified here could be investigated for relevance to organ donation.

There are two separate blood collection systems in the United States. A commercial system pays donors for plasma, and a voluntary system collects whole blood. An all-volunteer system for whole blood collection has been nearly universal in this country since 1975 "...to prevent the intrusion of undesirable factors (e.g., financial remuneration) into motivations to donate blood" (37). The American Red Cross collects about half of the whole blood; the American Association of Blood Banks, members of the Council of Community Blood Centers, and independent hospital blood banks account for the rest. About 80 percent of blood is collected at mobile sites. Blood drive recruitment is through high schools and colleges, and worksites (including businesses, local government offices, and public sector organizations) (37).

It is estimated that about half of the adult population should be eligible to give blood (37). According to a 1984 survey, about 8 percent of men and 5 percent of women reported that they had given blood in the past 12 months (38). Most blood comes from repeat donors. Women predominate among first time givers; men are far more likely to be repeat donors. Less than one-third of those who

have given a gallon or more are women. It is possible that the fewer numbers of women donors in the repeat donor category may be related to physical condition (e.g., low hemoglobin levels) rather than a lack of motivation (37).

Most donors are between 20 and 40 years old; adults in their 60s account for only 2-3 percent of all who donate (37). Apparently whites (41 percent of whom said that they have donated at least once) are more likely to donate than are blacks (32 percent) based on self-reported information (38). In response to one recent survey, 4 percent of blacks in comparison with 7 percent of whites said that they had donated within the last 12 months (38).

Frequent donors tend to have higher incomes than nondonors, and higher educational levels than occasional or nondonors. Blue collar and clerical workers are less likely to donate than those with managerial, professional, and technical job titles.

Reasons given for donating include altruism (e.g., emotional satisfaction, heroic feelings, heightened self-esteem); social pressure (e.g., worksite drive, personal or telephone request); a need within their community (strongest when there is community support for donation); personal experience with a need for transfused blood (friend or family member); getting a "medical exam," and blood typing or cholesterol testing (sometimes offered) (37).

The motivational force of altruism is not clear, but altruism alone may not be sufficient to motivate individuals to donate. Research (37) suggests that additional incentives (e.g., competition, discount coupons, raffles) result in greater donation rates. However, one researcher concluded that "only some people report donating for a reward, such as money, or time off from work; for most donors, reward does not appear to be a major motivational factor" (39).

Interestingly, one study found that respondents did not consider mass media appeals as "having been asked" to donate (40). Additional research would be needed to identify to what extent combining mass media and personal interaction strengthens motivational appeals.

Factors that appear to inhibit blood donation include medical ineligibility (actual, perceived, or rationalized); fear (e.g., of pain, needles); physical reactions from previous donation experience; apathy; and inconvenience (time, delays, inconvenient collection hours or location, lack of privacy) (37). Similarly, apathy (3) and fear also appear to be barriers for organ donation (4).

One study (41) reviewed in the NRC report describes a four-stage process to increase the number of blood donors. First, identifying negative attitudes among potential donors and developing messages to shift or neutralize those attitudes.

Second, developing motivational appeals based on internalized motives, focussing on "self concepts" of potential donors. Then, working to achieve behavioral intentions to donate as a next stage towards behavior change related to donation. Finally, encouraging donation as a habit, to reinforce and reward donation behavior.

Recommendations are included in the NRC report for increasing the number of blood donors. These recommendations are based upon research findings of barriers and incentives to donate and reflect the principles of effective program design (as summarized earlier in this paper). Recommendations for increasing the number of black blood donors, for example, include using community-based social networks, appropriate role models, and convenient donation locations. More specifically, this report recommends :

- recruiting at worksites employing large numbers of minorities; use of minority volunteers.
- recruiting on college campuses through a black fraternity and/or a black caucus.
- making donation relevant to blacks (e.g., point out blood needs among the African American population).
- tying in with Black History Month or other pertinent events.
- offering sickle-cell screening at the donation site.
- involving African American community leaders in planning and as spokespersons (37).

Although there are salient differences between blood and organ donation, some of the motivations, and barriers to motivation, may be similar. A more thorough review of motivational studies related to blood donation would identify strategies that could be tested for application to increasing the number of organ donors.

### **Application of Lessons Learned**

These model practices add to the lessons learned for application to organ donation programs:

1. In addition to broad program goals, focusing on achievable intermediate objectives such as public knowledge or community capacity-building, helps direct program activities. Including evaluation measures to track progress permits revision of program strategies as objectives are met.

2. **More successful programs commit significant resources to program planning and development and plan campaigns of extended duration; many have long range strategic plans.**
3. **A prerequisite to developing a successful program is market research to help identify target audiences. Additional market research with those audiences is needed to explore barriers and incentives to behavior change (organ donation). Motivational strategies and messages are built upon these perceptions of the target audience.**
4. **Formative evaluation (message and materials testing) is essential to producing messages and motivational strategies that will work.**
5. **Stronger programs result from working with other organizations or systems that can contribute complementary strengths (such as ties to and credibility with target audiences); coordination begins at the earliest program development stages.**
6. **Despite heavy competition for a finite amount of television public service time, it is possible to access sufficient time to reach significant numbers of viewers. To be effective, programs must produce high quality PSAs, market them to stations, localize (through local tagging and hand delivery) where possible, and target PSAs to audiences that can be reached when public service time is available. Many programs combine PSAs with other strategies (e.g., news relations) to increase message exposure through the mass media.**
7. **Legislation to mandate a behavior may be one useful strategy, in context with programs to build and maintain public support, educate and provide skills to target audiences. Legislation alone, without supportive strategies, such as incentives, penalties, and enforcement, is not likely to change behavior.**
8. **Coalition building can contribute to establishing a broad base of program support (at national, State, and community levels), leverage limited resources, assure consistent messages and strategies, and help assure attention to an issue over time.**
9. **Comprehensive, multifaceted, long-term programs, addressing individual change and those factors that support or block that change (including health care provider behavior) are more likely to produce significant changes in behavior.**

## **SUMMARY OF RECOMMENDATIONS: THE DESIGN OF A CAMPAIGN TO INCREASE THE NUMBER OF ORGAN DONORS**

Based on studies reported in the literature and the experiences of other public health and safety programs, it appears that information and education programs can contribute to increasing the number of organ donors given sufficient resources, longer term commitment, and adequate campaign planning and development.

Such a program should engage the mass media, community, and interpersonal communications (especially within the family). A communications program should be positioned within a broader program that addresses other essential components of change such as health care provider behavior, social norms, supportive policies, and systems that block or support behavior change.

Recommendations for developing such a program include:

### **1. Strategic Planning:**

Planning for an organ donor campaign should begin with a longer term commitment and strategic decision making that includes:

- measurable objectives representing intermediate progress towards program goals.
- multiple strategies based on behavior change and other relevant models and theories, lessons learned from previous organ donor, blood donor, and other health and safety campaigns.

### **2. Role of the Mass Media:**

Use of the mass media can be one way to effectively support increased organ donation:

- mass media strategies can increase and maintain individual and societal support for organ donation and can promote other program components.
- mass media campaigns should focus on media outlets matching the habits of target audiences, and be integrated with community outreach and health systems support.
- the use of public service announcements should be considered as part of a mix of mass media strategies.

- competition for media time and space, target audience attention, changes occurring both within the media industry and in the media habits of the public should be considered when making decisions about the most appropriate uses of the mass media.

### **3. Target audiences:**

Decisions about which specific population groups will be targeted are a prerequisite to the development of effective motivational strategies:

- once defined, market research should be conducted with them to build upon what is more generally known about barriers and incentives to organ donation, and to research motivational appeals with the most potential for promoting change.
- in addition to current knowledge, attitudes, and behavior, other contextual issues must be considered in designing motivational appeals for specific audiences, including family and cultural traditions, socioeconomic factors that affect an individual's willingness and capability to accept change, community customs and social norms, religious and political influences, and perceptions of the health care system.

### **4. Message and Strategy Development:**

The practice of social marketing, as applied by other health programs, will help guide effective message and strategy development:

- developing motivational messages and strategies should be based on the findings of market research conducted with target audiences.
- developing strategies to increase social support for organ donation and health care provider behavior are needed in addition to strategies to motivate individual and family change.
- communications strategies should be interwoven with strategies to address institutional, policy, and other barriers to donation.
- pilot studies or other tests of new programs can help identify needs for refinement before more extensive resources are committed.

### **5. Program Promotion and Marketing:**

In order to produce change, programs must be carefully developed and tested, but effective promotion and marketing of those strategies are equally necessary:

- marketing strategies should be planned to assure adequate target audience exposure to messages through the mass media and through community programs.
- adequate message exposure is a prerequisite to having an effect; both repeated exposures and exposure over time are needed.

#### **6. Evaluation:**

While the most critical measure of success is an increase in the number of donated organs, intermediate measures are needed to track progress and make any program adjustments needed to reach that goal:

- formative (message and materials pretests) evaluation should be an integral component of program development.
- process measures are both affordable and necessary.
- some outcome measures (such as tracking changes in target audience knowledge, attitudes, behavioral intentions, and behaviors) also are needed.
- evaluation measures are most useful if the results are used to refine program strategies.

#### **7. Coalition Building:**

To help assure optimal program success, collaboration and coordination at the national and community levels should be given serious consideration:

- consider including health professional associations, health service organizations, government agencies, national organizations with a community focus (social, fraternal, civic, and religious) that have credibility, access, and influence with potential donors.
- involve relevant organizations in the planning process and focus on establishing and nurturing linkages at national, State, and local levels.
- include mechanisms to facilitate information sharing between participating organizations to help maintain networks.
- consider appropriate roles for the for-profit sector (such as major employers, medical services, drug and equipment manufacturers).

## 8. Legislative Initiatives:

Legislation can contribute in several ways, including:

- giving a mandate and resources to the Federal government to develop programs to motivate and support increased donation.
- mandating certain behaviors, which can be useful as one of many change strategies, given related educational, incentive, and enforcement efforts.

## 9. Localization:

Both national leadership and community involvement are needed:

- nationally developed programs can be cost effective, but should be flexible to permit local tailoring to fit specific audience needs, as well as the religious, cultural, and other traditions and ethnic patterns of the community.
- policy makers, health care providers, and others who can facilitate or hinder the donation process can be the target of both national and local efforts.
- changing social norms in support of organ donation will require community involvement.

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# ON THE USE OF MASS COMMUNICATIONS TO PROMOTE THE PUBLIC HEALTH

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A key to continuing the improvement in Americans' health is the public's adoption of healthier lifestyles. Changes in lifestyle can be made only by a well-informed and motivated public. As a result, the mass media, as never before, have a vital role to play in advancing the public health.

Even in the case of diseases with a known biological cause, such as AIDS, choices in lifestyle and behavior can mean the difference between living and dying. Thus, when confronted in the 1980s by the menace of the AIDS epidemic, U.S. public health officials turned to the mass media as a means of quickly educating the American general public about the disease and appropriate prevention measures (DeJong & Winsten, 1991).

Beyond promoting changes in individual behavior, the mass media have an equally vital role to play in directing the public agenda to important health issues, reinforcing community-based programs, and building support for changes in institutional structures, public policy, or law that will support and sustain the efforts of individuals to alter their behavior.

Learning from both the successes and failures of past mass communication campaigns, public health advocates begin the 1990s with a renewed enthusiasm for using the mass media to promote the public health. Such enthusiasm will be heard at the Surgeon General's Workshop as participants debate how our nation can increase the number of organ transplantation donors. To help inform this debate, this background paper explores in general how public health advocates can effectively harness the power of the mass media.

## **THE ROLE OF MASS COMMUNICATIONS IN ADVANCING PUBLIC HEALTH: AN EVOLVING VIEW**

When the broadcast media emerged after World War II as a major force in American society, and as commercial advertising brought new sophistication to satisfying post-war consumer appetites, many public health advocates assumed that the presentation of factual information through mass communication campaigns would automatically result in changed attitudes and improved health behavior (Atkin, 1979; Griffiths & Knutson, 1960).

Subsequently, when several mass media campaigns produced disappointing results (e.g., Hyman & Wheatsley, 1947; Star & Hughes, 1950), this boundless optimism was replaced in the 1950s and 1960s by a decidedly more pessimistic view that the strategic use of mass media is doomed to failure (Atkin, 1979, 1981). It was recognized that mass communication campaigns could reinforce existing attitudes and behavior (Alcalay, 1983; Schlinger, 1976), but this outcome was viewed as being the most that could be achieved (Klapper, 1960). Little more could be done, it was argued, because the audience will choose to attend to and retain information that supports existing opinions (Bauer, 1964; Cartwright, 1949), and because it will employ various psychological defenses to fend off ego-threatening information (Bauer, 1964)<sup>1</sup>.

Skeptics noted that the apparent success of commercial advertising provided a misleading example, for the simple reason that influencing people's health-related behavior presents a far greater challenge than influencing their brand preferences (Griffiths & Knutson, 1960; Rehony, Frederiksen, & Solomon, 1984). Several considerations supported this skeptical view.

First, because of the widespread behavioral changes needed to bring about significant improvements in public health, health promotion campaigns must establish more ambitious objectives, even while usually having fewer financial resources. In contrast, commercial marketing campaigns are considered a tremendous economic success when they result in even a 1 percent increase in market share (Rosenstock, 1960; Schlinger, 1976).

Second, the behaviors that public health advocates seek to change are often ingrained habits or have accrued a cultural meaning or emotional significance that fortifies a resistance to change (Robertson & Wortzel, 1971). In contrast, commercial advertising is seldom designed to inculcate new attitudes or patterns of behavior, but to heighten and give direction to already existing attitudes and preferences (Lazarsfeld & Merton, 1971; Rosenstock, 1960; Wiebe, 1951). Moreover, while many of the benefits of health maintenance and disease prevention are delayed and uncertain, product consumption affords tangible and immediate gratification (Lefebvre, Harden, & Zompa, 1988; Schlinger, 1976).

Third, the very people who would be most responsive to a public health campaign may have already made the desired changes, leaving a target group of so-called

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<sup>1</sup> For addressing some health problems, however, the reinforcement of existing attitudes and behavior is precisely what is needed (Bauman, Brown, Bryan et al., 1988). When they are on the threshold of junior high school, nearly all children express a strong disliking for alcohol, tobacco, and other drugs and indicate that they do not intend to use them (DeJong, 1987). A key to prevention strategies, therefore, is to find ways to bolster those behavioral intentions as the children grow older.

"late adopters" that is much more difficult to persuade (Bloom & Novelli, 1981; Green, Kreuter, Deeds, & Partridge, 1980; Green & McAlister, 1984; Kasl, 1980). In many cases, that target group enjoys good health, at least currently, and this too diminishes their motivation to change, especially when such change is difficult to accomplish, painful, inconvenient, or expensive (Rosenstock, 1960). In contrast, commercial marketers try to reach consumers who are likely to want their product and can afford it (DeJong, 1989).

Finally, Wallack (1981, 1990a) notes that U.S. health campaigns often take place in a relatively hostile environment created by strong economic interests. For example, tobacco and alcohol advertisements encourage consumer indulgence, which undermines the less appealing messages of prudence and restraint offered by prevention education (Jacobson, Atkins, & Hacker, 1983)<sup>2</sup>. Beyond that, tobacco and alcohol companies, abetted by a financially vulnerable media, have limited the public's exposure to information about the long-term consequences of alcohol and tobacco use (Gerbner, 1990; Hacker, Collins, & Jacobson, 1987; Warner, 1985; Warner & Goldenhar, 1989; Weis & Burke, 1986) and sometimes exert political pressure to disrupt prevention campaigns (e.g., Wallack & Barrows, 1982-83).

This restricted vision of what mass communication campaigns can accomplish was reluctantly embraced by most public health advocates. One reason is that it contravenes the common wisdom that the mass media, especially television, exert enormous influence over our ideas, values, and behavior (Gerbner, 1987; Roberts & Maccoby, 1985). Moreover, both broadcast and print media are a cost-efficient way of reaching millions of people with health messages (Gerbner, 1987; Warner, 1987). Indeed, previous studies that were said to support a circumspect view of mass communication campaigns often focused on proportional success rates without taking into account the large audiences that mass media can have (Flay & Sobel, 1983; Warner, 1987).

By the 1980s a new view had evolved. The current perspective on mass communication campaigns is more balanced, based on the growing recognition that when long-term mass communication campaigns are designed and executed according to certain principles, they can play a meaningful role in changing health-related behavior and lifestyles (DeJong & Winsten, 1990a). The power of the mass media to effect behavior change is less dramatic than once hoped (or feared),

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<sup>2</sup> In several foreign countries (e.g., Austria, Norway, Greece), all forms of cigarette advertising have been banned, and the governments have launched vigorous anti-smoking campaigns (e.g., Doxiadis, Trihopoulos, & Phylactou, 1985). This absence of opposing information achieves what Lazarsfeld and Merton (1971) call a condition of "monopolization." As Flay (1986) has noted, the chances of achieving a total ban on tobacco promotion in the U.S., coupled with an aggressive anti-smoking campaign, are extremely remote.

but it is real. Mass communication campaigns can keep health-related problems and policy options at the top of the public's agenda and help bind community resources into a cohesive force for change; inform citizens about their community's attack on the problem and inspire their full participation; shift the meaning of health-related behaviors and thereby facilitate a shift in social norms; and motivate the adoption and maintenance of healthy lifestyle behaviors. The obstacles to changing health-related behaviors and lifestyles through mass communications are substantial but not insurmountable.

Public health advocates have a better understanding of what mass communication campaigns can and cannot do as a result of several important studies conducted during the past 20 years. Two successful campaigns, both focused on promoting changes in individual behavior, were especially influential: the Stanford Three Community Study, focused on cardiovascular risk reduction (Farquhar, Maccoby, Wood, et al., 1977; Maccoby, Farquhar, Wood, & Alexander, 1977; Meyer, Nash, McAlister, et al., 1980; Stern, Farquhar, Maccoby, & Russell, 1976); and the North Coast "Quit for Life" smoking cessation campaign in Australia (Egger, Fitzgerald, & Frape, 1983).

Failures were instructive too (e.g., Robertson, Kelley, O'Neill, et al., 1974; Vdry, 1974). A review of these campaigns made evident that the long period of skepticism about the strategic use of mass communications was strongly influenced by findings from short-term studies that were seriously flawed due to poor planning, inappropriate messages, or deficiencies in research design.

Thus, studying both the successes and failures of past campaigns, public health advocates have developed a more sophisticated understanding of how mass communication campaigns can change health-related behaviors and lifestyles. The remainder of this background paper reviews several important lessons that have been learned.

## LESSON 1: ESTABLISH A LONG-TERM COMMITMENT

The potential of the mass media for stimulating and reinforcing widespread changes in behavior can typically be realized only over a long period of time (Flay & Burton, 1990). Seduced by the apparent ease by which commercial marketers influence consumer brand preferences, public health advocates have frequently launched short-term advertising campaigns that have little chance of success (Bandy & President, 1982; Maccoby, 1987). For example, one well-known study evaluated an anti-drug television and radio campaign that lasted only 8 weeks (Hanneman, Eisenstock, Hunt, & Weinbeck, 1977). Not surprisingly, the campaign was found to have no effect. While this example is extreme, in general, past

efforts have often ignored the fact that attitude and behavior change in response to mass communications is "usually characterized by a slow process of erosion and accretion rather than by one of sudden upheaval and conversion," (Roberts & Maccoby, 1985, p. 547). Commercial marketers know this too: brand loyalty (or "goodwill") in fact takes years to nurture and develop (Bovee & Arens, 1986).

The value of a long-term perspective is evident when we consider the role of mass media in the evolution of U.S. social norms regarding the acceptability of tobacco smoking. Once viewed as a sexy, glamorous habit, smoking today is seen as a sign of poor self-discipline; to be a smoker now is to carry the weight of stigma (Cooke, 1989; "All Fired Up," 1988). This evolutionary change, which began with the Surgeon General's widely publicized report in 1964, has had a dramatic effect on public health. While 43 percent of the U.S. adult population smoked in 1964, under 30 percent did so in 1985; between 1964 and 1985, reduced tobacco consumption resulted in the avoidance of an estimated 789,200 premature smoking-related deaths (Warner, 1989). Through news reports, anti-smoking advertising, and fewer portrayals of cigarette smoking in entertainment programming (Signorielli, 1990), the mass media played a major role in stimulating, amplifying, and sustaining this gradual, and eventually radical, shift in smoking norms and behavior (DeJong & Winsten, 1990a).

## **LESSON 2: APPLY A BEHAVIOR CHANGE MODEL TO IDENTIFY INTERMEDIATE OBJECTIVES**

Very few mass communication campaigns can be expected to produce an immediate change in behavior (McGuire, 1984, 1985; Roberts & Maccoby, 1985; Skirrow, 1987). Whether a campaign can achieve that objective depends largely on the specific problem being tackled -- its complexity; the level of public concern about it; at what stage in the behavior change process the target audience can be found; whether early or late adopters are being targeted; and the personal, interpersonal, institutional, and societal barriers to change (Atkin, 1981; Wallack, 1990a). Hence, rather than focusing on immediate behavior change, it is often more realistic and appropriate to concentrate on achieving intermediate objectives that set the stage for or otherwise contribute to behavior change in the long-term (Farquhar, Maccoby, & Solomon, 1984; Flora, Maibach, & Maccoby, 1989).

A useful framework for understanding these intermediate objectives is the communication/behavior change model developed for the Stanford Three Community Study (Maccoby & Alexander, 1980)<sup>3</sup>. This model elaborates a series

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<sup>3</sup> *This framework was inspired by Cartwright's (1949) description of the three stages of change that a campaign must achieve in order to influence behavior -- an increase in awareness and knowledge (cognitive structure); a change in attitudes, leading to a heightened motivational*

of steps in the behavior change process which can be addressed through various mass communications channels. Specifically, mass communication campaigns can accomplish the following objectives: 1) increase awareness of a health problem and establish it as a priority concern; 2) increase knowledge and change beliefs that impede the adoption of health-promoting attitudes; teach new behavioral skills; and 4) provide supports for sustaining behavior change.

Increase awareness of a health problem and establish it as a priority concern.

Mass communications can be used to get the public thinking about a health issue, a function commonly referred to as "setting the agenda" (Roberts & Maccoby, 1985). The objective at this stage is to present information that makes an issue interesting, understandable, and personally meaningful, leading ultimately to self-appraisal and a consideration of possible action (Bandy & President, 1982; Griffiths & Knutson, 1960; McGuire, 1984, 1985; Roberts & Maccoby, 1985; Skirrow, 1987).

Increase knowledge and change beliefs that impede the adoption of health-promoting attitudes.

Roberts and Maccoby (1985) argue that changes in cognitions are a necessary precursor to eventual changes in attitudes and behavior: ". . . any influence of mass media content depends on how people interpret messages relative to previously established conceptualizations of the world -- fundamentally a cognitive effect," (p. 547). Attitude and behavior change, they assert, can eventually follow, making changes in knowledge and beliefs important outcomes in and of themselves (Fishbein & Ajzen, 1975).

Demonstration of a campaign's impact on knowledge, beliefs, and attitudes is often dismissed as unimportant because of the often-cited inconsistency between attitudes and behavior (Bandy & President, 1982). In fact, attitudes are good predictors of behavior when the attitude and behavior are measured at corresponding levels of specificity (Ajzen & Fishbein, 1977). Thus, general attitudes toward drugs will not necessarily predict whether a person will try a marijuana cigarette at a particular time and place. To be predictive, the attitude measurement should be equally specific. Attitude-behavior consistency is also more likely when social norms support the behavior (Fishbein & Ajzen, 1975).

At the same time, it must also be remembered that attitude change is not a necessary precursor to behavior change (Bem, 1970), in contrast to past assumptions about the absolute primacy of attitudes in the behavior change

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*state (motivational structure); and engagement in the actual behavior (behavioral structure). The key to inducing a given behavior, according to Cartwright, is having an appropriate cognitive and motivational system "gain control of the person's behavior at a particular point in time," (p. 264).*

process. Indeed, a persuasive communication may induce curiosity to engage in new, low-risk behaviors on a trial basis, with a change in attitudes emerging later in consequence (Flay & Burton, 1990; O'Keefe & Mendelsohn, 1984).

It is important to note here that when detailed, complicated, or politically controversial information must be communicated, television and radio spots, billboards, and print advertisements can stimulate further information-seeking by promoting information hotlines (Pierce, Dwyer, Frape et al., 1986; Stein, 1986) or the availability of pamphlets and other written materials (Mendelsohn, 1973; Schlinger, 1976). It is critical that people not be merely exhorted to obtain additional information but that specific strategies be explained or modeled (Solomon, 1983). This has been a central feature of several public health campaigns, including national AIDS campaigns in the U.S. (DeJong & Winsten, 1991).

Teach new behavioral skills. Important behavioral skills can be taught through modeling or step-by-step instruction (Alcalay, 1983; Bandura, 1977). Until recently, behavior change was most often conceived in terms of altering existing patterns of behavior; that is, certain unwanted behaviors were to be suppressed, and other behaviors, already in the behavioral repertoire were to be brought forth. As a result, the power of the mass media to expand people's behavioral repertoire was frequently overlooked (Alcalay, 1983).

The performance of newly acquired behaviors can be enhanced by demonstrating how various barriers to behavior change can be overcome, thus increasing perceptions of "self-efficacy" (Bandura, 1984). Self-efficacy is not a global concept like self-esteem, but deals with a person's perceptions about his ability to act out a specific behavior at a particular time and place. Whether a person holds such a belief is predictive of subsequent behavior change, whether it is the suppression of existing behaviors or the acquisition of new ones (Strecher, DeVellis, Becker, & Rosenstock, 1986). Vicarious experience is an important source of information for efficacy expectations; thus, mass communications can be employed to change self-efficacy by modeling determined effort that leads to success. Performance of newly acquired behaviors can also be enhanced suggesting so-called "cues to action" in the physical and social environment that can stimulate a person to call up and apply a particular behavioral repertoire in the appropriate circumstances (Maiman & Becker, 1974).

Provide supports for sustaining behavior change. Learning and maintaining a new pattern of behavior requires that people know how to monitor their behavior, apply self-reinforcement strategies, and anticipate, eliminate, or cope with environmental or social stimuli that trigger unwanted or competing behaviors. Mass communications can be used to teach these self-management techniques (Bandura, 1977; Flay, DiTecco, & Schlegel, 1980).

Social support is also important for maintaining new behaviors. Mass communications can help here too by: 1) communicating the fact that others have also adopted new behaviors and are facing the same struggles in trying to maintain them (Mogielnicki, Neslin, Dulac et al. 1986); 2) stimulating the social support of opinion leaders, family, and peers (Green & McAlister, 1984; Rogers, 1983); and 3) teaching people how to elicit from others the support they need.

Application of the communication/behavior change model first requires that campaign planners establish where in the behavior change process the target audience can presently be found. From there, the campaign can try to move the audience sequentially through the remaining steps<sup>4</sup>. Consider the case of AIDS prevention. Presently, most American adolescents and adults know a great deal about what is required to prevent AIDS, thanks in part to national public awareness campaigns. At this point, the successful promotion of condoms requires moving beyond basic factual information about AIDS prevention to motivating messages that address the various psychological barriers that impede condom use and that present the personal and social benefits that their use can bring if approached in the right way (Solomon & DeJong, 1986, 1989; DeJong & Winsten, 1991).

With this model in mind, campaign planners should develop a strategic plan that divides the campaign into distinct phases, each with realistic, specific, and measurable objectives (DeJong & Winsten, 1990a; Green & McAlister, 1984; Maccoby & Alexander, 1980). Once the planning phase is over and measurable objectives are set, campaign organizers will have a framework that can be used to guide media selection, message development, and campaign evaluation (Maccoby & Solomon, 1981; Solomon, 1982).

While this point seems obvious, reviewers of mass communication campaigns have frequently noted that campaigns often have unrealistic goals, because the objectives are vague or defy valid and reliable measurement, because the use of mass media to effect the desired change is unfeasible, or because insufficient time and resources have been committed to the campaign (Bandy & President, 1982; McGuire, 1984; Mendelsohn, 1973; Schlinger, 1976; Solomon, 1982; Wallack, 1980, 1981).

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<sup>4</sup> *It should be remembered, however, that people do not always go through this sequence of steps in exact order, especially if the choices among behavioral alternatives are unimportant to them, or if they have somehow been induced to perform the behavior in the absence of prior attitude change (McGuire, 1989; Solomon, 1989).*

### LESSON 3: APPLY THE "CONSUMER" ORIENTATION OF SOCIAL MARKETING

By the late 1970s, several reviewers of mass communication campaigns had noted that the public health community knew too little about modern marketing (e.g., Schlinger, 1976). In recent years, however, Federal health officials and other public health advocates have become increasingly sophisticated in designing and executing campaigns, primarily as a result of the "consumer" orientation that characterizes Madison Avenue's approach to marketing. This section describes the central tenets of this so-called "social marketing" approach<sup>5</sup>.

All campaign messages should be directed to a well-defined target audience. In the argot of marketing, a target audience should be "segmented" into subgroups with similar geographic, demographic, psychological, and problem-relevant characteristics (Flay & Burton, 1990; Maccoby & Alexander, 1980; Solomon, 1983). With this information, campaign planners can develop strategies that are appropriate for each segment (Simon, 1974). The target audience can be members of the general public or business and government leaders.

Commercial marketers rely on a variety of market segmentation techniques. At a minimum, markets are typically divided according to geographic location (e.g., urban, suburban, or rural residence) and consumers' demographic characteristics (e.g., gender, age, race/ethnicity, education, occupation, income, religion). More recently, so-called "geo-demographic" techniques have been developed whereby an individual is classified into one of 40 lifestyle categories defined by the social class and consumer spending patterns of that person's postal "zip code" area (Townsend, 1985).

"Psychographics" classifies consumers on the basis of their psychological make-up and lifestyle. As defined by Mitchell (1983), psychographics describes "the entire constellation of a person's attitudes, beliefs, opinions, hopes, fears, prejudices, needs, desires and aspirations that, taken together, govern how one behaves," (p. vii). The most popularly used system for adults is the Values and Lifestyles (VALS) typology developed in 1978 by SRI International (Mitchell, 1983). A new version of this typology, designed to correct deficiencies in the original system, was released in the mid-1980s.

For any mass media campaign designed to change health behavior, it is important to have a "psychographic" system for segmenting the audience. Typically,

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<sup>5</sup> *Social marketing is defined by Kotler and Zaltman (1971) as "the design, implementation, and control of programs calculated to influence the acceptability of social ideas and involving considerations of product planning, pricing, communications, distribution, and marketing research," (p. 3). In short, social marketing is the application of commercial marketing and distribution strategies to the promotion of social goals (Kotler, 1984; Solomon, 1989).*

however, commercially available systems, with their focus on consumer spending, will be inadequate to the task. Thus, campaign planners often "customize" their own typology based on problem-specific research, beginning with focus group or one-on-one interviews and moving on to formal survey research (e.g., Lastovicka, Murry, Joachimsthaler et al., 1987; Slater & Flora, 1991).

U.S. "market segments" that deserve special consideration are non-English speakers. Too often, English-language campaign materials are translated for minority group audiences, with cultural nuances ignored (Farquhar, Fortmann, Maccoby et al., 1985a; McAlister, Ramirez, Amezcua et al., 1987). There are distinct subcultures within these groups, each with its own history, customs, dialect, and patterns of health-related behavior. Because it will often be impractical to develop materials for each subgroup, care must be taken to create materials that transcend these differences and "ring true" to the largest number of persons possible.

There should be extensive use of formative research to develop a rich understanding of the target audience (Atkin & Freimuth, 1989; OCC, 1989). Focus groups are the qualitative method most frequently used by advertising researchers (Basch, 1987; Folch-Lyon & Trost, 1981). With this technique, a small group of eight to 12 individuals is interviewed in depth by a trained moderator. The moderator, following a previously developed agenda, creates a non-threatening, accepting atmosphere to draw out each participant and strives to facilitate discussion among the participants. Success is highly dependent on the skills of the moderator. Sessions are usually conducted at a facility that permits observers to watch from behind a one-way mirror.

The focus group technique is often viewed skeptically. The research usually involves a relatively small number of respondents. They are recruited to meet certain selection criteria and do not know one another, but they are not selected at random, so there is no guarantee that they are truly representative of the population as a whole. Moreover, the technique can be inappropriate for gleaning information about highly charged or embarrassing topics.

Some marketing researchers claim that the technique is largely ineffective with adolescents because of their heightened self-consciousness and sensitivity to peer pressure. Other researchers disagree, noting that a moderator with sufficient skill can work successfully with adolescents (Greenbaum, 1988). A type of focus group that seems especially effective with teens is the so-called phenomenological focus group; the respondents do not respond to direct questions, but are given an appropriate task to accomplish as a group without the moderator's help (Basch,

1987). With elementary school children, because of their more limited communication skills and attention spans, role-playing, fantasy play, drawing, and other experiential techniques are usually necessary to elicit useful information (Greenbaum, 1988).

In favor of focus group research, it can provide large amounts of rich, detailed information in a short period of time and at relatively little cost. Especially important is information on the target audience's speech patterns, body language, and style of dress. These observations can provide valuable clues as to how a product, service, or idea can be "positioned" and marketed.

An alternative technique is a series of private, one-on-one interviews conducted by a trained moderator or clinical psychologist. The interviewer follows a prepared protocol, but detailed follow-up questions may also be asked. There are several advantages of this technique. Issues can be probed in greater depth. Respondents are typically more willing to share highly personal information, and group dynamics do not bias the subjects' responses. Special facilities are not needed. On the other hand, this method is more expensive and time-consuming than focus group interviews. Moreover, clients or other members of the project team do not observe the interviews so that respondents will speak more freely.

The use of clinical psychologists for these interviews is intriguing. Recognizing that people's self-reports concerning the reasons for their behavior are frequently inaccurate (Nisbett & Ross, 1980), those who employ this method note that clinical psychologists have a range of projective techniques at their disposal to assess the psychological or emotional benefits that a product offers, benefits which are often not consciously acknowledged. Moreover, psychological methods or theories can be readily applied to explaining consumer behavior and generating advertising ideas. For example, products might be seen as answering basic ego needs, such as a need for self-esteem or dependency needs<sup>6</sup>.

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<sup>6</sup> Another useful framework for generating campaign ideas is provided by McGuire (1989). By his scheme, general theories of human motivation are organized into four broad categories. **Cognitive stability theories:** According to this set of theories, human behavior is motivated by a need to maintain beliefs and attitudes that are consistent. A strategy suggested here is to focus on the inconsistency between the target audience's values and their behavior. **Cognitive growth theories:** By these theories, human behavior is motivated by certain needs that are cognitive, rather than affective, such as a need for stimulation, or a need to believe in one's capacity to maintain control over the environment. **Affective stability theories:** By these theories, human behavior is motivated by a need to maintain a stability of affect. Fear appeals, for example, seek to induce a tension or stress that the target audience would then be motivated to eliminate. **Affective growth theories:** These theories, also emphasizing growth, deal with the realm of emotions, such as the need for love and acceptance.

Qualitative research is especially valued for the new insights it can generate (Bovee & Arens, 1986). Marketing researchers typically propose that this research be followed with surveys and other quantitative methods to test the hypotheses generated, but commercial clients often skip this step because of time or financial constraints or because they find the insights provided through the qualitative research to be especially compelling or at least consistent with their past experience (Szybillo & Berger, 1979). Public health advocates are likely to do the same, but whenever resources and time permit, findings from qualitative research should be validated through surveys or other more rigorous methods (e.g., Lastovicka, et al., 1987).

Once the development of campaign materials is underway, extensive pretesting must be conducted to ensure that they are appropriate for and appeal to the target group (Atkin & Freimuth, 1989; OCC, 1989). Many design options are available to campaign designers, and each has its strengths and weaknesses, as evidenced by both the findings of social psychological research and the successes and failures of past campaigns. Because the research on persuasion has revealed so many complex interactions among source, message, and channel variables, and because the results depend in part on the audience and the specific issue at hand, making a reasoned decision about which option to select is extremely difficult (McGuire, 1985, 1989)<sup>7</sup>.

As a result, it is common to find disagreement among the experts about how campaign messages should be designed. For example, consider the "style" of the campaign. Atkin (1979) notes that public communication campaigns are often dry recitations of factual information, with little attention to style or production values, and he urges that campaigns designers build in "excitement, drama, and humor" to buttress entertainment value. In contrast, Bauman et al. (1988) deliberately avoided a "flamboyant" style of advertising in their anti-smoking spots, based on a consultant's critique of previous anti-smoking messages as "self-conscious

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<sup>7</sup> McGuire (1989) presents a "communication-persuasion matrix" as a framework for reviewing the possible effects of various message design and implementation options. The matrix emerges from a cross-tabulation of "input variables" and "output factors." Input variables include source variables, such as communicator credibility and attractiveness; message variables, such as type of appeal (e.g., celebrity endorsement, humor, fear) or presentation of alternative viewpoints; channel (medium) variables, including the number and type of media used; receiver variables, including demographic and psychographic characteristics; and target variables, or specific features of the problem behavior itself. Output factors are the sequence of processes that mediate the impact of a persuasive communication on behavior, which Atkin and Freimuth (1989) have categorized in five stages: exposure, information-processing, cognitive learning, yielding, and utilization.

imitations" of commercials. They also noted that, while such advertisements might increase attention and even earn public accolades, they might fail in their mission if the audience is distracted from attending to or remembering the message (Benn, 1978)<sup>8</sup>.

As noted, these considerations are also confounded by the nature of the audience and the specific issue involved. For example, a "two-sided" approach, which acknowledges ideas or arguments in opposition to the advocated position, but then refutes them, is superior -- but only when members of the audience are highly sophisticated and well-educated, when they are initially opposed to the advocated position, and when they will later be exposed to information that supports that opposing perspective (Atkin, 1979).

Even when there is general agreement about which approach is best, it must be remembered that no "rule" of advertising works all the time and that widely successful strategies can be rendered ineffective through overuse. Cinematic techniques, formats, and styles that command attention and have strong audience appeal today can eventually become part of the background clutter that is ignored tomorrow. Audience values change over time, too. For example, appeals developed in the 1980s that drew on baby-boomers' need for self-fulfillment may not work in the 1990s as that generation moves on to other concerns, such as the need to build warm and nurturing relationships (Flay & Burton, 1990).

Past campaigns and research findings should be used, therefore, not as a blueprint, but as a source of ideas that need to be pretested within the context of a new campaign (Solomon, 1983). For this reason, with each step of campaign development, planners should conduct formative research involving representatives of the target group to double-check the appropriateness and potential effectiveness of campaign materials (Maccoby & Alexander, 1980). Unfortunately, careful formative research of this type is often not done (Palmer, 1981).

A formative research plan should also include television and radio managers and print editors -- the "gatekeepers" who control access to the media. These individuals will have their own ideas about what is appropriate and effective (Hammond, Freimuth, & Morrison, 1987). They also have responsibility for making sure that all advertising, including public service announcements, meet their station's standards of propriety and will not alienate important segments of their

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<sup>8</sup> *A further complication: Research suggests that if the distraction from a persuasive message is only enough to prevent silent rehearsal of counter-arguments to the message but not enough to interfere with message reception, such advertisements might actually be more effective (Festinger & Maccoby, 1964).*

audience (DeJong & Winsten, 1991; Flay & Burton, 1990). Therefore, they should be involved early on in planning and be given the opportunity to react to materials during each phase of the development process (Flay, 1986).

The principle method used in formative research at this stage is focus group interviews. One use of this research technique, to learn basic information about the target audience, was described earlier. This technique is also used to evaluate message concepts (that is, brief summaries of key benefits or "promises"), preliminary media executions, and finished products. Issues that can be explored through such research include the material's ability to command attention; audience comprehension and recall; aesthetic appeal; and the message's credibility, relevance, and acceptance by the target group.

How frequently campaign planners conduct this type of formative research obviously depends on the resources they have at their disposal. At a minimum, focus groups should be conducted to test preliminary executions, such as scripts, storyboards, and mock-ups of print advertisements. Tests of finished products are generally less critical<sup>9</sup>. Often, tests of preliminary message concepts can be incorporated into initial focus group research being conducted to learn about the target audience.

Mass communication messages should address the target audience's existing knowledge and beliefs. In order for a persuasive communication to succeed, it must anticipate the audience's points of resistance and then address them (Lefebvre, Harden, & Zompa, 1988). In the Health Belief Model (HBM) (Maiman & Becker, 1974; Janz & Becker, 1984), those resistance points are defined in terms of the target audience's underlying beliefs about a particular health problem and its prevention or cure.

These beliefs concern the following: the person's perceived susceptibility to the disease or health problem; the seriousness of the disease or problem if it is encountered, including health, social, and financial consequences; the effectiveness of the prescribed course of action in reducing the threat to health; and the barriers to executing that behavior, such as financial cost, inconvenience, pain, and lost time (Bloom & Novelli, 1981; Solomon, 1989). Also important is the person's perceptions of popular opinion and normative perceptions for the roles

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<sup>9</sup> *In some cases, however, this type of testing is essential. One example illustrates this point: the California Prevention Demonstration Program, a mass communication campaign aimed at reducing problems related to alcohol abuse. For an interim evaluation, those survey respondents who had seen each television commercial being aired were asked to say what they remembered about it and its message. Across the commercials, between 35% and 44% of the respondents misinterpreted them to be pro-drinking rather than pro-moderation messages (Wallack & Barrows, 1982-83).*

and behaviors that are appropriate to members of the society (Fishbein & Ajzen, 1975). Messages emphasizing that others have adopted a desired behavior can be especially persuasive (Farquhar, 1984).

The HBM framework is useful for organizing formative research and then guiding message content (Solomon & DeJong, 1986). For example, in designing messages for an anti-smoking campaign, Bauman et al. (1988) discovered that adolescents' expectations of certain positive and negative consequences to smoking was a good predictor of their later smoking initiation. They then designed their campaign to address these beliefs. Messages focused on short-term consequences of smoking, such as bad breath and loss of concentration and appetite; possible loss of friends; possible trouble with adults; and the supposed "fun" and "relaxation" of smoking.

Mass communication campaigns should communicate incentives or benefits for adopting the desired behavior that build on the existing motives, needs, and values of the target group (El-Ansary & Kramer, 1973; Lefebvre & Flora, 1988), a process that Lazarsfeld and Merton (1971) have called "canalization." The failure to do this is at the heart of many campaign disappointments.

Commercial marketers have long understood that people are more likely to attend to and remember messages that meet their needs or support values they believe in (Flay, 1986; Rehony et al., 1984). Accordingly, product advertising often plays on people's insecurities, desires, and aspirations, and then "positions" the advertised product or service as a means of meeting those needs immediately (Solomon, 1989). The key, therefore, is to establish the benefits of the product or service (Lefebvre & Flora, 1988; Ogilvy, 1985).

The experience of commercial advertisers makes clear that, in many cases, a health promotion campaign should emphasize benefits that are not related to health per se, but to universal and more salient human desires for beauty, acceptance, love, security, status, or wealth (Bonaguro & Miaoulis, 1983; McGuire, 1984; Roberto, 1972; Schlinger, 1976). In the past, health advocates focused too narrowly on trying to motivate people to change their behavior for the sake of their health rather than in response to other motives, a strategy that proved to be limiting and self-defeating. Instead, as explained by Cartwright (1949), people must be encouraged to "see the action as a path to an existing goal," (p. 261).

Commercial advertisers often play on young people's insecurity about their place in the world and their growing desire for autonomy. Health campaigns can do the same. To take one example, a campaign to discourage alcohol, tobacco, and other drug use can: provide accurate information on the actual level of substance use among preteens and adolescents, thereby showing that far from "everyone" uses these substances; urge young people to encourage one another to refrain from experimenting with and using these substances (Bauman et al., 1988); present

peer role models -- older adolescents who are independent, mature, and popular without drinking, smoking, or using other drugs (McAlister, Perry, & Maccoby, 1979); and illustrate peer approval for refusing or stopping substance use (Liepold, 1986; Worden, Flynn, Geller et al., 1988). Moreover, such campaigns can encourage young people to select a peer group or clique that does not use these substances and helps bring out their best qualities (McLeroy, Bibeau, Steckler, Glanz, 1988). A good example is the "Be Smart. Don't Start!" campaign sponsored in the mid-1980s by the National Institute on Alcohol Abuse and Alcoholism (Atkin, 1989a).

Because of the importance of social influences in substance use, campaigns aimed at preteens and adolescents should also focus on the important role of social pressure, both direct and indirect, from peers, family, and the media; ways in which tobacco and beer advertisers try to persuade people to use their products (Atkin & Arkin, 1990; Flay & Sobel, 1983); specific counterarguments to refute arguments made by others in favor of substance use (McGuire, 1985); and alternative strategies for refusing various offers of alcohol, tobacco, and drugs from peers or family members (Polich, Ellickson, Rueter, & Kahan, 1984; DeJong, 1987). The underlying message is that refusing to give into pressure to experiment with and use alcohol, tobacco, and other drugs is a true demonstration of independence and freedom.

Commercial advertising experience also makes clear that, whenever possible, the target audience's attention should be drawn to the immediate consequences of behavior that have a high probability of occurring. This is especially true for campaigns directed to preteens and adolescents.

Again consider the case of preventing alcohol, tobacco, and other drug use by youth. Young people need to be taught the facts about the long-term impact that substance use might have on their health and well-being. This is most important when there is a cloud of mythology and misinformation about the addictive potential and long-term effects of a particular drug, as was the case for cocaine before the National Institute on Drug Abuse (NIDA) began its public awareness campaign, "Cocaine: The Big Lie" (Johnston, O'Malley, & Bachman, 1988). But while an awareness of long-term risks will dissuade many young people from substance use, the deterrent effect will be far from universal. By age 12, for example, children have been told repeatedly that tobacco use is dangerous, but a large number still begin to smoke anyway (Evans, Rozelle, Maxwell et al., 1981).

It is important to understand why information about the long-term sequelae of substance use have limited effect. First, even when the credibility of factual information is accepted, people might question whether it really applies to them (Atkin, 1979). Most young people take good health for granted, and many view the dire, long-term consequences of substance use as too distant and too unlikely

to be of concern to them. Second, their own observations may lead young people to conclude that experimentation does not necessarily result in addiction, and that regular use does not necessarily result in severe health consequences. Because many people do not understand the probabilistic nature of risk, this uncertainty is an opening for denial (DeJong, 1987). Third, for most young people, substance use is occasional, not daily, and typically occurs in social situations. As a result, they might overestimate their own capacity to control the extent of their substance use, believing that they are fundamentally different from those who develop a drug dependency. In fact, in some cases this belief might even stimulate curiosity about a substance and lead to experimentation (Polich et al., 1984).

In trying to dissuade young people from smoking cigarettes, for example, an emphasis on long-term risks of heart disease and cancer will have little apparent effect in delaying experimentation or reducing use. Instead, the emphasis should be placed on immediate consequences that have a high probability of occurrence (Flay & Sobel, 1983; Job, 1988). With greater impact, prevention programs now emphasize readily noticeable effects such as discoloration of the teeth, body and mouth odor, loss of concentration and appetite, and the deterioration of physical performance (Bauman et al., 1988; Evans et al., 1981). This strategy is also reflected in a recent public service campaign, "Nic, A Teen," by the federal Office on Smoking and Health, which portrays smoking as being unattractive to desirable members of the opposite sex.

Health campaigns should explore the use of "image" or "lifestyle" advertising to promote an active, healthy lifestyle. Commercial advertising of this sort allows consumers to envision the transformation of a less desirable past to a more desirable future by manipulating images of the consumer as a person with intelligence, power, status, and popularity (Chapman & Egger, 1980; Graham & Hamdan, 1987). In essence, image advertising associates product consumption with the "good life," as defined by the target audience. It rarely seeks to elicit an immediate behavioral response, but instead tries to evoke an emotional response that can catalyze later changes in behavior (Schwartz, 1983). As a result, such advertising needs to be repeated more frequently than advertising that uses a more direct sales pitch (Benn, 1978).

Image advertising is commonly used to promote cigarettes, especially in women's and youth-oriented publications (Altman, Slater, Albright, & Maccoby, 1987). Advertising for Virginia Slims cigarettes is illustrative. The launch of this brand coincided with the woman's movement, and the advertising copy has always stressed women's emancipation and growing freedom as an appeal to "liberated" women (Benn, 1978; Rehony et al., 1984). At the same time, the ads have a distinctly feminine aura, suggesting that Virginia Slims smokers can compete with men without sacrificing their femininity. This juxtaposition is apparent in the campaign slogan "You've Come a Long Way, Baby."

Another example is provided by malt liquor advertising directed to low-income black male consumers. A great deal of such advertising emphasizes the extra "power" of the drink, which does have a higher alcohol content than beer, and ties its use to promises of sexual power and conquest (Postman, Nystrom, Strate, & Weingartner, 1987). In contrast, ads for cognac and other liquors, which are designed to appeal to upwardly mobile and economically successful blacks, portray the product as a sign of elegance (Hacker et al., 1987).

Other image advertising associates a product with stories, vignettes, themes, or characters that tap into cultural myths. In so doing, these ads evoke the culture's ideals and give expression to profound and universal emotions (Schwartz, 1983; Chapman, 1986). Most important, by evoking particular myths, these ads communicate the essence of those people who use the product and their place in the world (Chapman & Egger, 1980). As a result, consumers see aspects of their real or desired image portrayed in the advertising, and the product becomes a vehicle for expressing or gaining that identity. The quintessential example of this type of advertising is the campaign for Marlboro cigarettes, which exploits the American myth of the "frontier," a free, open space where a resourceful and self-sufficient man can start fresh and make his way in the world. The "Marlboro Man" is a man of inner-strength -- self-confident, tough, straightforward, and independent; he is portrayed, essentially, as the embodiment of American individualism and potency.

Chapman and Egger (1980) assert that anti-smoking appeals directed at preteens and adolescents also need to use "image" advertising. One strategy they suggest is to present a mythical character with whom this group can identify, a character who demonstrates his power and independence by choosing not to smoke. A similar strategy was applied in a drunk-driving prevention campaign just pilot-tested in California, "The Driver," which was designed to promote the designated driver concept (SYSTAN, 1987). "The Driver" is portrayed in television spots as a classic American hero, the handsome loner who thinks and acts apart from others, but is also willing to take charge when others must be rescued from themselves.

Image advertising can be used more broadly to promote a health-enhancing lifestyle, one that is incompatible with substance use and other behaviors that put health at risk. For example, the Alberta Alcohol and Drug Abuse Commission (AADAC) in Canada has operated its "Make the Most of You" campaign since 1981 with a focus on encouraging and assisting teens to adopt a healthy lifestyle. Through a combination of print and electronic media and school- and community-based programs, the campaign shows that adolescents, with peer support, must take an active role in their own growth and development by involving themselves in fun yet healthful activities. In this context, substance use and other high-risk behaviors are portrayed as impediments to teens' achieving their own goals and

aspirations. An evaluation incorporating a quasi-experimental research design, with Manitoba used as a comparison area, has produced encouraging results (Thompson, 1988).

A variation of this general strategy is to label members of the target audience as "winners" and to present the desired behavior as an integral part of that image (e.g., Wallack & Barrows, 1982-1983). Labels provided by others can influence a person's subsequent behavior (DeJong, 1979), though their impact is far greater when they are based on observations of past behavior (Kraut, 1973) or are otherwise personalized (e.g., Strenta & DeJong, 1981), conditions that cannot be met easily, if at all, through mass communication channels (DeJong, 1988). Still, this approach might be valuable in certain cases. Alternatively, Schwartz (1983) suggests that mass communication campaigns can use "shame" to motivate desired behaviors, essentially by confronting members of the target audience with any discrepancy between their self-image and their actual behavior (see also, Ball-Rokeach, Rokeach, & Grube, 1984).

Fear appeals should be used only under limited circumstances. A continuing controversy in the U.S. concerns the use of fear appeals. Most experts have concluded that fear campaigns are extremely difficult to execute and rarely succeed (Atkin, 1981; Bandy & President, 1982; Boster & Mongeau, 1984; Job, 1988). Indeed, they argue that there is a real risk that fear appeals will backfire, making the problem behavior even more resistant to change (Kleinot & Rogers, 1982; Rogers & Mewborn, 1976).

To work, the onset of fear should precede an explication of the simple, concrete steps that people can take, and fear onset should then reinforce the desired behavior to confirm its effectiveness. This is harder to do than it sounds. If the appeal is too mild, or if the threatened punishment seems too unlikely or remote in time, people will not be motivated by it. If the threat is too strong, or if the behavioral prescription being offered as an alternative is inadequate to alleviate the induced fear, people might tune out the message, deny its validity, derogate the source's credibility, or adopt a fatalistic attitude (Job, 1988; Solomon & DeJong, 1986).

The central difficulty is the impossibility of anticipating or modulating in advance the level of fear that will be generated by a particular set of campaign materials or to judge whether the fear reduction or other benefits resulting from the prescribed action will be adequate to motivate behavior change (Bandura, 1986). Moreover, the target audience's response to the fear appeal will also vary according their perceptions of their own vulnerability. If the audience has low anxiety, a fear appeal might serve to raise concern about the problem and motivate action. But if the audience is already anxious about the problem, this type of appeal might interfere with comprehension or a rational consideration of options (Bandy &

President, 1982). A complicating factor is that members of the same target audience will vary on this dimension, again making the appropriate strength of the fear message difficult to establish.

Despite these considerations, fear appeals continue to have strong intuitive appeal and are frequently used by advertising professionals in health promotion campaigns. One reason for this is that focus group participants usually rate strong fear appeals as highly motivating and effective. But this is true even when subsequent experimental studies show those appeals to be ineffective (Job, 1988). The reason for their continuing allure is clear: In general, the threat of punishment is relied upon to control behavior when its causes are insufficiently understood or those causes are difficult to change (Bandura, 1986).

Compounding the confusion is the lack of definitional clarity about what constitutes a "fear appeal." In their zeal to promote alternative approaches, some experts extend their concerns about fear appeals to any message that focuses on the negative consequences of certain behaviors. Further adding to the confusion, of course, is that such campaigns do occasionally work (e.g., Advertising Council, 1991; Chu, 1966). As noted before, however, this is usually the case when the audience has low awareness or anxiety about a problem (Flay & Sobel, 1983). In 1987, for example, an annual survey of high school seniors found a decline in reported cocaine use; the investigators attributed this decline to a heightened awareness of cocaine's potential to kill even first-time users, due to the widely publicized death of basketball star Len Bias and the mass media campaigns that followed (Johnston et al., 1988)<sup>10</sup>. On the other hand, once people are already aware of a problem, other means of influencing their behavior, such as modeling appropriate skills and demonstrating the benefits of alternative behaviors, must be found.

The use of celebrity spokespersons should be approached cautiously. A celebrity is often used in product advertising as a means of drawing attention to the product or to show that it is "in fashion" (Graham & Hamdan, 1987). Many public service campaigns have used this tactic as well. A celebrity's involvement will typically include public service announcements and other educational materials,

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<sup>10</sup> *It should be noted that when school-based programs were started in the 1960s, educators believed that the key to effective prevention was to warn young people about the dangers of substance abuse. It is now recognized that programs which only emphasize consequences are of limited value. First, investigators found evidence that, among some youth, such programs might stimulate curiosity about drugs and a rise in experimentation (Bandy & President, 1982; Polich et al., 1984). Second, such programs often resorted to exaggerated "scare tactics," which adolescents detected and discounted.*

publicity events, promotional tours, and fund-raisers. If the spokesperson's association with the message becomes strong enough, his or her presence alone can evoke recall of the message (Benn, 1978).

Even so, there are risks to using this strategy. First, the message may be overwhelmed by the celebrity's presence and ultimately forgotten (Atkin, 1979; Ogilvy, 1985). Second, celebrities can lose their lustre; among adolescent fans in particular, perceptions of entertainment and sports stars often change very quickly (Graham & Hamdan, 1987). Third, celebrities can suddenly become newsworthy in ways that directly undermine the campaign or are otherwise inappropriate<sup>11</sup>.

In selecting a celebrity spokesman, the watchword is caution. A celebrity should be selected whose public image fits the underlying strategy of the campaign, not just because he or she is available (Bandy & President, 1982). Available data on the celebrity's popularity among different demographic groups should be examined, and formative research should be undertaken to test the target audience's perceptions of the celebrity's trustworthiness<sup>12</sup>, credibility<sup>13</sup>, and attractiveness (McGuire, 1985). Most important, people who know the celebrity, and whose judgment can be trusted, should be consulted for their advice whenever possible.

Campaign planners should seek opportunities to promote a product or service whose use is consistent with the campaign's health theme (Rehony et al., 1984). Perhaps the classic example of this approach is the promotion of condoms as part of family planning or AIDS prevention programs (Altman & Piotrow, 1984; DeJong, 1989; Sherris, Lewison, & Fox, 1982): The central benefit of this approach is that it allows the direct application of commercial marketing and advertising strategies (Black & Harvey, 1976).

Campaign planners can often develop a new product or service that can be promoted as part of their program (Lefebvre & Flora, 1988). A good example of

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<sup>11</sup> *In the case of substance abuse prevention messages, there is also a fourth consideration: Adolescents often view celebrity messages skeptically, because they suspect the celebrity was paid to deliver the message or because they believe that many stars are substance users (Harvard Business School, 1987).*

<sup>12</sup> *Perceptions of trustworthiness will be undermined if the source of the message is seen as lacking good will or having manipulative intent. As a result, young people, especially those who are rebellious against adult authority, may view any adult spokesperson with suspicion (Bauman et al., 1988).*

<sup>13</sup> *Because of the documented importance of credibility, it is tempting to rely on scientific experts to provide health promotion messages. In some cases this will backfire. Schlegel (1977) cautions, for example, that adolescents who see themselves as relatively sophisticated about drugs may view all others, including scientific "experts," as less credible than their friends (see Smart & Fejer, 1972).*

this strategy is provided by the Pawtucket Heart Health Program, which is focused on cardiovascular risk reduction (Lasater, Lefebvre, & Carleton, 1988; Lefebvre, Peterson, McGraw et al., 1986). Commodities publicized through the mass media include a cookbook and a "Four Heart" restaurant program through which eateries offer low-fat, low-salt menu options. Another possibility is to promote coupon books that offer free or discounted products and services whose use is consistent with the public health campaign (Bollier, 1989). It should also be recalled that community-based intervention programs (e.g., self-help groups, screening/counseling events, smoking cessation programs) can also be promoted (Lefebvre et al., 1988).

A related tactic is contest sponsorship (Graham & Hamdan, 1987). For example, as part of their radio-based anti-smoking campaign, Bauman et al. (1988) included a special promotion, the "I Won't Smoke" Sweepstakes, as a means of encouraging peer involvement and interpersonal communication about the campaign. Entrants sent in an entry form with their name and address; at their option, they could sign a pledge not to smoke. Entrants could enroll friends in the drawing in return for cash awards. During the drawing itself, the prize doubled in value to \$2,000 if the winner's entry form indicated that he or she was a non-smoker.

Another possibility is for a health promotion campaign to establish links with commercially available products or services. In this strategy, called "cause-related" marketing, advertising for the product or service also carries a public health message (Moses, 1988). While it is ideal for there to be a direct link between the commodity and the health message (e.g., life insurance with drunk-driving prevention, physical fitness equipment with smoking prevention), such a connection is not strictly necessary. For example, the Frito-Lay Corporation, one of the country's largest makers of potato chips and other snack foods, agreed to donate money to the non-profit Just Say No Foundation with each customer purchase, a promotion announced in advertising and on its packaging with a brief anti-drug message.

Public health advocates can also emulate a strategy used by tobacco and beer companies -- the official sponsorship of sporting events, concerts, and other cultural or youth-oriented activities. For example, Canada's "Break Free" campaign became the official sponsor for the Arctic Winter Games and the Student Regional Games and distributed "Break Free" toques and headbands as part of those events (Liepold, 1986). Because such events are often financially dependent on the fees paid by their sponsors, use of this strategy by public health advocates will be limited unless they can negotiate with a product or services company to co-sponsor the event.

#### **LESSON 4: STIMULATE INTERPERSONAL COMMUNICATION**

Stimulating interpersonal channels of communication can enhance a mass communication campaign in several ways (Flay & Burton, 1990; Rogers, 1983). First, communication through a social network ensures that the message is spread beyond the original audience. If discussion of a topic is frequent, then any new information provided through the mass media is more likely to be attended to and remembered. Second, interpersonal communication is generally very effective for delivering complex information and persuasive messages. Third, interpersonal communication can increase the likelihood of new behaviors being tried, adopted, and maintained (Flay, 1986).

In using a mass communication campaign to stimulate this process, it is important to target messages to a community's opinion leaders or "trend-setters" (Black & Farley, 1977; Rogers & Shoemaker, 1971). Katz and Lazarsfeld (1955) describe this as a two-step flow of communication, from the sources of mass communications to informal opinion leaders, and then from these leaders to others.

The importance of this approach is underscored by studies on the impact of mass media on youth at high-risk for drug abuse. In their review of the literature, Bandy and President (1982) noted that the more often students use drugs, the less likely they are to believe information conveyed through the mass media. One study they reviewed found that non-users rely primarily on the mass media to learn about drugs, whereas drug users rely primarily on information from their friends and their own experience.

#### **LESSON 5: USE A VARIETY OF MASS COMMUNICATION CHANNELS**

A variety of communication channels should be used to provide a clear and consistent message, thereby reinforcing one another (Atkin & Arkin, 1990; DeJong, 1989). Particular channels should be selected according to the target audience's media preferences and the objectives of the campaign (Alcalay & Taplin, 1989).

Television is an attractive medium because of its large and diverse audience, which creates the capacity for bringing immediate attention to an important issue or concern. On the other hand, television programming is passively consumed, which limits the type of information that can be conveyed (Atkin, 1979). In general, television is excellent for providing short, uncomplicated messages, evoking emotional reactions, establishing evidence of new social norms, and modeling behaviors that can be easily taught.

Because each television show's audience varies in its demographic profile, narrowly defined audiences can be targeted. Current trends toward the "fractionalization" of television, caused primarily by stronger independent stations, cable channels, and syndication of first-run shows, also provide opportunities for targeting specific audiences such as young people (Atkin & Arkin, 1990; Graham & Hamdan, 1987). On the other hand, use of these media greatly increases the logistical demands on campaign planners.

The potential of radio, especially for reaching adolescent audiences, has not been fully appreciated by public health campaign organizers. Radio shares many of television's advantages, but obviously does not carry the impact of the visual medium. On the other hand, radio calls upon the imagination more than television, which may be an advantage for certain types of messages. Radio is also much less expensive, which allows greater repetition of the messages. Moreover, the variety of stations on the air facilitates the targeting of messages to very narrowly defined groups, which can be identified through marketing reports used by the industry. For a national campaign, a major disadvantage of radio is the large number of independently owned stations that need to be approached, even with a focus on major markets. For certain audiences, such as adolescents, nationally syndicated programs with celebrity "disk jockeys" might provide a more feasible venue.

The print media are less able to command attention than the broadcast media, but they can be used to reach finely differentiated target groups. And because print advertisements, brochures, and feature articles can be reread and invite reflection, they are better suited for presenting rational arguments or detailed information (McGuire, 1989).

A media plan should rely on audience rating systems and formative research to identify which specific stations, programs, or print media are the best vehicles for reaching the target audience at the lowest cost per contact. Obviously, the right "media mix" varies according to the particular audience being addressed.

An issue that cannot be satisfactorily answered is what does, in fact, constitute "adequate" exposure. Public communication specialists have not extensively studied this issue in health campaigns because, historically, they have relied on public service time or have had small budgets to work with. Only two broad generalizations can be offered as guidance. First, repetition helps draw attention to the message (Solomon, 1983), facilitates learning, and increases liking for the message. However, repetition can be counterproductive if it is excessive and turns the message into a cloying annoyance (Bornstein, 1989). Second, airing ads in high-frequency bursts (or "flights") is superior to having the same number of ads drawn out over a longer period (Atkin, 1979).

Precise guidance is lacking, however, since the right amount of exposure depends on too many variables -- the nature of the target group, the precise objective, the complexity and entertainment value of the message, the nature and extent of competing messages, and so forth. Because there is no valid way to measure advertising effectiveness, even commercial advertising agencies do not always know which media should be selected or how frequently they should be used to achieve a particular advertising objective (Sissors & Surmanek, 1987). Audience tracking studies can be executed as the campaign is launched to gauge audience exposure to the campaign message. In general, such studies will not be a priority for health campaigns operating on limited budgets. But if severe doubts about the media plan develop, focus groups could be used in lieu of a formal audience survey to see how the plan might be modified (Solomon, 1989).

While public health advocates typically turn to the traditional media -- television, radio, and print -- for mass communications campaigns, there is, in fact, a diversity of media venues to be considered, including billboards, transit cards, newsletters, videotapes, and booklets. New advertising venues will continue to emerge. The Whittle Corporation developed several new venues during the 1980s, including commissioned books distributed free to the nation's opinion leaders; message boards for school gyms; and, with much controversy, daily news programming beamed to high schools via satellite. Other new developments include screen advertising in movie theaters (Atkin & Arkin, 1990) and the use of "dial-in" phone messages, which are promoted in billboard and print advertisements (OSAP, 1990).

## **LESSON 6: TAKE STEPS TO ENSURE AUDIENCE EXPOSURE TO THE CAMPAIGN**

Many public service campaigns that use television and radio simply fail to reach their intended audience (Flay, 1986; Flay & Sobel, 1983; Warner, 1987). Public service advertising developed by the Advertising Council and others is typically used by broadcast stations as "filler" and is often aired at off-hours with small audiences. Of particular concern, television public service ads are infrequently aired during prime time when preteens and adolescents are viewing (Hanneman, McEwan, & Coyne, 1973). This has been a long-standing problem, but it has been worsened by the loosening of broadcasters' public service obligations during the 1980s (Atkin & Arkin, 1990)<sup>14</sup>.

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<sup>14</sup> *In response to this concern, there were calls at the December 1988 Surgeon General's Workshop on Drunk Driving for commensurate time for "responsible drinking" messages as a counterweight to beer and wine advertisements (OSG, 1989). A similar lift was given to the anti-smoking movement in the late 1960s when the Federal Communications Commission (FCC) applied the fairness doctrine to tobacco advertising on radio and television and required stations to provide anti-smoking groups with free time to air their views (Flay, 1987). When tobacco advertising was*

Because campaign organizers want to ensure audience exposure to their campaign, the competition for donated time is fierce. A public service campaign's success in winning donated time depends in part on the issue involved and its perceived importance to media "gatekeepers" who establish public service priorities for each broadcast station. The Centers for Disease Control's AIDS campaign, for example, received more than \$28 million in donated air time from October 1987 through February 1989. A 1989 survey showed that 22 percent of U.S. adults recalled seeing or hearing during the past month a public service announcement with the slogan "America Responds to AIDS" (Dawson, 1989). It has also been observed that local gatekeepers will respond more favorably to public service spots that are "creative" and that have local program or agency taglines or allow a local station to add their own (Freimuth & Van Nevel, 1981; Hammond et al., 1987; Goodstadt & Kronitz, 1977).

Public health advocates have responded to the intensified competition for public service time by trying to build relationships with the media gatekeepers (Maccoby & Alexander, 1980). For example, in implementing the Asbestos Awareness Campaign, the project staff made special efforts to persuade the gatekeepers in 16 target communities to air the public service announcements, including personal contact, press kits, and fact sheets (Freimuth & Van Nevel, 1981). At the national level, the Harvard Alcohol Project was able to secure the cooperation of the three major networks to produce and air prime-time advertising to promote the "designated driver" concept (DeJong & Winsten, 1990b).

Some recent campaigns have purchased air time, using it exclusively or in combination with public service time (Bauman et al., 1988; Wallack & Barrows, 1982-83; Worden et al., 1988). This strategy is controversial within the public health community. While some health advocates focus on the need to get their messages on the air in the best time slots, others express concern that paying for media time will cause the broadcasters to demand payment for other public service advertising (Bloom & Novelli, 1981; Dessart, 1990).

Clearly, however, the restricted financial resources of nearly all public health agencies limit the extent to which this approach can be used, especially with television. Even the U.S. Department of Health and Human Services, which sponsors numerous health promotion campaigns through the Public Health Service, generally does not have funding for buying airtime (Warner, 1987). Some local stations have recently received publicity for selling air time for public service campaigns at greatly reduced rates (Meyers, 1989), but the cost still remains too

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*banned from the broadcast media in 1971, the mandate for anti-smoking advertisements ended as well (Wallack, 1981). Similar action by the FCC on alcohol advertising now appears to be extremely unlikely (Colford, 1989).*

high for most public health programs. Radio, billboards, and transit cards represent more realistic alternatives for paid public health advertising (Arkin, Denniston, & Romano, 1990).

Corporate sponsorship might provide a partial answer to this funding problem. For example, anti-drug spots developed by the Media-Advertising Partnership for a Drug-Free America are frequently aired through a combination of donated time, both nationally and locally, and corporate sponsorship.

Another possibility is to work directly with broadcasters to develop a new campaign. In local communities, a broadcast station might want to develop an exclusive, station-sponsored campaign, one that focuses the station's energy on a single problem of public concern (Wishnow, 1983). Occasionally, a major network will undertake such a campaign as well, as evidenced by CBS's involvement in the "Be Smart. Don't Start!" campaign (Atkin, 1989a).

In station-sponsored campaigns, newscasts, documentaries, talk shows, public service announcements, and editorials work in sync to inform and motivate the public and to offer solutions, either in the form of individual/collective action or a change in public policy. For some campaigns, the station or network will work in partnership with business, government, and voluntary organizations to create a direct intervention, such as print materials, smoking cessation kits (Sallis, Flora, Fortmann et al., 1985), and special events. Station managers find that such campaigns serve the station's needs by bringing community recognition and acclaim, which in turn increase ratings for local programs. Corporate sponsors can be asked to provide funding in return for on-air mention of their involvement.

For certain issues, such campaigns provide a unique opportunity for public health advocates to achieve their health promotion objectives. For example, in Washington, D.C., WRC-TV sponsored a prenatal health care campaign, "Beautiful Babies: Right from the Start," which featured a series of news reports, documentaries, public service announcements, and editorials. Most notably, local obstetricians participated in distributing coupon books that offered a variety of products and services at reduced cost, many of them directly related to prenatal and child care. As a result of the campaign, more than 60,000 coupon books were distributed. After 18 months, prenatal visits to public health clinics had increased 22 percent and infant deaths had declined 6 percent (Bollier, 1989), although campaign organizers acknowledge that the campaign's contribution to these changes cannot be proven.

## LESSON 7: INCORPORATE THE STRATEGIC USE OF TELEVISION ENTERTAINMENT AND NEWS PROGRAMMING

Mass communication campaigns have traditionally involved the use of public service advertising, including radio and television spots, print ads, billboards, posters, and printed literature. More recently, several public health advocates have argued that campaign planners should think more expansively about how the mass media can be used to reach the public, moving beyond the realm of public service announcements to include news and entertainment programming as part of a single, unified campaign (Atkin & Arkin, 1990; Mendelsohn, 1973). The failure to use such programming as vehicles for health education represents a missed opportunity. Beyond that, however, this failure frequently results in the public being exposed to conflicting messages that undermine the campaign (Atkin, 1979). The advantages and limitations of using entertainment and news programming are reviewed here.

### Television Entertainment Programming

As the "most effective purveyor of language, image, and narrative in American culture," (Marc, 1984), television is an important influence in shaping cultural norms, public opinion, and behavior. Television programming not only mirrors social reality but helps shape it, by communicating what constitutes popular opinion and by influencing people's perceptions of the roles and behaviors that are appropriate to members of a culture (Roberts & Maccoby, 1985; Signorielli, 1990). For many people, and for children and adolescents especially, television programming is a key source of information about how the world works and how one should behave in that world (Atkin, 1989b; Roberts, 1989).

Unfortunately, because plots and script lines are selected primarily for their entertainment and artistic value, a great deal of the health-related information that is presented on television is inaccurate, misleading, or antithetical to good health (Atkin, 1979; NIMH, 1982). For example, recent data show that, while drug and tobacco use is infrequently shown on television, the portrayal of alcohol use averages several "acts" per hour, far more often than several other more popular beverages, including water (Signorielli, 1990). In combination with beer and wine advertising, this barrage overwhelms the message from infrequently aired public service advertising that urges preteens and young adolescents to abstain (Wallack, 1990a).

As a result, public health advocates have pursued two strategies for working with the entertainment industry to promote lifestyle changes and healthier behavior: 1) consulting with producers, writers, and directors concerning the content of regular entertainment programming (Breed & DeFoe, 1982; Montgomery, 1989, 1990),

and 2) collaborating in the production of special programming around health promotion themes (Mendelsohn, 1973).

Consultation with the Entertainment Industry. While lobbying the U.S. entertainment industry has been common over the last 20 years, this strategy has been given new impetus by the highly publicized Harvard Alcohol Project, a university-based campaign designed to prevent drunk driving through promotion of the designated driver concept via entertainment programming and network-sponsored public service announcements (DeJong & Winsten, 1990a, 1990b; Winsten, 1990). After three television seasons, messages consistent with the project's agenda have appeared in over 100 shows, including both dialogue and the display of a designated driver poster developed by the project. While several would-be imitators have been inspired by the Harvard project, several facts about it point to its limitations as a model for other health promotion efforts.

The director of the Harvard project was afforded access to top executives of major Hollywood production studios through the direct intervention of Dr. Frank Stanton, former president of CBS and, at the time, a member of Harvard's Board of Overseers. As Montgomery (1989) notes, producers in general have sought to keep outside lobbyists at arms length. As a result, "Hollywood lobbyists" usually devoted a number of years to building a small network of supporters in the industry, largely through hosting seminars, panel discussions, or lectures. In more recent years, however, the most successful lobbying efforts have been set up by industry insiders or greatly assisted by them and have used those personal connections as a basis for private discussions with individual producers (Stevenson, 1990). Obviously, few public health advocates can rely on that kind of insider support and will find access extremely difficult to achieve.

The designated driver concept itself has several important features that distinguish it from other public health topics and make it a more attractive theme for producers and network executives. First, Mothers Against Drunk Driving (MADD) and other advocacy groups had already aroused public concern about the drunk driving problem. Because shifts in social norms regarding the acceptability of driving after drinking had already begun, the role of the television industry could be accurately described as one of reinforcing an emerging trend rather than "engineering" a new one. This fact helped deflect criticism that a systematic effort to influence public opinion and behavior through entertainment programming was an abuse of concentrated media power.

Second, the designated driver message could be easily incorporated into programming on a routine basis, especially since scenes involving alcohol use are a staple of television programming (Breed & DeFoe, 1981; Gerbner, 1990). The introduction of other public health topics -- drug abuse, AIDS, teenage pregnancy, organ transplantation -- represents a more radical departure from standard

programming fare. Many of these health issues lend themselves to dramatic treatment, but only as a special episode or program. Such programs might be worthwhile for drawing attention to an issue, but they should not be seen a tool for bringing about substantial change over the long-term.

Third, the designated driver message, by emphasizing individual responsibility to prevent the drunk driving, meets the television industry's need to do something positive while not alienating the alcohol industry, on whom broadcasters depend for a significant portion of their advertising revenue ("Advertiser Report," 1990; Wallack, 1990a). Indeed, many public health experts worry that the Harvard campaign has taken the pressure off the television networks to modify alcohol advertising practices that appeal to minors. In general, the television industry is more likely to focus on politically non-controversial subjects or solutions -- an important limitation (Montgomery, 1990).

A restriction commonly shared by any effort to use television entertainment programming to communicate a public health message is the inability of outside organizations to control programming content. For example, guidelines developed by the Harvard Alcohol Project emphasize that promotions of the designated driver concept should not imply that it is socially acceptable or even expected that the driver's companions will drink to excess (DeJong & Winsten, 1990b). Even so, a few television episodes that mentioned the designated driver concept did so in a way that directly violated this important guideline.

Development of Special Programming. A second option for working with the entertainment industry is to collaborate in developing special health-related programming. While programs aired nationally are an occasional possibility (Montgomery, 1989), true collaboration is more likely to occur at the local level. As one example, the ongoing Stanford Five Community Project initiated its education program with the airing of a locally produced hour-long documentary ("Heart Health Test") that provided general information on cardiovascular risk reduction (Farquhar et al., 1985a). Development of special programming is particularly useful for audiences that are not well-served by the major networks, such as Latinos (McAlister et al., 1987; Mendelsohn, 1973).

### News Programming

Public health advocates have long recognized the importance of obtaining favorable news coverage to support the objectives of a health campaign designed to promote behavior change. Especially valued is the greater visibility and the "third-party endorsement" of campaign messages that news stories can bring (Alcalay & Taplin, 1989; Goldman, 1984).

In recent years, this strategy has been given renewed prominence by public health advocates wanting to promote changes in public policy. What they call the "media advocacy" approach features a variety of public relations strategies to stimulate media coverage that will serve to reframe how the general public and opinion leaders conceptualize a public health problem, and to promote a consideration of public policy options (NCI, 1988; Wallack, 1990b). This strategy is especially important when the policy changes being urged threaten commercial advertisers who financially support the media.

A number of guidelines should be followed in seeking news coverage. First, it is important to have clear objectives for what is to be achieved through news coverage. Publicity for its own sake is an insufficient reason. In 1988, for example, the Harvard Alcohol Project issued a press release announcing that the major television production studios had agreed to introduce the designated driver concept in entertainment programs. The resulting page-one story in The New York Times (Rothenberg, 1988) served several purposes: giving additional visibility to the issue of alcohol-impaired driving, directly promoting the designated driver concept, and establishing the institutional identity and stature of the Harvard Alcohol Project itself. But the principal rationale for issuing the press release was to solidify the production studios' commitments through public exposure, an objective which was achieved.

There are other considerations to using this strategy successfully. Foremost, the press announcement must present information that has real news value<sup>15</sup>. Public health advocates too often assume that all of their activities, because they are important, are also "newsworthy" (DeJong & Winsten, 1990a). Instead, public health advocates must understand how news institutions define the "news," the incentives to which reporters and editors respond, and their preferences for how news information is packaged and presented (Atkin & Arkin, 1990; Bantz, McCorkie, & Baade, 1980; Stuyck, 1990).

Generally, for health-related information to be defined as news it must be more than new. The story must also have aspects that make it especially attention-grabbing. Meyer (1990) lists several factors that contribute to a story's appeal: timeliness, geographical proximity, prominence of the people involved, human (emotional) interest, controversy, novelty, and potential impact on people's lives. Stuyck (1990) adds another important factor: the story's potential for creating more informed health consumers. Thus, campaign planners must think creatively about how they can get reporters interested in their message or story.

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<sup>15</sup> As explained by Alcalay and Taplin (1989), press releases can announce an upcoming event and invite the press to cover it; issue a public statement on a news development or issue; or provide background information that gives perspective on late-breaking news.

There are several standard ways of achieving this. One is to issue a survey report or other research findings that give new insight into a health problem and its solutions (Wallack, 1990b). For local news coverage, national data have to be given a local perspective (NCI, 1988). Another is to announce upcoming program events. Indeed, when deciding what steps to take next in a program or campaign, planners should take into consideration the public relations value of the various alternatives (Goldman, 1984). The American Cancer Society, for example, found a powerful idea in its Great American Smokeout, which continues to generate news coverage year after year (Flay, 1987). Yet another means of generating news coverage is to create "media events" such as receptions, speeches, policy debates, awards ceremonies, or special fund-raising events (Player, 1986; Wallack, 1990b; Warner, 1987). Staging events for television is especially important, as stories with a strong visual element are given higher priority (Klaidman, 1990).

Another consideration is that the press announcement must be timed properly so that it does not compete with other stories (DeJong & Winsten, 1990a). While campaign planners cannot fully anticipate the flow of world and national events, certain days are typically "slower" news days than others. Knowing this, staff for the Harvard Alcohol Project issued its aforementioned press release in late August, when Congress is typically in recess and many news-making organizations are enjoying a vacation lull.

To maximize its serious consideration, a press release is best addressed to reporters with whom the campaign planners have established credibility over time, perhaps by serving as a background source for other stories. On occasion, relationships with the press can be nurtured by offering periodic exclusives, although it must be cautioned that overusing this strategy might eventually alienate those relationships. Relationships with print reporters are especially critical, since local broadcast media often rely on area newspapers when determining what stories to cover.

A relatively new means of generating press coverage is the distribution of so-called "video news releases," which are professionally produced program segments suitable for use on evening news programs, TV magazine shows, or documentaries. Unfortunately, production expenses do not make this a reasonable alternative for many public health agencies (Kleiner, 1989; Davis, 1988). On the other hand, "audio news releases" for use on radio might be an effective alternative, especially if only a limited number of radio stations are targeted.

In considering the advantages and disadvantages of trying to generate supportive news coverage, public health advocates must recognize that the news media are an imperfect instrument for communicating health messages (Stuyck, 1990). First, because broadcast news programming thrives on political controversy, it provides limited opportunities for providing clear and consistent messages health messages.

This fact was amply demonstrated by press coverage of New York City's announcement of its 1987 AIDS campaign aimed at promoting condom use among heterosexuals. Several television reports aired the campaign's spots as part of their news coverage, thereby furthering the objectives of the campaign. On the other hand, these reports also featured interviews with a clerical spokesman for the Catholic Archdiocese of New York, who objected strongly to the "graphic" portrayals in the campaign's television spots and their implicit endorsement of "promiscuity." In further support of his attack on the campaign, this spokesman asserted that the condom's high failure rate made it a poor choice in AIDS prevention efforts. This claim, which failed to account for consumers' sometimes improper or inconsistent use of condoms (Sherris et al., 1982), was not challenged in any of the news reports.

Second, the competitive pressures on news reporters frequently resulted in incomplete investigative reporting and the sensationalized treatment of tentative scientific findings, both of which contributed to public confusion and panic. In one especially important case, a study reported in a 1983 issue of the Journal of the American Medical Association hinted that "routine contact" among household members might be sufficient for AIDS transmission to occur. Although subsequent studies showed that the disease was not spread through casual transmission, and although these studies were covered in turn by the news media, the initial stories nevertheless had a residual effect (Milavsky, 1988). This residual effect was sustained in the mid-1980s by continuing coverage of public hysteria about AIDS, as manifested in the boycotts of schools attended by AIDS victims, public arrests of AIDS patients by police wearing protective gloves, and so forth.

Recognizing the inherent limitations in using news coverage to carry forth a health promotion message, some health advocates have begun to create their own publications, a strategy also used in the commercial sector. The Philip Morris tobacco company, for example, publishes Philip Morris, a "lifestyle" magazine that is distributed free to self-identified smokers. At one level, the magazine serves as a company-controlled venue for its standard print advertising, but the magazine also reinforces the reader's self-definition as a smoker by publishing articles, features, and consumer advertising that associate this identity with an active, upscale lifestyle. The magazine also presents a political agenda that portrays smokers as an "oppressed" minority; direct mail solicitations sent to subscribers encourage them to put pressure on State and local politicians to defeat anti-smoking ordinances and legislation (Sylvester, 1989). A public health counterpart to Philip Morris is Zoot, a slick and highly popular "lifestyle" magazine distributed free to teens by the Alberta Alcohol and Drug Abuse Commission (AADAC) in Canada as part of its general campaign to promote healthy lifestyles that exclude alcohol, tobacco, and drug use ("Unique Magazine," 1988-89).

## **LESSON 8: DEVELOP MASS COMMUNICATION STRATEGIES THAT WORK IN SYNC WITH COMMUNITY-BASED PROGRAMS**

Both the Stanford and North Coast studies suggest that mass communications alone, when properly designed and executed, can produce behavior change. Even so, both sets of investigators later turned to demonstration projects that used mass media in tandem with community-based programs -- the Stanford Five Community Study (Farquhar et al., 1985a), and the "Quit for Life" campaign in Sydney, Australia (Dwyer, Pierce, Hannam, & Burke, 1986; Pierce, et al., 1986).

It has long been recognized that a media-driven health promotion campaign is more likely to succeed in changing behavior when other program components are in place, a condition that Lazarsfeld and Merton (1971) have called "supplementation." Accordingly, many researchers emphasize that media approaches should work in sync with community-based program components that involve long-term, face-to-face education and community reorganization (Alcalay & Taplin, 1989; Flay, 1986; Solomon, 1983; Wallack, 1980). Media can support these local programs in several ways. In turn, these programs can reinforce a media effort by giving shape to an audience that is primed to attend to the media campaign (Flay, Hansen, Johnson et al., 1988; LaRose, 1989) and by helping link the media campaign to local concerns and issues (O'Keefe & Mendelsohn, 1984).

Those who favor using mass communications with community-based programs note that many problems, such as cancer prevention and cardiovascular risk reduction, involve altering long-standing habits and complex behavior patterns. The Stanford study described earlier showed that a media campaign alone, while producing an reduction in overall risk, had a demonstrable impact only on fat consumption but no long-lasting effect on smoking or leisure-time physical activity. The same issue arises with substance abuse. While some have endorsed using mass communication campaigns to reach high-risk youth whose profile makes their abuse of drugs more likely (Worden et al., 1988; Wallack, 1986), most investigators do not endorse this approach, since a person's psychological make-up is a product of life experience and is extremely difficult to change even with direct, intensive intervention. As a result, many programs try to induce members of target audience to participate in programs with face-to-face intervention or to use specially crafted self-help programs (Lefebvre et al., 1988).

In other cases, standard mass communications approaches will be thwarted because of political controversy. For example, to encourage condom use for AIDS prevention, there is a need for motivating messages that focus on how condom use can bring sexual pleasure; failure to do so means ignoring the principal psychological barrier that impedes condom use by U.S. consumers (Solomon & DeJong, 1986, 1989). Reacting to widespread public sentiment against contraception, and wanting to avoid the political or economic pressures that would

ensue, television broadcasters have established standards that make it impossible to use paid or public service advertising for this purpose (DeJong & Winsten, 1991)<sup>16</sup>. With these restrictions in view, health advocates would better focus on community-based education programs that stress condom promotion or local social marketing programs (DeJong, 1989; DeJong & Winsten, 1991). Local broadcast media could support these programs by publicizing them and directing people to information hotlines.

Mass media campaigns can be used in several ways to enhance the effectiveness of community-based programs (Flay, 1986; Wallack, 1980, 1981). First, mass communications can be used to enroll new program participants, recruit volunteers, or win financial support. Second, mass communications can announce the availability of self-help materials, ongoing program activities, and special events (Flay, 1986; Mendelsohn, 1973). Third, mass communications can reinforce the instruction provided by school-, worksite-, or other community-based programs, including skill development, self-monitoring, and other maintenance activities (Flay, 1986). In this case, the mass media materials should also work on their own, since many of those who are most in need of prevention education attend school irregularly (Worden et al., 1988) or are not reached by community programs working under limited budgets. At a minimum, messages from the mass communications campaign and these other components should be consistent; ideally, their activities should be guided by an integrated campaign strategy.

While having mass media and community-based programs work together is, in principal, a sound idea, the issue of cost-effectiveness and other practical concerns should not be forgotten. Hornik (1989, p. 312) expresses strong reservations about the widely held view that interpersonal channels should predominate: ". . . from the point of view of cost, of feasibility, and of sustainability, organizing a face-to-face network is rarely possible." In his own study of a Swaziland program to promote oral rehydration therapy (ORT), Hornik found that a series of radio programs, given their broad reach among the target audience, were a much more effective strategy than using interpersonal channels such as clinic-based health care professionals, health extension agents, and trained community volunteers.

Warner (1987) makes a similar point, noting that a mass communication campaign needs only a small success rate to produce change among a far group of people than can be reached through conventional community-based programs that have much higher success rates. Cost-effectiveness is therefore a more suitable

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<sup>16</sup> *Television entertainment programming offers greater leeway for introducing motivating messages, but they cannot be incorporated into programming often enough to make a critical difference and must be "balanced" by the inclusion of opposing viewpoints (Montgomery, 1990). News programming, because of its focus on political controversy, is similarly limiting.*

criterion for judging health promotion strategies. Even so, major health promotion projects have devoted very little attention to assessing per unit costs (McGuire, 1984).

### LESSON 9: USE MASS COMMUNICATIONS TO FOCUS ATTENTION ON THE SOCIAL, ECONOMIC, AND CULTURAL FACTORS THAT IMPACT HEALTH-RELATED BEHAVIOR

So far we have examined campaigns from the standpoint of trying to effect change in the knowledge, attitudes, and behavior of individuals. An increasing number of public health experts have argued that a number of health problems, especially those resulting from lifestyle behaviors, can only be understood and dealt with by focusing on the social, economic, and cultural context in which they occur (Atkin & Arkin, 1990; Alcalay, 1983; Gerbner, 1990; McLeroy et al., 1988; Wallack, 1984, 1986, 1990a).

In their view, it is inappropriate and self-defeating for prevention campaigns to put the onus on the individual for changing his behavior while failing to change the business and legal environment in which that behavior occurs. Ultimately, changes in institutional structures, public policy, or law can lead to greater resources being allocated to a problem and to environmental and social changes that will support and sustain the efforts of individuals to alter their behavior. In the case of adolescent substance abuse, for example, there is a need for increased public debate on issues related to the cost, availability, and promotion of alcohol and tobacco (Mosher & Jernigan, 1989), and on policy changes that might discourage substance use, such as stricter enforcement of laws prohibiting alcohol sales to minors, the elimination of cigarette vending machines, and increased excise taxes to provide funding for school- or community-based programs that provide direct, high-intensity interventions for high-risk youth (Tobacco Education Oversight Committee, 1991).

In this context, the agenda-setting function of mass communications can be more broadly conceived to include targeted messages to official policymakers (Wallack, 1986) or community opinion leaders (Black & Farley, 1977; Rogers & Shoemaker, 1971). Directing awareness campaigns to business and civic leaders, what Schwartz (1973, 1983) calls "narrowcasting," can be an especially powerful way of moving a problem to the top of a community or national agenda. As one example, the first phase of a Swedish campaign to promote condoms was to sell national opinion leaders on the importance of combatting venereal disease and to improve the condom's image as an acceptable, even respectable contraceptive (Ajax, 1974). Having established the need for concerted action, campaign organizers were able to move ahead with a marketing effort that included

introducing new condom brands and specialty retail outlets<sup>17</sup>. Importantly, business and civic leaders can be reached through radio and newspapers whose lower advertising rates make a paid campaign feasible (Alcalay & Taplin, 1989; NCI, 1988).

An important role for social marketing approaches is to promote citizen involvement in community-based efforts to promote social, institutional, environmental change. As one example, parents of preteens and adolescents can be recruited to participate in local parents' groups that sponsor alcohol- and drug-free parties, cooperate with police in monitoring local conditions, and advocate changes in public policy, such as the development and enforcement of stricter school policies, more conscientious enforcement of existing laws on the sale and distribution of alcohol to minors, and new legislation setting a legal limit of .00 percent BAC for underage drivers or imposing driver's license sanctions for the purchase or possession of alcohol by minors.

In the end, once legislation or other policy changes have been implemented, mass communications provide a superb vehicle for publicizing them -- not just through news coverage, but also through special advertising and promotions. In drunk driving prevention, for example, widespread publicity of "sobriety checkpoints" and other law enforcement measures has proven to be essential. In the absence of such publicity, such efforts have no discernible impact (Ross, 1988).

## LESSON 10: INCLUDE PROCESS AND OUTCOME EVALUATIONS AS PART OF THE CAMPAIGN

Early program planning should incorporate both process and outcome evaluation activities to monitor progress and demonstrate project impact (Lau, Kane, Berry, et al., 1980; Wallack, 1984). Unfortunately, the common failure to evaluate mass communication campaigns has impeded progress in understanding what works and what does not (Arkin et al., 1990).

The behaviorist tradition of most campaign evaluations (Gitlin, 1978; Wallack, 1984) has failed to capture the diversity and complexity of mass media effects,

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<sup>17</sup> On occasion, a mass communications campaign will need to focus on convincing opinion leaders and the public at large that a particular institution should take responsibility for addressing a health problem. A substance abuse prevention campaign by the Alberta Alcohol and Drug Abuse Commission (AADAC) began in this way. Because the AADAC had been associated in the public mind with efforts to control and treat derelict alcoholics, the first step of the campaign was to use advertising to position the AADAC as an innovative, forward-looking agency that was concerned about youth and alcohol while not being "neo-Prohibitionist" (Skirrow, 1987).

many of which, as noted before, set the stage for or otherwise promote behavior change in the long term. Evaluations should be designed to capture these effects. As one example, if a campaign's objective is to move an issue to the top of the public agenda, the project's success can be established by tracking the number of news stories before and during the campaign, the number of legislative proposals submitted and passed, the number and size of grassroots advocacy groups, and so forth (Roberts & Maccoby, 1985; Wallack, 1980).

In most cases, evaluators will rely on the collection of survey data. Researchers often express concern about the honesty of self-reports, especially when they concern socially undesirable or criminal behavior such as illicit drug use. Even with respondents remaining anonymous, however, their answers to survey questions are known to be influenced by a desire to give socially acceptable answers. Moreover, the data's validity might change over time, perhaps in response to the very campaign being investigated, if admission to the behavior in question becomes more or less socially acceptable (DeJong & Winsten, 1991; Wallack, 1986).

These concerns are important, but certain precautions can be taken to minimize them. Respondents are likely to provide valid and reliable information if they are reassured that their answers will be kept in confidence (Rouse, Kozel, & Richards, 1985). In addition, the survey instrument can be carefully constructed to build in reliability cross-checks. Also, questions that measure respondents' propensity to give socially desirable answers, such as the Marlowe-Crowne scale (Crowne & Marlowe, 1964) can be included to factor out that source of bias.

To complement these survey data, program evaluations can also collect community-level data on product sales or other objective indicators that would be expected to change in response to the campaign. Doing so only makes sense, of course, when the campaign is of sufficient intensity and duration to reach a sizable proportion of the community.

### Local or Regional Campaigns

To test the impact of a long-term local or regional campaign, the research design of choice is a "quasi-experimental" design in which the knowledge, attitudes, behaviors, and health outcomes of people in experimental communities exposed to the campaign are compared to those in similar control communities (Farquhar et al., 1984; Flay & Cook, 1989). Fiscal limitations often restrict the use of each experimental condition to just one community (Flay & Cook, 1989). The design is called "quasi-experimental" because the communities are not randomly assigned to experimental conditions.

A pre-campaign survey, conducted either by telephone or face-to-face, is typically administered to establish baselines in both experimental and control communities.

Subsequent surveys are conducted during and after the campaign with the same respondents to assess change (these are called "cohort" or "panel" surveys). Subsequent data analyses often focus on those persons at greatest health risk, when they can be identified (Flay & Cook, 1989). To control for the effects of repeated testing, companion surveys are often done that involve a new, independently drawn sample ("cross-sectional" surveys). Ideally, that sample should be drawn at random from the target population<sup>18</sup>. Depending on the project, physiological measures might also be recorded.

The later surveys typically include questions that assess each individual's exposure to the campaign. The most conservative approach to analyzing the data is to include all respondents, regardless of their exposure. But it is useful in some cases to conduct post hoc analyses that compare those who have been exposed to the campaign with those who have not, recognizing that the lack of random assignment to these subgroups makes the meaning of such differences ambiguous (Lau et al., 1980). Brown, Bauman, and Padgett (1990) have identified another significant drawback: Respondents often cannot report accurately whether they have been exposed to a campaign, especially when the campaign's materials do not stand out from those of similar campaigns.

The principal difficulty with this quasi-experimental design is that the communities will differ in important ways before or during the study (Flay & Cook, 1989; Lau et al., 1980). Even when efforts are made to match the two sets of communities on a score of relevant variables, there is always the possibility that other unmeasured differences between the communities will contribute to or mask any differences in outcome. Only the random assignment of very large numbers of communities to treatment conditions can obviate this problem, but that is fiscally impossible in most cases.

Another threat to the validity of this design is the occurrence of events that affect one community more than another (Campbell & Stanley, 1983; Cook & Campbell, 1979). Concern over this potential problem has promoted organizers of the Pawtucket Heart Health Program to conduct content analyses of the major newspapers in each of its test communities and to conduct yearly interviews with health agency officials to learn about other interventions and their participation rates (Assaf, Banspach, Lasater et al., 1987; Lefebvre, Lasater, Carleton, & Peterson, 1987).

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<sup>18</sup> *The highly touted Media-Advertising Partnership for a Drug-Free America (Black, 1988) conducted both a benchmark and one-year follow-up studies using matched samples of children ages 9 to 12, teenagers ages 14 to 17, college students, and adults. So that respondents would remain anonymous, the evaluators used a "mall-intercept" procedure to recruit questionnaire respondents. Unfortunately, this procedure results in the selection of non-random samples.*

A final limitation is that the mass media interventions themselves are complex, which makes it impossible to derive definitive inferences about what each individual component adds to the campaign. For this reason, the quasi-experimental research design employed by Bauman et al. (1991) is especially noteworthy. In this study, three different campaign variations were tested in different communities: radio spots alone; radio spots, plus a sweepstakes; and radio spots, a sweepstakes, and television spots.

### National Campaigns

Testing the impact of a national campaign is extremely difficult, for with use of the national media, it is usually impossible to create meaningful comparison groups. An exception is when the intensity of the campaign can be varied across media markets. The Media-Advertising Partnership for a Drug-Free America reported, for example, that greater change in negative attitudes toward drugs was found in ten U.S. media markets that received a 50 percent greater exposure to the campaign materials (Black, 1988). Unfortunately, the high-exposure areas were not selected at random and may have differed in important ways from other areas of the country.

A good alternative is to collect time-series data on attitudes and self-reported behavior. A good example is the work by Warner (1989) on the impact of the anti-smoking crusade that began with the Surgeon General's report in 1964 and that included extended news coverage, anti-smoking public service announcements, and other media elements. Warner's strategy was to develop mathematical models that described trends in per capita cigarette consumption in the United States before 1964, to project post-1964 consumption based on those models (that is, as if the intensive anti-smoking campaign had never occurred), and then to compare those projections to actual consumption<sup>19</sup>. Warner (1977) notes several deficiencies in this commonly used measure of tobacco consumption, particularly that it masks changes in the composition of the smoking population and that it does not distinguish changes in smoking status from a mere reduction in smoking.

There are limitations to the time-series method. First, time-series modeling requires that reliable and valid data are available for an extended period of time. In many cases, the only data available will be broad indicators, such as statistics on alcohol-related traffic fatalities, rather than specific indicators of project objectives,

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<sup>19</sup> *The predictive mathematical models include the following variables for each year studied beginning in 1947: the value of the cigarette price index; the natural logarithm of the last two digits of the year, which reflects a natural increase over time in the smoking population, primarily due to more widespread use by women and increased consumption by existing smokers; and the per capita consumption for the previous year, which reflects the contribution of "habit."*

such as greater use of designated drivers. Such measures must often come from survey data. Unfortunately, many projects will find that detailed surveys on their topic area have not been done before.

A second limitation of the time-series method is the extreme difficulty of disentangling a mass communication campaign's contribution from that of other programs or even from broader historical trends or events. For the purposes of program evaluation, the time-series technique requires that there be a signal event whose occurrence can be precisely defined in time, such as the beginning of a new anti-smoking campaign in a government-controlled media environment (e.g., Doxiadis et al., 1985) or the introduction of a new concept such as designated driver (DeJong & Winsten, 1990b). In the field of public health, however, the occurrence of such events at the national level is rare.

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# **94 PERCENT AWARENESS AND STILL NOT ENOUGH DONORS**

## **CAN PUBLIC EDUCATION INCREASE ORGAN DONATION?**

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### **Introduction**

Every public opinion survey regarding organ donation and transplantation shows one undisputed fact: the American people are very aware of organ donation. They always respond at rates over 90 percent to questions about awareness. Yet, the donor shortage goes on. Something must still be needed that will translate awareness into a larger supply of organs.

This paper explores the role of public education in that relationship. It looks at what we in the transplant community have done to educate the public and what we would like to do. It also examines some of our basic assumptions and some of the conventional wisdom which has guided our planning. It isn't possible to calculate the amount of money, time, and energy we have devoted to public education. It has been considerable. We have achieved an awareness of 94 percent (1). That is a major accomplishment. Still, we don't have enough organs.

Can public education increase organ donation? The answer is no, not by itself. It is unrealistic to think that if we could just educate the public more, or better, the shortage would disappear. Public education is important, but it alone cannot increase the supply of organs. Its role is a supportive one, not a primary one. That concept challenges our basic assumptions about what public education can and should do and how we should conduct it.

Why is organ donation so different?

- It is not something you can do yourself.
- It is not something that benefits you at all.
- You cannot cause it to happen.
- It depends absolutely on someone else doing something.
- It is extremely unlikely.
- It occurs only after you're dead.

Traditional health education planning models have to be reconsidered when we apply them to these circumstances.

We usually think of public education in mass terms. But, the really important people are the 12,000 or so families who will be in a position to agree to organ donation next year (2). Campaigning to reach all 250 million Americans is not cost effective when we understand that currently half the families who actually could donate aren't even asked (3).

Public education has to fit within a total effort to raise the supply of organs. That means a concentration on the supportive and maintenance role of public education in allocating a community's scarce resources. A 94 percent awareness rate means the job is maintenance. Education should support the real circumstance of organ donation. That occurs in a hospital waiting room when one family hears one question. That's when we can tell if our education is working. If they've heard of organ donation, talked about it, and know it's what their loved one would have wanted, we've been successful.

The goal of public education is "To maintain a level of public awareness of organ and tissue donation which will favorably dispose families toward donation if they are ever asked to grant permission." Many things have to fall into place in order for organs to be donated. Public education can help the process be successful, but it can't go beyond that. We can't expect families, at that particular time in their lives, to seek the donation opportunity. That's why public education can't increase organ donation; it can only help the process be successful once the process has begun. Until that process begins a lot more frequently, public education will remain a secondary challenge. This does not mean that public education is unimportant. It is, and we're still going to do it. We need to maintain the excellent level of awareness that we've reached.

The time of organ donation opportunity is an emotion-laden, stressful, personal and private part of a family's life. We want our education to have predisposed the family toward agreement. We don't need to give them all the facts or details. We just need to have created the right atmosphere in their minds so that it seems more natural to say yes. To do that we hope they have a sense that:

- Transplantation is "good".
- Organ donation is the "right" thing to do.
- When a person dies "senselessly," the only "good" possible is organ donation.
- The person who died, a "good" person, would have wanted his or her family to do the "right" thing.

If those ideas are the sense of the situation in the family's mind, the process will be successful. Our planning should concentrate on what creates that sense, what reinforces it, and what would work against it. Those questions are the foundation of a new approach to public education.

Our educational framework should be built on a few basic, easily assimilated, simple themes, frequently repeated. We should skip the details; they are too negative, too easily misunderstood and too complicated. We want people to feel that organ donation is good, the "moral" thing to do.

Our mission is not to raise the educational level of the American people. Our mission is to increase the number of organs donated in this country so there can be more transplants. Public education is an important part of that. This Surgeon General's workshop gives us an opportunity to reflect on our successes and our challenges. It should be a catalyst for us to re-examine our thinking, evaluate our assumptions, clarify our intentions and renew our commitment to support our mission with effective public education programs.

### **Current State of the Art**

A 1987 Gallup Poll conducted for the Dow Chemical Company, reported that 94 percent of all Americans were aware of transplantation and organ donation (4). In general, the series of public opinion surveys conducted during the 1980s have consistently reported very high awareness (5). The latest poll, taken in 1991 for the Partnership for Organ Donation, reported that 84 percent of Americans actually support the donation of organs for transplantation (6).

In spite of that high degree of public awareness, the transplant community continues to face a severe shortage in donated organs. In April 1991, the Institute of Medicine released a study of the End Stage Renal Disease Program called for by Congress. In that study, the IOM reports, "Kidney transplantation...is the preferred treatment for a majority of ESRD patients...The major factor limiting access to transplantation is the shortage of available kidneys" (7).

Information revealed in the various polls illustrates the continuing problem:

- "The population is aware of transplantation...People remain supportive of transplantation, yet ambivalent about organ donation" (Battelle, 1987)(8)
- "84% of those aware of organ transplants have heard about organ donor cards" (Gallup, 1986)(9); "20% of those aware have completed an organ donor card" (Gallup, 1987)(10)

- "92% of those aware of organ transplants say they heard about them on TV" (Gallup, 1985)(11)
- "Surveys indicate that the public's awareness of transplantation is high, but its enthusiasm for donation is lower..." (IOM, 1991)(12)
- "67% of those aware of organ transplants see an organ donor as loving, generous person who cares about others. Even among respondents not likely to donate their own organs over half (53%) picture this type of person" (Gallup, 1985)(13)
- "If the family knew of their loved one's wishes, 94% said they would honor the request; if the family members did not know, only 54% would donate the relative's organs" (Gallup, 1991)(14)
- "73% said they would likely want their organs donated upon death. 76% of whites and 45% of blacks" (Gallup, 1991)(15)

These polls describe the public's perception of the relationship it has with the transplant community. We have done a good job of creating and sustaining awareness. However, that awareness hasn't translated into more donation. The IOM points out the inconsistency between polls showing that the public is aware and the worsening shortage, "...the number of all kidney transplants grew an average of 5.5% per year from 1974 through 1978, then at more than 10% annually from 1978 to 1986. Since 1986, however, no growth has occurred, and the numbers have actually decreased slightly" (16).

It is interesting that the trend stopped in 1990. The United Network for Organ Sharing's data reports that the number of transplants actually increased in 1990 over 1989 by 15 percent. That rate was made possible by an increase in cadaver donors of 11 percent. There were 4,357 cadaver donors in 1990; that's up from 3,923 in 1989 (17). It's too soon to tell whether that indicates an upward trend in dealing with the shortage or a one-time uptick.

What is clear is that the number of organs donated does not begin to meet the need for transplants. Those waiting for a transplant has grown to over 23,000 (18). It is also clear that the number of cadaver donors is not anywhere near the number of medically suitable potential donors. The IOM reports, "Actual acquisition may be one-third to one-half the potential pool" (19).

Howard Nathan and associates conducted a study of the donor pool in Pennsylvania and surmised that half of the potential donors were never considered

for donation. He places the size of the potential donor pool at between 38.3 and 55.2 donors per million population per year. If those donations were realized, there could be twice as many donors and more than twice as many transplants (20).

Public education programs exist throughout the United States sponsored by national, regional, and local organizations. Every conceivable tactic is being tried by some organization somewhere. The sponsors of the messages may be totally committed to organ donor education or only marginally interested. The scope of the programs may be national or local, and their content may be coordinated within an area or not. It isn't possible to calculate the dollars being spent or the time being invested in these programs.

Edith Oberley and associates undertook a study of the educational programs underway in 1991 and reported, "Programs continue to be local and uncoordinated ....TV is underused and often badly targeted....few programs are minority targeted....no easily identified message....lack of consistency....language levels too high." She describes one unfortunate common denominator of many of the programs: "...public education has often been an afterthought as transplant related organizations have focused on professional education and administrative concerns" (21).

The major national organizations all appear to be planning an increase in their public education programming. UNOS is working with the J. Walter Thompson advertising firm. The Association of Organ Procurement Organizations is working with a design firm on graphic representations of the need for organ donation. Many other programs, such as the Dow/NAACP and the National Kidney Foundation's New Year's Resolution Campaign, are ongoing. Most other national members of the transplant community are committed to public education as well.

Public education requires a large investment of scarce resources. Organizations can benefit from exchanging ideas before developing expensive programs. Programs are more effective when they are planned and developed in a coordinated fashion and supported by the shared experience and knowledge of all those interested. Sharing would also facilitate clarity and consistency in messages which are currently diverse.

The UNOS Board of Directors approved a resolution that UNOS "participate in the formation of a multi-member coalition to coordinate national efforts in order to improve organ donation throughout the United States" (22). UNOS bases its concept on its current clearinghouse which compiles information on past and present educational efforts. This expansion would not replace the current planning processes and needs of the large and diverse group of member organizations. To

be successful, the consortium would not compete with its members for funds or public recognition, nor would it seek funding or conduct its own programs. It would serve as a clearinghouse for future programs in public education.

### **Historical Analysis and Evaluation of Organ Donation Education Programs**

Transplantation began to make headlines in 1954 with the exciting news that a kidney had been successfully transplanted between two individuals (23). The identical twin transplants were one of the scientific breakthroughs of the 50s. The Reader's Guide to Periodical Literature reports that 19 articles on the subject of transplantation appeared in 1954 alone (24). Twenty-five more articles appeared in the next 2 years (25). Typical was an article in Good Housekeeping entitled "Spare Parts for the Human Body" (26). Identical twin transplants, followed by closely related living donors, were the only procedures commonly done before 1964.

Interest in transplantation grew as the operations became more common, especially when they began to involve non-living donors. The Reader's Guide shows the average number of articles per year increased from 13 during the late 50s to 34 in the 60s (27). This coincided with the launch of a campaign to pass the Uniform Anatomical Gift Act (UAGA) in the late 60s. Medical and lay organizations enlisted public support in getting the measure adopted by all 50 States. That was accomplished by 1969 following an all-time high in magazine articles of 85 in 1968 (28).

One of the most publicized events in the history of transplantation was the first heart transplant in 1967 (29). Extensive media coverage from Capetown, South Africa was a major landmark in making the public aware of organ donation and transplantation as a clinical therapy. This boosted the early efforts to gain public support through donor cards which were made possible by the UAGA.

The National Kidney Foundation, the American Medical Association and other groups began a major effort to distribute donor cards in the early 1970s. Signing a donor card became a theme of most efforts to reach the public about organ donation. Thousands of cards were distributed at health fairs, in grocery bags, in direct mail pieces and as part of fund raising campaigns. They became the focus of television public service announcements, posters, billboards and even stickers saying "I Love You... With All My Kidney."

Another landmark was the inclusion of transplantation and dialysis in the Medicare program in 1972. This coverage stimulated a phenomenal growth in the number of people waiting for a transplant. When the program began in 1973, 15,000

Americans were on dialysis. Today that number exceeds 115,000. The demand for transplantation and the mechanism for paying much of its costs grew out of the one sentence addition to PL 92-603 (30).

Another catalyst for public awareness of transplantation was television star Gary Coleman. For several seasons one of NBC's most popular shows was *Diff'rent Strokes*, starring the 4' 9" Coleman. Much media attention was focused on the fact that Coleman had received two kidney transplants by the time his show entered syndication (31). Coleman discussed his transplants and the need for organ donation on talk shows and in interviews. He became the spokesman for The National Kidney Foundation and appeared in TV and print ads for several years.

The pace of transplantation and organ donation education picked up in the 1980s. More organs were being transplanted and the need for donation was highlighted throughout the decade by on-going media events and news coverage. President Reagan appealed on television for donors for children awaiting liver transplants (32). Organ donation was in the news, and messages about it were disseminated by many groups. The National Newspaper Index shows a steady increase in the annual number of articles in major papers from two in 1981 to 37 in 1990 (33).

The Federal Task Force on Organ Transplantation, created by the Transplant Act of 1984, specifically reviewed public education initiatives, concluding: "Programs were local, uncoordinated, inconsistent and redundant. Programs lacked specific goals and were not evaluated...Not targeted to minorities...if effective, the ethnic donor profile would more closely resemble the pool of recipients...TV use was uncoordinated and uneven in quality" (34).

Between 1987 and 1989, the American Council on Transplantation analyzed current public education programs under a contract with the Division of Organ Transplantation. Some of its analyses were: "Fears about donating are not adequately addressed... Programs do not convey the message that transplants work... Almost 50 percent of programs do not have an evaluation component... Programs do not meet the specific needs of defined audiences... Programs are generally targeted to the 'general public'... Programs use the same message for several different audiences" (35).

The IOM Study reflects on public attention in the 80s with these conclusions: "The public's willingness to donate organs may be influenced by the newspaper and television publicity that transplantation receives. There may be negative effect of adverse publicity, such as that about anencephalic donation or cross-species transplants. The news value of organ transplantation may also be of limited or declining interest to newspapers and television. These dramatic procedures received substantial television coverage from 1983 through 1986, as public

attention focused on the plight of a small number of individuals, often children... Data developed by the IOM staff suggest that the novelty of organ transplantation may have worn off and that the story may be less newsworthy" (36).

Those three authoritative studies present a discouraging picture of the efficacy of public education in the 80s. This is especially true since spending on public campaigns increased during the same period.

During the 1980s and early 90s, there were many events and projects designed to reach the public with a message about organ donation. They illustrate the best of intentions and uneven results. The plans were mostly made in isolation and carried out with insufficient resources. Groups did all they could, but success was not reflected in the rate of donation. It might be useful to review public education at a time when the field was rapidly changing. These are not an all inclusive history of the decade, but a glimpse of how we tried to reach people because we thought they should support our cause.

One of the first events of the decade was the birth of National Organ and Tissue Donation Awareness Week (37). It began as a single day in 1983 when The National Kidney Foundation brought its Honorary Spokesman, comedian Pat Paulsen, to Washington, D.C. to roam the halls of Congress in search of dignitaries to sign donor cards. Paulsen, known as a perennial Presidential candidate, secured the signatures of several Congressmen and Senators. Modest press coverage resulted, and support was received by the United Steelworkers of America and other groups.

The project was repeated the next year with similar results. Press coverage increased when photos were sent to the Congressmen's home town papers. The following year's ceremony was organized through the American Council on Transplantation and supported by the Dow Chemical Company and their public relations firm (38). Its highlight was the signing of a donor card by Vice President George Bush. The Vice President's participation caused a noticeable increase in publicity as did the services of a professional public relations firm.

The day was expanded into a week and coordinated by ACT for the next several years. Events were sponsored in Washington and included receptions on Capitol Hill and ceremonies featuring recipients and representatives of organizations involved in transplantation. ACT prepared kits with ideas for local activities, which were sold to groups around the country. Many local activities were conducted by ACT member organizations and others. The National Week has decreased in emphasis over the past few years. However, many community projects are still carried out by OPOs and other local groups.

The formation of the ACT was a significant development. ACT grew out of meetings called by Surgeon General C. Everett Koop to determine better means of coordinating activities within the transplant community (39). It was given a substantial boost with seed money from the Dow Chemical Company that facilitated its organization and initial programs (40). ACT described its mission as follows:

- To motivate the public to donate organs and tissues for transplantation;
- To improve donor identification and referral to organ/tissue recovery programs;
- To promote recovery and use of multiple organs and tissues from available donors; and
- To promote equitable distribution of organs and tissues.

"To these ends, the Council provides the ONLY national public policy forum to address and seek consensus on social, psychological, ethical and economic issues involved in organ/tissue recovery and transplantation. This national forum provides the opportunity for all individuals and organizations concerned with organ and tissue transplantation to have an active voice in the discussion and formulation of public policy regarding transplantation" (41).

ACT's early funding and the support of influential members of the transplant community gave it many opportunities to become a focal point in the education effort. It held workshops, produced materials, and facilitated exchange of information at its meetings. It received a government grant to research and compile information on educational programming. The result was publication of the Source Book, a reference guide to educational efforts around the country (42). ACT remained in operation throughout the decade, although it was hampered in later years by inadequate financing. It closed its doors early in 1990.

One personal event made national news when in 1986, United States Senator Jake Garn of Utah donated one of his kidneys to his daughter Susan (43). Senator Garn, the only member of Congress to ride in the space shuttle, was widely recognized for his donation and has served in a number of honorary capacities since the transplant.

A landmark in the public policy history of transplantation was the passage of The Transplant Act of 1984 (44), sponsored by Congressman (now Senator) Al Gore of Tennessee. One stimulus for the law was publicity generated by a physician's plan to set up a kidney brokerage business which would have arranged the buying and selling of kidneys from willing live donors. This received considerable, and usually negative, national press attention, and focused attention on the provision of the Act that would outlaw sale of organs. The Transplant Act also called for the

establishment of a national organ procurement and transplant network (OPTN) to ensure effective organ sharing and the convening of a Task Force to study transplant issues and make recommendations (45).

The organization chosen as the OPTN was the United Network for Organ Sharing (UNOS) headquartered in Richmond, Virginia. UNOS undertook the substantial challenge of devising national sharing policies and procedures and involved the entire transplant community in its deliberations. UNOS has a strong interest in education, including public education, and serves as a major information resource for the media, the public, and the members of the transplant community. It has established a clearinghouse which includes information on national and local educational programs.

UNOS joined a number of other organizations interested in organ donation and public education. The American Association of Critical Care Nurses/NKF resource guide published in 1990 lists 30 different national organizations with roles in educating the public about organ and tissue donation (46).

Since the close of the 80s, public awareness activities have continued with some notable achievements. Among them are the award of a Nobel Prize to two American pioneers in the field of transplantation, Dr. Joseph Murray of Boston and Dr. E. Donnall Thomas of Seattle (47). The U.S. Transplant Games were held in Indianapolis in October 1990 and featured athletic competition by 400 recipients of vital organ transplants (48). A White House reception was hosted by First Lady Barbara Bush in April 1991 to salute the entire transplant community and its work (49). And this Surgeon General's Workshop brings focus to the responsibility we have to search for new and better solutions.

#### **Traditional Primary Sources of Public Education in Organ Donation**

For most people, transplantation is not a part of their own personal world. It is a rather exotic medical treatment involving other people. The media is the basic source of experience with transplantation and organ donation for the majority of Americans.

News coverage of transplantation has been consistently available when developments warranted. When the story was dramatic, like appeals for children needing liver transplants, the coverage was extensive. The first heart transplant (50), the conception of a child to be a bone marrow donor (51), the donation of a baboon heart (52), the living donation of a part of a liver (53), the donation of a kidney by a United States Senator all were reported (54). Also, bad publicity can be extensive. When a physician wants to sell kidneys (55); when foreign nationals are transplanted ahead of Americans (56); when blacks wait twice as long for a

transplant, it's news (57). Table 1 shows that throughout the 1980s, coverage in the country's leading newspapers was growing and fairly frequent (58).

The National Kidney Foundation's clipping service estimates that over 50 newspaper articles on organ donation appear each week in the United States (59). Table 2 shows the number of general interest magazine articles published annually in recent years (60). Local events, from dedication of new hospital facilities to mayors signing donor cards, make the news. Individual recipients also stimulate coverage, from Michelle Kline, a transplant recipient who was Miss Pennsylvania, to the youngest, or smallest, or thousandth recipient.

Television is the most frequently recommended medium for public awareness or education messages, and was so cited by the Federal Task Force on Transplantation, the IOM Study, the Oberley study, and the ACT Report (61). In today's society, television is a dominant force in determining public sentiment. It also is a highly structured business and contrary to the impression of many people, is under no obligation to run our public service announcements or devote time to our cause. It is required to broadcast "in the public interest" but it has a lot of latitude in defining that term. That means, organ donation must compete with every other good cause for media attention.

Early in 1991, several network TV series inaccurately depicted the organ donation and transplantation process. They addressed some of the worst fears and barriers to donation the polls have identified (62). On *L.A. Law*, a person needed a kidney transplant and the lawyers arranged to buy the organ from a woman who agreed to claim to be a relative (63). On *Knot's Landing*, a main character needed a liver transplant and a relative bribed the hospital staff to give him a donated liver rather than to the first recipient in line, who consequently died (64). The most outlandish story was on a segment of *Law and Order*, where a surgeon was paid a lot of money to kidnap a person and remove his kidney, leaving him to die, and then transplanting the organ into a rich patient (65). Even the sitcom *Doogie Howser, M.D.*, had a segment in which the decision about donating organs was presented in a rather coercive way (66).

More people saw these four shows than any of the television coverage of the shortage of donors. There were many angry phone calls and letters after the shows aired. Still, the concept of organ donation was put before millions of Americans. Is this publicity necessarily bad? It's beyond the scope of this paper to explore that question. However, these fictional portrayals may have started more family discussions than all the public service announcements broadcast this year.

Public service announcements (PSAs) are an integral part of a total media campaign. They are used by local stations, cable systems, cable channels and the

broadcast networks. They are the mainstay of charities and causes and are everyone's first thought in educating the public. Studies show they can be effective (67).

A 1991 study, "Measuring Advertising Effectiveness", was conducted by the Advertising Research Foundation in cooperation with the Ad Council and the American Cancer Society (ACS) (68). The study took 2 years and cost over \$1 million. It measured the public impact of one PSA in four markets: Eau Claire, Wisconsin; Marion, Ohio; Grand Junction, Colorado; and Pittsfield, Massachusetts. The PSA was devoted to awareness of colon cancer, and it measured response by assessing actions related to consulting a physician and getting tested. The study found, "...the use of public service advertising alone not only increased awareness, but also reinforced people's beliefs, fostered their intent to act and inspired potentially life-saving action" (69).

The study used only one ACS TV spot which was repeated frequently. An assessment was made of the number of people who took some action after seeing it. It utilized purchased air time in which the PSAs were substituted for regular commercials. This allowed the study to target the audience it wanted to reach. That time used came to over \$25 million. The campaign was successful in the opinion of the study's authors. A large number of people, especially men whom they had specifically targeted, saw their doctor and were tested.

The study proved that a public service announcement used consistently and frequently for a long period can provoke action leading to better health. However, the methodology was totally unrepresentative of a typical public service campaign. Thus, the results are terribly misleading. In the real world, the effectiveness of this study could never be duplicated.

The study states, "To control media placement, they relied on three national advertisers...to donate some of their paid advertising time for running this campaign." That simply is not going to occur for us on any meaningful scale. The study continues "...a concerted effort was made to target men by placing more PSAs than usual in sports, prime-time and early news programming" (70). Such accessibility is not possible when PSAs compete for donated air time. Organ donation might also reach more men if corporations such as Proctor & Gamble, Gillette and General Motors were to purchase \$25 million worth of time for it. That is not realistic.

The study summarizes, "If the major goal of a public service advertising campaign is to build awareness, this study showed that an average level of advertising can accomplish this goal. It also showed that consistency and targeted media placement are important in increasing awareness. The longer a public service

campaign runs, the more awareness can be expected to increase. The more targeted the media placement, the more awareness will increase among the target audience" (71).

The main premise of the study is stated as follows, "...consistency and targeted media placement are critical in maximizing the effectiveness of public service advertising." The study proves that statement. However, we cannot duplicate the experience reported in that study. We have to deal with the real world of donated TV time (72).

The effectiveness of a public service campaign can be increased by the participation of the Ad Council (73). This coordinating group is very important in securing donated creative services from professionals and critical in getting placement from the networks and, to a lesser extent, local stations. The Ad Council operates today under new rules, adopting causes rather than specific organizations. It helps coalitions develop funding sources and secure the best creative talent (74). The Ad Council seal confirms that a spot has been competently done, thoroughly researched, and deserves premium placement.

The study by the Advertising Research Council describes the typical Ad Council Project: "In 1989, total donated media support for the more than 30 Ad Council campaigns ranged from a low of \$6 million to a high of \$100 million. Fully three-quarters of these campaigns fell within the \$6 to \$30 million range, which means that the value of donated media averaged approximately \$18.2 million a year for each campaign" (75).

William Clotworthy, former Public Service Director for the NBC Television Network, devotes 50 percent of his available time to Ad Council or Media Partnership (the recent campaign on drug abuse), 10 percent to NBC's own public service program, and the remaining 40 percent to all other causes (76). Harvey Dzodin, Vice President of Commercial Clearance for the ABC Television Network, reports that only Ad Council or Media Partnership spots go over the network in non-coverable (local stations can't substitute local spots or commercials) time (77). These are two of the "gatekeepers" who actually decide what television does with our messages.

Another common practice is to use celebrities to convey messages. A large number of celebrities have been involved in reaching the public about organ donation, including Bill Cosby, Delta Burke, Whoopie Goldberg, Gary Coleman, Pat Paulsen, Pernell Roberts, Bea Arthur, Carl Lewis, Sugar Ray Leonard, and others. The National Kidney Foundation conducted a nationwide mail survey of 1100 television public service directors in April 1991 (284 responses were tallied). They were asked to rate the importance of various factors in devoting air time to a campaign. Only 33 percent rated the appearance of a national celebrity very

important in their decision making; 27 percent rated it not important. In fact, local celebrities rated higher with 41 percent saying they were very important and 18 percent saying they were not important (see figure 8) (78). Celebrities do call attention to a cause or an issue, however they increase the cost of a campaign and the production requirements.

Much effective communication happens person-to-person. Such avenues are typically part of a balanced educational campaign. By their nature, they are local activities and are the responsibility of local transplant community members. These tactics run the gamut from health fairs and donor signing events to a concerted effort to speak to every service club in the area once a year. Service clubs are frequently good prospects for co-sponsorship of a donor card campaign. The Lions Clubs have led the way for many years with their commitment to the Eye Bank program. National organizations frequently develop materials which can be used by local representatives in meeting the public and disseminating information. Religious institutions, places of worship, community organizations and schools all offer opportunities for contact with the public. They are places where Americans get information upon which they build their attitudes.

Another important venue for dissemination of information is drivers' license bureaus (79). Most states allow a notation on drivers' licenses that the holder wishes to donate organs and tissues. Some have an actual donor card on the license. When people get or renew a license, there is a major opportunity for education. Only a few States require that the question about organ donation be asked and answered. Most leave it up to the individuals involved to notice that the license can be a donor card. In several areas, organizations have made a major push to educate license examination personnel and to create a display of information in each station. In Maine a major campaign has been launched with the Lions Clubs and the National Kidney Foundation of Maine. The District of Columbia Organ Donation Program also had an excellent relationship with drivers' license examiners. They have a presence in every drivers' license bureau which gets the attention of everyone who comes in.

The opportunity is especially compelling when a young person gets their first license. If they say yes the first time, it may become a life-long habit. It is also significant that people under 18, as first-time drivers frequently are, need a parent's signature on the donor card. That creates a family discussion.

An important aspect of translating opportunities for reaching people into actual changes in attitude, is to provide a mechanism for them to get further information or have questions answered. TV spots are frequently required to carry a phone number for further information. Posters and other signs, direct mail pieces and

displays can feature a number or an opportunity for follow-up. Within a community there are usually several sources of such information. Agreement among the organizations may make the access consistent and reliable.

### **Attitudes and Barriers Which Impact on Organ Donation Public Education**

The transplant community has identified attitudes the public may have which negatively impact their support for donating organs. Typical barriers are:

- Distrust of the medical care system
- Discomfort with the topic of death
- Discomfort with the topic of organ donation (80).

The community is also familiar with the characteristics of those who are likely, and unlikely, to donate. Oberley reviews the subject: "Research has generated a very clear and consistent demographic picture of persons most likely to express willingness to donate their organs after death. Without exception, studies have described the likely donor as white, younger rather than older, having more education and enjoying a relatively greater yearly income (Battelle, 1985; Gallup, 1987; Perryman, 1990). Conversely, the same studies have described those least likely to express willingness to donate as being black, over 45-55 years of age, with low income and little education" (81).

One of the comments from the Surgeon General's Advisory Workshop Committee sums up another major barrier to successful organ donation: "A primary reason for refusing to donate is, 'we've never discussed it and we don't want to think about it now'" (82).

Another barrier is the concept of "brain death" which the general public does not understand. Many in the transplant field recommend abandoning the term, choosing to talk about death without the qualifier. It is a confusing term. A 1985 Gallup Poll showed: "Less than half (45 percent) believe correctly that a person must only be considered clinically brain dead in order to have that person's organs donated" (83).

Another comment from the Workshop Advisory Committee: "A major problem in promoting organ donation is the fact that it deals with the subject of death and our society does not discuss death" (84).

Barriers to organ donation include the disparity between blacks and whites in awareness and willingness to donate. In 1986, Jeff Prottas stated, "On each

attitude question Black Americans are less supportive and aware of organ donation than are Whites." Prottas continues, "In our society there is a strong connection between a person's race and the ... education he or she has received. For this reason, it is possible that the strong effect of race on attitudes may be misleading; it may be that it is really a person's educational level that determines attitudes not his race." However, Prottas goes on to state, "...in each case the effect of the race variable is stronger than that of the education variable...These findings imply that if we compared a group of people with the same amount of education we would still find significant differences by race" (85).

The Institute of Medicine summarizes the problem: "Black individuals account for 28 percent of the incident ESRD patient population, even though they represent only 12 percent of the U.S. population; their incidence of renal failure is nearly four times that of whites. Regarding kidney transplantation, black ESRD patients represent about 30 percent of those on waiting lists but wait nearly twice as long to obtain a kidney as do whites; they receive over 22 percent of cadaver transplants and 12 percent of Living Related Donor transplants. They donate slightly over 8 percent of cadaver organs" (86).

All these barriers work against the acceptance of our educational messages. They are attitudes we need to change and fears we need to address. It is a formidable task to create a single educational campaign which deals successfully with all these factors. The basic response we have supported has been the concept of "altruism," that organ donation is "right" and that people should support organ donation and give permission when asked. We have concentrated on message content, believing that the public ought to pay attention because it is important. However, organ donation is not very important to the public. Television public service directors are excellent barometers of public issues in their community. In the NKF survey, they were asked to rate the importance of organ donation relative to the issues (figure 5). The largest response was "5". AIDS came in number one.

Organ donation also is not as visible as we think and certainly not as visible as we hope it can become. Seventy-five percent of the public service directors rated the visibility of organ donation in their communities a "5" or below (figure 4) on a scale of one to 10 (87).

The NKF conducted a more intensive telephone survey in 14 communities seeking the opinion of the public service directors, the local OPOs, and the local NKF Affiliates. In that study (figure 1), 86 percent of OPOs thought organ donation was greater than "5", as did 60 percent of NKF Affiliates, but only 34 percent of the public service directors thought it was greater than "5" (88).

Public service directors have a good sense of the importance and visibility of public issues in their community. We must compete for their attention. A study by

Needham, Porter, Novelli in 1985 for the National Heart, Lung and Blood Institute indicated that public service directors receive 15 public service spots a day. They have 175 different spots in their rotation at all times (89).

We cannot control access, we can only compete effectively for it. One of the means of competing most effectively is to know where the control actually is and how best to influence it. That rests with the group referred to as "gatekeepers".

### **"Gatekeepers" for Public Education Campaigns**

"Gatekeepers" are people who control access to the mediums through which we seek to reach the public. Every medium has its gatekeepers. Every group of gatekeepers has a set of rules and regulations for access. They also have ideas and preconceptions about what interests and benefits their public.

Schools have superintendents and boards of education; newspapers have editors; service clubs have program chairmen; health fairs have committees; drivers' license bureaus have supervisors and television has public service directors. All of these people are in positions to decide whether or not our messages are used. We cannot reach an audience without going through these people. Yet, organizations which have a mission of educating the public usually do not find out what these people think before they create their campaigns. For instance, not one organization involved in producing television public service spots about organ donation is a member of the National Broadcast Association for Community Affairs (90).

Since television is so vital to the organ donation public education effort, the results of the NKF survey of television station public service directors (mentioned earlier) can be informative. In addition to specific questions, the respondents were also asked for advice (appendix 1) and several responded on the need to listen to them, to public service directors. For example:

- "Get to know the public service director and station policies on PSA placement."
- "Make a personal contact with the Program Director and person responsible for PSAs and get to know them. Find out what they want and need and work with them."
- "MORE organizations should do research so they provide airable spots!!"(91)

The most important survey result was the overwhelming sentiment that television campaigns should be local: 92 percent of the public service directors responding said the "local angle" of a spot was the most important, or very important factor in their decision to allocate air time. Only 18 percent of the respondents thought a

nationally produced spot was the most important, or very important factor in their decisions about air time (figure 8) (92).

When evaluating available spots, respondents said they base their decisions on the local aspects of the campaign and the PSA itself. It also helps to have the spots delivered by a local representative: 54 percent of the respondents were more likely to use a spot if it was distributed by hand or by a local representative of the organization. Only 19 percent said they were more likely to use a spot delivered by mail (figure 6). Some of the comments make this point very strongly:

- "Our license and mission is to serve our local audience in terms that relate to their lives and needs."
- "Testimonials from recognizable, hopefully local, recipients of transplants would play well here."
- "Local angle and local contact numbers are very important to my station."
- "Try to localize....This way the frequency of air time increases." (93)

The results of this survey are entirely consistent with the survey of 30 public service directors done in 1985 by Needham, Porter, Novelli which found: "When participants were asked to specify what criteria they use in deciding whether or not to air a PSA, comments by nearly three-quarters of the overall sample related to local impact." The study said that play on a station can be increased by: "producing a greater number of locally oriented spots containing a reference to where people can get more information, sending spots with local tags...." In general, the 1985 survey concludes: "Seven out of ten respondents say that local contact influences them either to a moderate or great degree" (94).

National organizations may place too great an emphasis on network television's participation in campaigns. The networks have their own gatekeepers, rules, and practices which work to the disadvantage of issues like organ donation. For example, local stations can "cover" a network public service spot with a local spot or a local commercial (95).

There are spots which are placed in "non-coverable" slots, broadcast over every station on the network. However, access to those slots is extremely limited. ABC network limits such spots to Media Partnership or Ad Council campaigns, and use 10 to 15 each week. All others must compete for the 20 to 30 slots available, all of which are "coverable" (96). It is possible for local stations to pick up network spots. They can use them as they are broadcast, or get them "off line" from a network feed of currently in-use spots. However, the survey showed that 83

percent of local public service directors "seldom" or "never" pick up network spots, and only 3 percent of major market public service directors "frequently" pick up network spots (figure 3) (97).

These results clearly suggest what any cause-based group must do to reach intended audiences. The gatekeepers are in charge. Getting to know them and working with them is vital. The best message in the world, with the best content and the best production, will be received only if the gatekeepers allow it.

### **National and Local Public Education Campaigns on Organ Donation**

The national organizations which produce public education campaigns on organ donation must maintain a spirit of cooperation. An exchange of information on plans and campaigns should benefit each organization without compromising any group's ability to meet their own internal needs. For instance, each organization will have a unique set of needs in addition to the goal of increasing organ donation. Some of those needs are:

- to create public awareness of the organization and its value to the community;
- to inspire public support, including financial support;
- to establish a programming presence, so the public understands what funds accomplish through the organization;
- to inspire and motivate the organization's own volunteer corps, or prominent supporters;
- to use resources available to it; such as an offer of participation from a celebrity;
- to demonstrate an ability to produce materials of high quality which impress volunteers and supporters.

Secondary goals (after the primary goal of increasing organ donation) are perfectly legitimate and often complement the mission of the education campaign. It is impossible for an organization to ignore all of these factors in planning a campaign. The problem arises when these things create pressure on the campaign, which may result in higher costs, production problems, or a lack of clarity in the message. This can compromise effectiveness of a campaign. However, when these needs are acknowledged and dealt with honestly, the results of a campaign can still be good.

Another common problem in campaign creation is the tendency to over-produce materials, especially TV spots. High quality does not necessarily mean expensive or glitzy. When creativity is allowed to charge ahead unrestrained, production can get out of hand very rapidly. Four color printing, glossy paper, celebrity studded

TV spots, elaborate sets, and fancy video graphics, all make things impressive. However, the real utility of these tactics must be measured against the goal.

Again, our advice on television comes from the public service directors who were asked to rate factors in the effectiveness of TV spots. 49 percent said emotion was most effective. 44 percent said education was most effective. Their comments advise staying away from the fringes of advertising. Shock was listed as only 10 percent effective (figure 8). Some of their comments were:

- "Don't rely on celebrity - - confront the basic issue head-on."
- "Don't be clever - - remember that PSAs are aired over and over. Don't be melodramatic..."
- "That the announcement be very simple, clear, easy to understand."
- "Simplicity is best."(98)

One of the principal responsibilities of the national campaign planning process must be the absolute commitment to accuracy. The television networks demand that complete justification accompany the script of any TV spot they are asked to run. All claims have to be substantiated. The networks will reject a spot which cannot fully explain why it states what it does. This is especially true for the national campaign which will be implemented locally.

Another ingredient of any campaign is evaluation. In the survey of 14 area OPOs and NKF Affiliates, the respondents were asked if they routinely evaluated the effectiveness of their campaigns. 69 percent of the OPOs said yes. 54 percent of the NKF Affiliates said yes (figure 2) (99). Evaluation is harder on a national basis. However, the evaluation that matters most is the rate of organ donation. 1990 results notwithstanding, we haven't been doing very well in the past few years.

Consistency is another issue which gets considerable attention from organizations trying to reach the public about a single issue. 64 percent of the OPOs in the survey reported that they make an effort to be consistent within their community. 54 percent of NKF Affiliates reported a similar effort (figure 2) (100). Nationally there is almost no consistency and no formal mechanism at present to strive toward. Since the evidence presented here suggests that local campaigns are more utilized (certainly on TV) the need for locally consistent messages is reinforced.

One of the most repeated criticisms of past efforts in public education on organ donation is the lack of message targeting (101). This is very hard to remedy. Mass appeals can't be segmented by audience under our circumstances. We can't control our placement on television. Since we rely on free public service time, the only group we can be sure to target are insomniacs (since late at night is a common time slot for public service). One mass campaign can't target minorities,

or women, or young people. If the desire is to specifically target such audiences, the evidence tells us that it will be necessary to design unique campaigns for them, and deal with the gatekeepers in a specific way.

Mass campaigns, especially on television, reach very large numbers. They are designed to appeal to the population in general. Their audience is the 250,000,000 people who live in the United States. If that represents 75 to 80 million families, our statistics indicate that less than 1 percent of those families will be confronted with an actual organ donation situation next year (102). So, 99 percent of the people we are targeting for our mass media campaign will not directly be in a position to help us meet our goal (increasing the number of donations).

Allocation of scarce resources is one of the decision making processes the transplant community goes through every day. No organization has enough money, time, or volunteers to do everything necessary to dramatically raise the rate of donation. Therefore, we have to make choices. The types of public education campaigns we do is one choice. Allocation of resources between public education and professional education is another. Some of the information examined in this paper may prove helpful as we face those choices.

Howard Nathan states: "Educational efforts directed toward the general population with an accent on minority groups are capable of producing a modest increase in actual donors [emphasis added]. Educational programs aimed at increasing the organ donor pool should design methods to identify these individuals (missed donors)...improvement in donor recognition...could be achieved by creating focused educational programs targeted toward health-care professionals in hospitals identified with the largest 'donor gaps'" (103).

The Institute of Medicine Study also focuses on the dynamic in the hospital when the actual determination of donation is made. It states: "Cadaver donation involves a complex process between the attending physicians and nurses caring for the recently deceased potential donor, the organ procurement professionals and the family of the deceased. The initial encounter with the family is critical. It is most effective when made by professionals who show respect to the family and communicate a sensitivity that acknowledges their grief. However, if the requestor is uncomfortable, or lacks answers to important questions, the result is often refusal" (104).

Again, Howard Nathan points out that in Pennsylvania during his study, there were 147 actual donors, 91 refusals and 114 to 215 families who were never asked (105). If the real determination of success for organ donation education efforts is in the number of organs donated, the problem is apparent in that statistic. Polls

showing general public awareness deal with a universe, 99 percent of which will not be in a position to decide about organ donation.

The Institute of Medicine studied only the renal program. However, it reflects the entire field of transplantation when it states: "The committee wishes to underline the urgency of increasing the organ donor supply as the central issue in making kidney transplantation available to increasing numbers of ESRD patients. Public and professional education, recommended consistently over the years, should be continued, but working assumptions should be re-examined and efforts possibly re-focused and the effects on increasing the availability of organs should be monitored closely" (106).

### **Conclusions**

A review of public education in organ and tissue donation, and the concepts described in this paper, lead to the following conclusions about the transplant community's need for an effective relationship with the American public.

1) The goal of public education in organ and tissue donation should be:

To maintain a level of public awareness of organ and tissue donation which will favorably dispose families toward donation if they are ever asked to grant permission.

The elements of the "level of awareness" which will pre-dispose families are a sense that:

- a) Transplantation is "good".
- b) Organ donation is the "right" thing to do.
- c) When a person dies "senselessly", the only "good" possible is organ donation.
- d) The person who died, a "good" person, would have wanted his or her family to do the "right" thing.

The most important factor in predisposing families toward donation is knowledge that it is what their loved one would have wanted (107). The best source of that knowledge is a family discussion of organ donation and transplantation.

2) We must realize that organ donation is a unique health education concept. Some of the factors which make it different are:

- a) It is not something you can do yourself.

- b) It is not something that benefits you at all.
- c) You cannot cause it to happen.
- d) It depends absolutely on someone else doing something.
- e) It is extremely unlikely.
- f) It only occurs after you are dead.

Our educational planning should include these realities.

3) We should set much more realistic goals for public education based on the following ideas:

- a) In organ donation, public education is a supportive, not a primary activity.
- b) 94 percent awareness means the main job is maintenance.
- c) We shouldn't strive for total understanding of the concepts because they are too:
  - i) complicated
  - ii) negative
  - iii) easily misinterpreted
- d) We should stick to basic, easily assimilated, simple themes and repeat them without the details.

4) We must invest our money and effort carefully, thoughtfully, and honestly. We should always know why we are doing things and what we expect to accomplish. To the extent we want to focus solely on increasing organ donation, these concepts should be considered:

- a) The resource investment mix between public and professional education should be carefully analyzed based on the likelihood of positive results.
- b) National television campaigns are very expensive and not likely to be cost effective or produce significant results.

5) Local public education campaigns and activities are much more important than national ones and will bring better results.

- a) The vast majority of educational message "gatekeepers" are local.
- b) These "gatekeepers" overwhelmingly advocate messages that have a local angle and local focus for action.
- c) The national role should concentrate on creating model materials and concepts for local adaptation and use.

- d) Local campaigns should be broadly based using a cooperative approach among the local transplant groups.
- e) Consistency within a community is important; consistency with the rest of the country is less so.

Television is usually our first thought when we want to reach the nation. However, the access to national television is extremely limited. There isn't much network time, most of that time is committed to a few select issues, and stations cover national spots with local ones anyway. To communicate with the American people through public service announcements, we have to concentrate on working with local TV stations.

6) Public education encompasses a large variety of tactics. It is not limited to mass media.

- a) Media campaigns should be supported by local community involvement. TV Public Service Directors advocate events and always want further information resources to back up spots they play. They even suggest asking them to co-sponsor events.
- b) Health fairs, donor card signings, speakers bureau, work-site campaigns, and countless other tactics can be the most effective means of reaching people.
- c) Cooperation and efforts toward a consistent message are very important on the local level. Organizations can share the planning and cost.
- d) There should be standard ways for the public to request further information or contact with knowledgeable representatives of organ donation.

Hands-on public contact is time consuming but it reaches people directly and involves them in thinking or talking about organ donation. Speakers bureaus and health fairs reach relatively few people yet they cause people to focus on, and possibly to talk to their family about, organ donation.

7) We should spend more time realistically evaluating our educational efforts. Each campaign objective should be examined carefully:

- a) Though the primary goal of education is raising the rate of donation, other goals such as the organization's need for recognition are complementary and perfectly reasonable.
- b) Secondary goals are valid; however, they shouldn't predominate.

- c) Secondary goals sometimes raise the cost and guide the creative process in campaigns.

It is reasonable for an organization to expect its public image to be enhanced by effective educational campaigns and its own volunteers and supporters to be inspired by its campaigns. However, accomplishing those secondary goals doesn't mean that the mission of increasing organ donation has been advanced.

8) Donor cards, a long-time tool of public education programs, should continue to be distributed widely. Though signing a donor card is part of our message to the public, they are primarily a catalyst for family discussion.

- a) The fact that donor cards are legal documents should be de-emphasized. Their use is in awareness, not in recovering organs legally.
- b) We should focus on who witnesses a donor card signing, and urge that it be a family member.
- c) Donor cards, or notations on drivers' licenses are very important opportunities to reach the public.
  - i) We should make drivers license examination locations part of our public education program.
  - ii) We should educate young people when they obtain their first license.

9) We should realistically analyze the audiences we seek to reach with our educational messages. Our mission is not to educate the American people. Our mission is to increase organ donation. Therefore,

- a) It is reasonable to concentrate first on the people with whom we have the greatest chance for success: the people most likely to donate.
- b) We want to reach the 12,000 or so families who will face, or could face, a decision about organ donation next year. We don't know who they are, but thinking about them might help us do a more effective job of education.
- c) The more we know about those 12,000 families, including projection about which ones are likely to be asked and which ones are likely to say yes, could be very valuable.

10) We need to target some audiences even though we know they are less likely to donate today. This is especially true of African Americans. Their need for

organs is clear and so is the need for them to donate. But, planning such campaigns must include some special elements:

- a) Campaigns targeted at minority audiences are harder.
- b) They are much less cost-effective.
- c) The primarily White leadership of the transplant community needs additional help, advice and participation, before it can produce effective targeted campaigns.
- d) Adequate resources must be devoted to such a targeted campaign. It cannot be a slight variation of some other effort. It is worse to do an inadequately planned or planned or executed campaign than to do nothing.
- e) The results of targeted campaigns should be evaluated on their own criteria.

All educational planning must take into account the special circumstances of the minority community need for more organ donation.

11) We must focus on realistic expectations. We should be creative, enthusiastic, optimistic, and persistent, but our sights should be firmly set on what is attainable.

- a) To most people, our issue is a "5". AIDS, drug abuse, education, the homeless, jobs, crime are all more important to somebody and some are more important to everybody. The public can focus on only a few "10's" and organ donation isn't going to be one.
- b) Networks devote their available public service time first to the Media Partnership, the Ad Council, their own "house" campaigns and then to everybody else.
- c) Effectiveness depends totally on utilization and utilization is most often out of our control. We can target an audience, but, if we can't control placement, we can't expect to reach the targets.
- d) We should resist the temptation to buy television time or recruit someone to buy it for us. A paid campaign would be extremely expensive, could not be sustained over a long period of time, and it would destroy our ability to get free public service time in the future.

- e) We must educate the "gatekeepers" about whom we know very little. They decide what reaches their audience.

12) An intensive study of the current donor pool should be undertaken. Information about today's donors, potential donors, and unrecognized donors can help us anticipate tomorrow's needs and opportunities.

- a) Which families get asked about donation today and which do not?
- b) Which families say yes to donation and which say no?
- c) Of the families not asked, are there some likely to say yes and some likely to say no?
- d) Which families are most able to increase the number of organs donated? Can we target educational activities at them?

13) The next public opinion poll done by the transplant community should examine the impact of inaccurate or bad publicity on public attitudes toward organ donation. In 1991, organ donation was falsely portrayed in several popular television series. What really resulted from that?:

- a) Is bad fiction taken for bad fact?
- b) Can even outlandish presentations stimulate discussion and interest in organ donation?
- c) How can the transplant community use such portrayals, seen by millions, as a catalyst for positive results?
- d) How should we respond when these things happen?

A 1985 Gallup Poll showed that 92 percent of the people who were aware of transplants heard about them on television. If such dramatizations are going to occur, it might be possible to turn them to our advantage.

14) A national public education consortium is needed. Exchange of information on plans and ideas would be very valuable to every organization which invests time and money in organ donation education. The consortium should be a clearinghouse created solely for the exchange of information:

- a) It should not conduct its own programs.
- b) It should not raise money.
- c) Its administrative expenses should be shared by the member organizations.

- d) It should concentrate on how to facilitate better educational campaigns on the local level throughout the country.
- e) It should provide a regular forum for discussion of member's initiatives.

The UNOS clearinghouse could easily be expanded to serve as the focal point for this consortium.

15) The Federal Government should not play a visible role in the public's awareness of organ and tissue donation. The transplant community understands and appreciates the vital role played by the government but it may not be productive to associate the government with organ donation in the public's mind.

- a) Among some, a distrust of the medical establishment is a major barrier to accepting organ donation. If we add distrust of the government to that equation, the situation could be worse.
- b) The government will have a distinct role in furthering organ donation education; however, it should be a supportive role acting through other organizations.
- c) The visibility of organ donation education should remain with the private sector even when actual programs are funded by the government.
- d) Any perception that the government is monitoring who is willing to be a donor, or who is or is not donating is a very strong negative.

In this sensitive personal dynamic, the role of the government has to be circumspect. This is not a criticism of the many ways government facilitates organ donation. It just has to be careful in the fragile relationship between organ donation and the public.

16) Organ donation has always rested on a foundation of pure altruism. The "Gift of Life" has always been a freely given gift. The continuing shortage, however, has led some people to begin considering non-traditional approaches. Our educational campaigns and efforts should not be modified now. However, if we consider non-traditional approaches, we should evaluate them from a public reaction perspective.

- a) A study should be undertaken of the public reaction to concepts such as financial incentives for donation, maintaining a registry of potential donors, requiring a decision about organ donation at some point (drivers'

- licensing or hospital admission) and presumed consent.
- b) Full debate and discussion should be encouraged on all these non-traditional approaches before they are tried.
  - c) Pilot trials of these approaches should be conducted to test their effectiveness and acceptance by the public.
  - d) Relevant laws and regulations should be modified so that the trials can be conducted thoroughly.
  - e) Intensive effort should go into the public relations aspects of each step in this process so that decisions are made with the attitudes of the public as clearly in mind as possible.

### **SUGGESTED RECOMMENDATIONS FOR THE SURGEON GENERAL**

- 1) A national consortium of organizations doing organ donation public education programs should be formed under the auspices of the United Network for Organ Sharing.
- 2) The Ad Council should be asked to adopt organ donation as a major campaign.
- 3) A national television campaign should not be developed unless organ donation is adopted by the Ad Council and funding is available through its sources.
- 4) The Congress should authorize the Department of Health and Human Services (DHHS) to conduct pilot tests of non-traditional approaches including financial incentives.
- 5) The Division of Organ Transplantation (DOT) should make "seed money" grants available for the formation of local coordinating groups.
- 6) The DOT should fund in-depth studies of the public's attitudes toward non-traditional methods of facilitating organ donation.
- 7) The DOT should fund demonstration projects on educational programs targeted at minority audiences.
- 8) The DOT should fund an in-depth study of the current donor pool to project similarities and differences among the four groups of families (asked and said yes, asked and said no, weren't asked and would have said yes, and weren't asked and would have said no).
- 9) DHHS should indicate the special circumstance of organ transplantation, that donated organs are required before medical treatment is possible, and therefore

**creates a unique need to include public attitudes in planning government sponsored medical care initiatives.**

**10) DHHS should form an inter-agency group to consolidate information on transplantation and organ donation programs of various government agencies.**

**11) That inter-agency coordinating group should promote the need for a public awareness focus in the scientific and public health work being done in transplantation.**

**12) The Secretary of DHHS and The Surgeon General should continue their leadership in regard to this issue and stimulate greater attention to it within the government.**

**13) The Surgeon General should sponsor a follow-up workshop in 2 years to evaluate progress made on implementing the recommendations coming from this workshop.**

## Appendix I

**The National Kidney Foundation, Inc.  
Survey of Television "Gatekeepers"  
April 1991**

### **SURVEY COMMENTS**

**Question: What advice would you give to organizations planning to produce television public service announcements on organ donation?**

#### **FORMAT**

- Generic without time or date. Put all time lengths (to fill variety of station formats) on one reel, that is 10, 15, 20, 30, and 60 second formats. Do variations so several spots can rotate without spot getting "tired".
- Supply varying lengths of spots but not several 30 second spots with different themes.
- Be sure to produce 60 and 20 seconds as well as 30 seconds.
- Often P.S. Directors are limited by how many spots of a certain length are available in their PSA rotation. You increase your chances for air time by giving the P.S. Director options.
- At our station there is less competition for air time for PSAs other than 30 second. Short spots fit better--20, 15, even 10 seconds.
- Guidelines for PSA's from WTXF-FOX 29:** We air 10, 20, 30 and 60 second PSAs in accordance with daily availabilities. For consideration: Send 1" videotape reel accompanied by cover letter, IRS non-profit tax-exempt number statement, scripts/storyboards, and background information. Include full name and address of organization and contact person. WTXF-TV must have this information to process and to issue monthly performance reports. Don't send slides. Allow for a 6-week processing period. All tapes are screened for content and technical. If selected, the public service announcement airs for 6-months or until the specified kill date. A monthly performance report

will be sent to organization providing contact information. Please enclose a self-addressed stamped envelope.

-Offer 1-3 different lengths and make the spot so it will hold the interest of viewers.

### APPROACH

-Keep it simple-provide a call to action for your viewer. Don't try to give too much information in :30. More organizations should do research so they provide airable spots!!

-Include a racial balance, i.e., it affects all races and socio-economic backgrounds. There's a concern for lack of minority donors.

-Sensitive subject; personal...some might think talking or "body parts" too personal. A sensitive subject needing a sensitive approach.

-Spots must be generic, cannot ask for specific donations.

-Make a generic spot with no end date.

-Make good spots but don't try to get too technical as people don't understand technical side of most things. Also make spots kind of simple and not too deep.

-Get creative and make sure you have universal appeal (to all age groups) or produce different spots aimed at different demographics. Include local phone number on spot, if available.

-Be creative with your presentation of the message. Be careful to make the spot "work" in all parts of the country (urban/rural). Make part of the spot a "call to action" to get the viewer to do something, or simply to be more aware.

-Be sure to appeal to the minority audience.

-Keep it simple so it can have a long play...repetition is your best promotional weapon when time is needed for people to decide to join the effort.

-Make sure the spots are well produced and don't use "talking heads", there is nothing more boring than a spokesperson on camera talking for several seconds.

**-Offer the viewer a sense of revelation while communicating the information! Show real life situations/happy endings?/not happy endings? More information needed for general public to get comfortable with idea.**

**-Although I indicated that education signals effectiveness, keep in mind that education is only possible when you have the public's attention. How? Emotional, shocking, humor, etc.**

**-Include the following: emotional (touching, tear jerker, cute, shocking, etc.) music that demands your attention and holds it, fast moving - all information quick and to the point. 30 second spots are best.**

**-I would present it as real and graphic as could be done, along with someone who is in the public eye.**

**-I have done a half-hour program on organ donation and am intellectually convinced myself. I think the BIG problem is that of describing what DEAD is.. some organs (all?) may be harvested prior to what people believe DEAD to be! This is a big problem. The organ donation program really must depend on an enlightened, courageous and informed person. Even the best of us wince a bit!**

**-Produce it in a way where it is informative and educational yet entertaining. Too often I find PSA dull or slow-paced which entices viewers to switch channels. Good video and music helps.**

**-Show how simple it is to be an organ donor. Explain the steps needed to be an organ donor. Education on how to be a donor.**

## **MESSAGE**

**-Testimonials from recognizable, hopefully local recipients of organ transplants would play well here. Recipients expressing the quality of life slant. Also, testimonials from family members of organ donors. Again, using local people.**

**-Testimonials by organ donor receivers; how the organ donation saved their lives, for example.**

**-Show more than a "talking head". Give good reasons why the general public should support this effort.**

- Use the Human Interest ("This could happen to you/someone you love" angle.)
- Address the (hopefully false) contention that families of organ donors receive unanticipated bills to cover expense of removing, transportation and processing donated organs - bills which previously were assumed to have been the responsibility of the donee.
- Use faces - maybe a child's true story about receiving an organ so he/she could live.
- Find local recipients willing to be interviewed. They're much more interesting than "celebrities". When there's a local story call the local news media that day.
- Let people know how vital it can be in saving a person's life, and how easy it's to agree to be an organ donor on your driver's license. I would probably provide more time for kidney disease PSAs if the PSA demonstrated just how many people suffer from this problem and how life threatening it is.
- The people I know who don't like the idea of organ donation think it is "sick" to have their organs removed, even if they are dead. If you can get around this attitude, it will be a success.
- Perhaps testimonials from prominent recipients of organs. Or an emotional plea from someone in need - emphasize the waiting anxiety.

## LOCALIZATION

- Provide useful materials to local chapters, so they can be localized. Our license and mission is to serve our local audience in terms that relate to their lives and needs.
- Localize with local phone number. I would encourage the organizations to find a local angle, make the spot hard hitting and emotional and have a media showing to local stations to debut and distribute the spot.
- Appeal to a large variety of people and localize it (tag at end). We're a small town and sometimes these services are not available locally -- an 800 number would be nice.

**-Try to localize, by leaving room for a local tag or putting local phone numbers. This way the frequency of air time increases.**

**-A brief explanation. A toll free number to have more information sent to them. People are more likely to respond to a phone number.**

**-Local first! Red Cross encompasses all kinds of organ donations.  
DON'T OVERLAP!!**

## **PRODUCTION**

**-PSAs get the most airtime here if they are unique or inventive in some way. Produce a spot that will make me notice it -- and the audience will too.**

**-Maintain high production standards, i.e., proper lighting, good visual effects, correctly spelled. Also, make the spot interesting and appeal to viewer's emotions.**

**-Make sure the quality of the tape is superb! High broadcast quality with a message that a wide audience range can relate to.**

**-Contact with station; quality production; send it in the format that station prefers.**

**-Get best script and production values possible -- emulate successful Cleo award-winning commercials and win over PSA Directors to your cause.**

**-Quality of the piece -- audio-visual. Professional voice is a must. This is the first thing that either makes or breaks a PSA.**

**-Keep production values high and lighten the content to whatever degree possible! Give a choice of videotape format -- be very specific about kill dates.**

## **DISTRIBUTION**

**-Send script and storyboard with tape -- don't ask for tape back, make it easy for us because we receive several PSAs a day.**

**-Send storyboards with tape.**

- Don't send VHS. Keep dealings with the station short.
- Make personal contact with the P.D. and person responsible for PSAs and get to know them, find out what they want and need and work with them. Inform them about your cause and how it impacts on your area. Make them a partner, as much as they desire.
- Do something to make your PSA special -- packaging, follow-up phone calls. etc. Create an exceptional on-air product.
- Get to know the public service director and station policies on PSA placement.
- Do not rely on PSAs only -- try to tie spots locally through news/health reports.
- Send cover letter stating purpose of spot, importance, rationale and storyboard.
- Call and let us know the PSA will arrive and after we receive spot do a follow-up call.
- It really helps to send accompanying information, including what the PSA is about, how long it should air, who the target audience is, the name, phone and address of a contact person.
- Send tape to station 3 weeks prior to air date. Select a specific campaign time frame.

#### OTHER SUGGESTIONS

- Solicit the assistance of a local PR or media firm to develop a specific campaign: 1) awareness; 2) local examples of help; 3) future plans or developments which will provide local citizens in all demographic groups with a better life.
- I would advise you to solicit the help of an ad agency who donates their service to non-profits.
- Make sure not sponsor-ridden, i.e., "this message brought to you by...,etc."

**-Plan a local campaign using all media, a local celebrity or influential person and a hospital or major medical organization sponsoring it.**

**-Please try to work with a local TV network affiliate to sponsor your campaign. Have your local cable (TV) company co-sponsor, if possible, so that the PSAs run on a variety of channels in addition to the Affiliate using one of their news anchors. You can often get news series out of a station's sponsored campaign and much better PSA air times and frequency.**

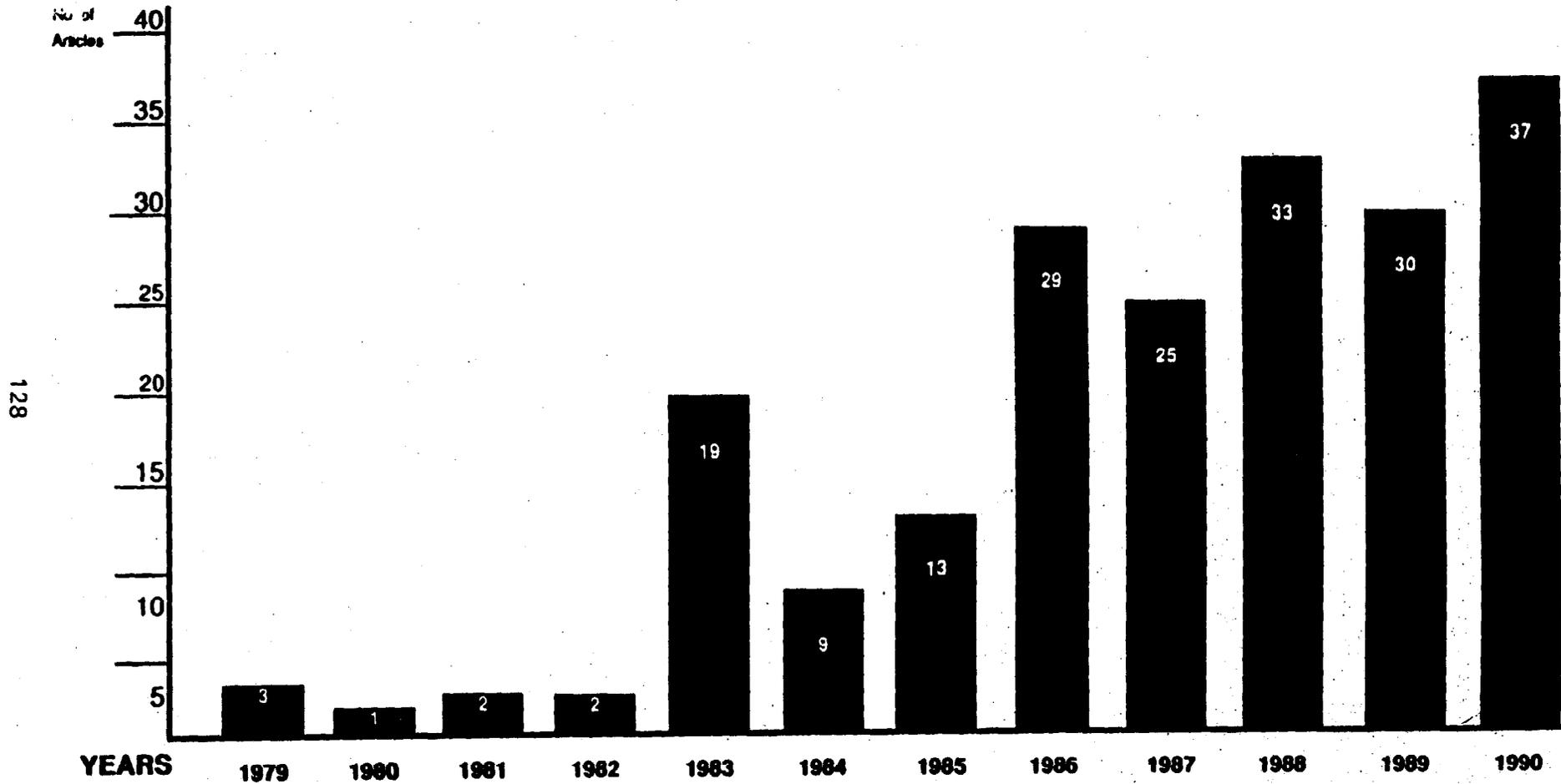
**-We need more Spanish PSA (Spanish language) spots, and also involve all Radio Stations (Spanish). Seems to me that radios are the forgotten ones!**

**-No commercial mention of any kind in either audio or video (even if a sponsor is underwriting the production cost of the spot).**

**-Do not promote fund-raising efforts (We're non-profit).**

**Table #1 (Graphic Representation)**

**NEWSPAPER ARTICLES ON  
TRANSPLANTATION 1979-1990**



**Sources: New York Times, Wall Street Journal, Christian Science Monitor, Washington Post, Los Angeles**

**National Kidney Foundation, Inc. Survey of Newspaper Articles Relating to Transplantation 1979-1990  
April 1991**

Table #2

**SUMMARY OF ONLINE SEARCH OF THE READER'S  
GUIDE TO PERIODICAL LITERATURE, 1983-1990**

**Topic: Transplantation**

<u>YEAR</u>	<u>NUMBER OF ARTICLES*</u>
1983	59
1984	86
1985	45
1986	69
1987	72
1988	95
1989	57
1990	70

\* General transplantation articles posted.

Figure #1

# VISIBILITY OF ORGAN DONATION

IN 14 MARKETS  
(PERCENTAGE AT EACH RATING LEVEL)

<u>SCALE</u>	<u>NKF AFFILIATES</u> N = 14	<u>ORGAN PROCUREMENT ORGANIZATIONS</u> N = 14	<u>PUBLIC SERVICE DIRECTORS</u> N = 14
*10	0%	7%	0%
9	7	0	0
8	0	29	0
7	36	43	17
6	21	14	17
5	21	0	22
4	0	7	17
3	7	0	11
2	0	0	11
1	0	0	5

\* 10 = Highest rate of visibility

National Kidney Foundation, Inc. Survey on Visibility on Television Gatekeepers and NKF Affiliates and Organ Procurement Organizations Regarding Promoting Organ Donation  
April 1991

Figure #2

# NKF AFFILIATE & OPO ASSESSMENT

## OF COMMUNITY PUBLIC EDUCATION EFFORTS

### IN 14 MARKETS

	<u>AFFILIATES</u>	<u>OPO'S</u>
<b>Make Effort for Consistency</b>		
Yes	50%	64%
No	46%	43%
<b>Evaluate Effectiveness</b>		
Yes	54%	69%
No	46%	21%

National Kidney Foundation, Inc. Survey of NKF Affiliates and Organ Procurement Organizations  
Regarding Promoting Organ Donation  
April 1991

Figure #3

# LOCAL PUBLIC SERVICE DIRECTORS

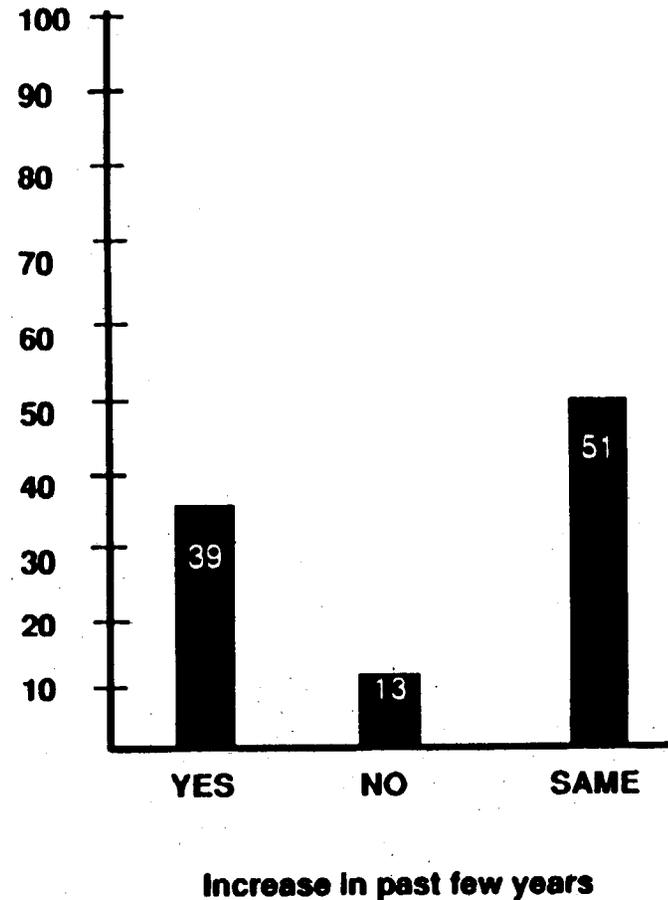
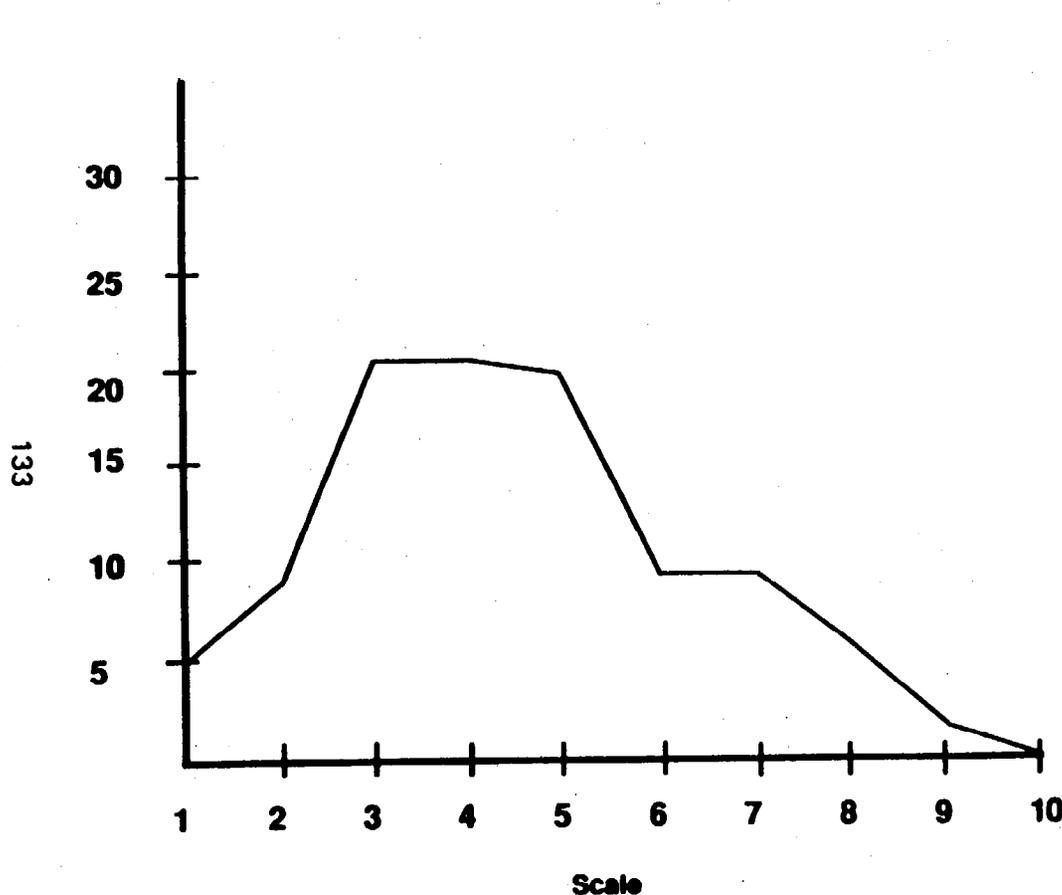
## REPORTING ON PICKING UP NETWORK SPOTS

	<u>FREQUENTLY</u>	<u>SELDOM</u>	<u>NEVER</u>
MAJOR MARKETS (N=35)	3	14	18
SMALLER MARKETS (N=243)	44	140	59
TOTAL (N=278)	47	154	77
%	17%	55%	28%
		83%	

National Kidney Foundation, Inc. Survey of Television Gatekeepers Regarding Promoting Organ  
Donation  
April 1991

Figure #4

# VISIBILITY OF ORGAN DONATION ACCORDING TO PUBLIC SERVICE DIRECTORS (N=278)

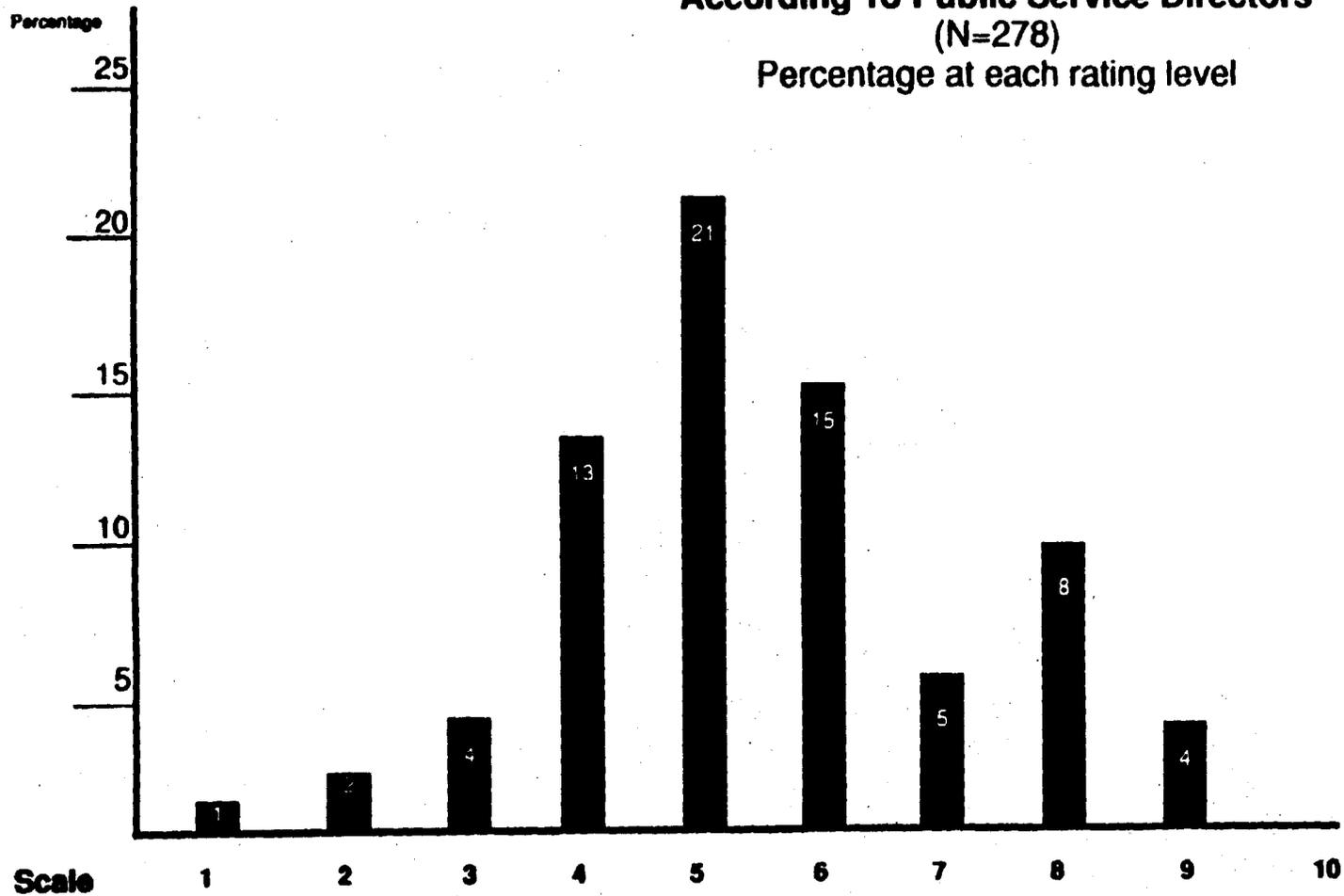


National Kidney Foundation, Inc. Survey on Television Gatekeepers Regarding Promoting Organ Donation

April 1991

**Figure #5**

**IMPORTANCE OF ORGAN DONATION  
According To Public Service Directors  
(N=278)  
Percentage at each rating level**



**1 = most important (AIDS RANKED #1)**

**National Kidney Foundation, Inc. Survey of Television Gatekeepers Regarding Promoting Organ Donation  
April 1991**

Figure #6

# LIKELIHOOD OF PUBLIC SERVICE DIRECTORS

## TO USE SPOTS

As Affected By Method of Distribution

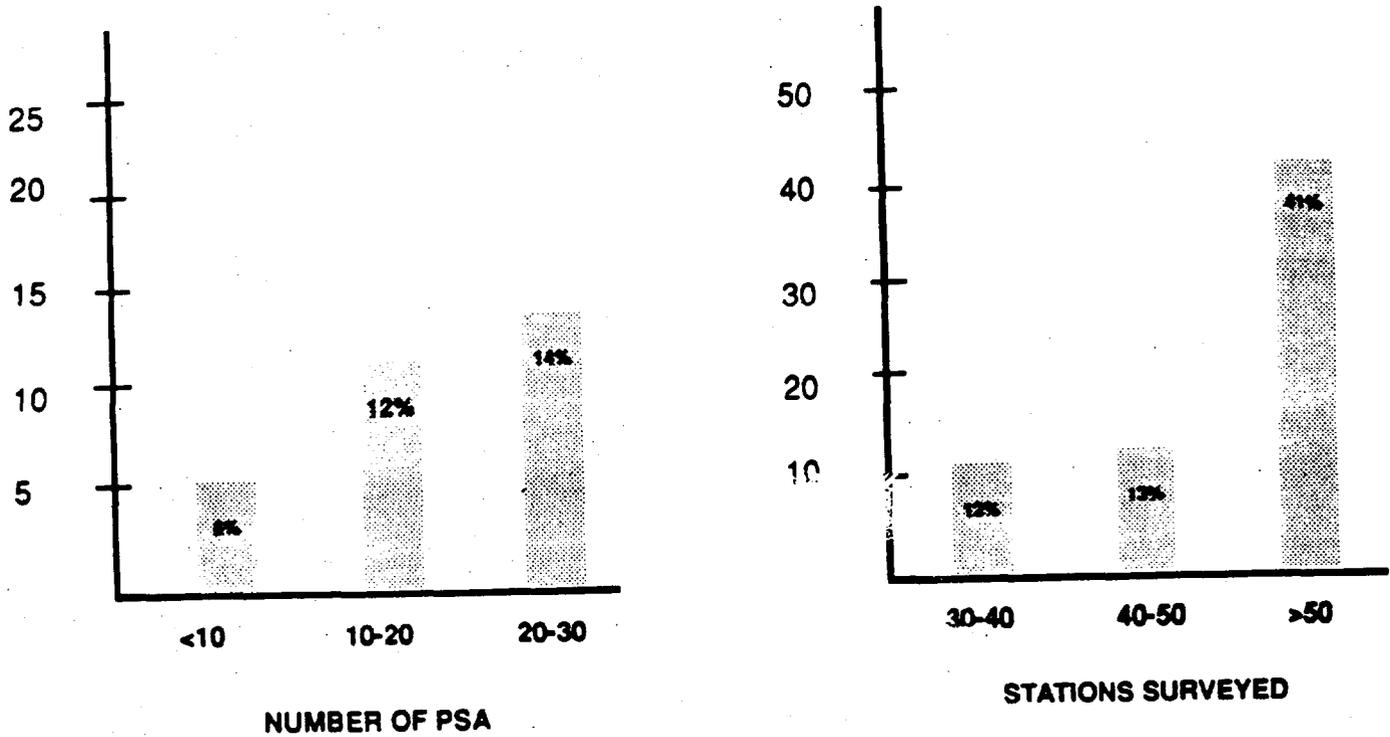
<b>BY AN AGENCY</b>  5%	<b>BY HAND / BY LOCAL REP</b>  54%
<b>BY MAIL</b>  19%	<b>ALL EQUAL</b>  18%

Figure #7

# NUMBER OF PUBLIC SERVICE ANNOUNCEMENTS AIRED PER WEEK

(N=278)

## ALL SUBJECTS

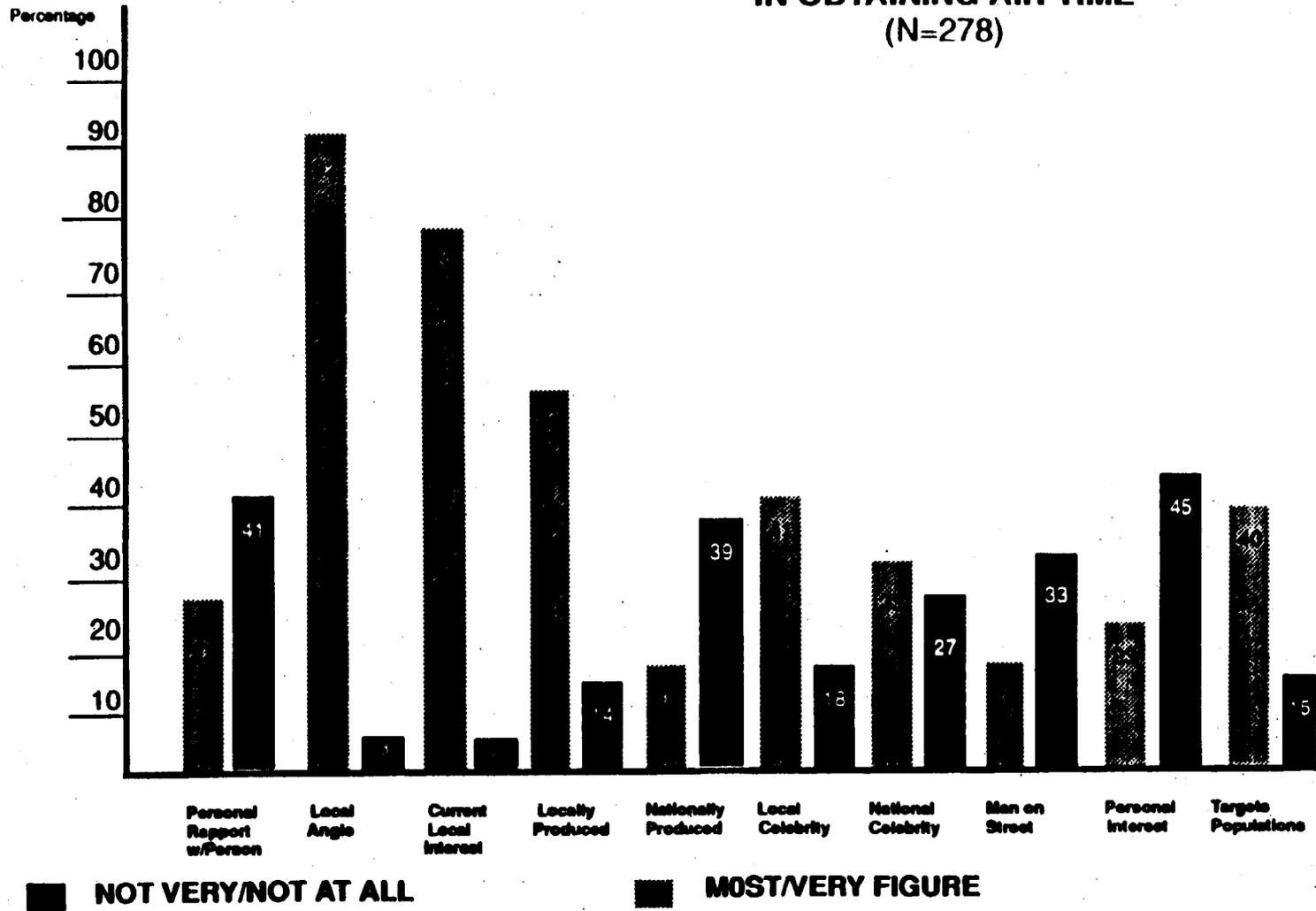


National Kidney Foundation, Inc. Survey on Television Gatekeepers Regarding Promoting Organ Donation

April 1991

Figure #8

### IMPORTANCE OF VARIOUS FACTORS IN OBTAINING AIR TIME (N=278)



137

National Kidney Foundation, Inc. Survey on Television Gatekeepers Regarding Promoting Organ Donation  
April 1991

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# **ORGAN/TISSUE DONATION IN AFRICAN AMERICANS: A NATIONAL STRATAGEM**

*Clive O. Callender, M.D., Department of Surgery, Howard University Hospital*

## **ABSTRACT**

In spite of the recent overall improvements in organ donation rates per million in 1990, African Americans (A.A.) continue to be less likely than White Americans (W.A.) to become donors (11.3 vs. 21.8). To improve A.A. donation, the following data were shared with the A.A. community: 1) A.A. renal disease incidence rates are disproportionately high, 1.3 to ten times those of W.A.; 2) the A.A. kidney graft survival rate is 10-20 percent lower.

Sharing these data resulted in: A.A. transplant awareness increasing from 10 percent to 24 percent; A.A. signing donor cards increased from 7 percent to 24 percent (1985-1990 Dow Gallup Polls); the number of A.A. receiving kidney transplants and becoming organ donors doubled nationally (Health Care Financing Administration [HCFA] data 1982-1989). The message was carried by ethnically-similar messengers who form the core of this successful A.A. volunteer community-based grassroots effort, the District of Columbia Organ Donor Project (DCODP).

A national Minority Organ/Tissue Transplant Educational Program (MOTTEP) designed after this volunteer community organization is presented as a model to increase A.A. donor rates nationally.

## **Introduction**

The state of transplantation is problematic for all groups, but most problematic for the African American community as a result of unique medical predispositions, donor difficulties, and harsh socio-economic conditions (1,2). The incidence of end stage renal disease (ESRD) in A.A.s with hypertension continues to rise despite a decline in deaths among A.A.s traceable to hypertension, heart disease, and stroke. The incidence of ESRD is almost seven times greater in A.A.s with hypertension than in their White counterparts. Furthermore, even though A.A.s represent only 12 percent of the American population, they make up 30 percent of patients on dialysis (3,4,5).

*\*The terms African American and Blacks are used interchangeably throughout this paper.*

Presently, three options are available for patients who develop end-stage kidney disease: peritoneal dialysis, hemodialysis, and organ transplantation. Unfortunately, no group, regardless of race, takes full advantage of transplantation: all groups overwhelmingly choose hemodialysis to combat kidney disease (80 percent Whites vs 90 percent A.A.) (5). These statistics are particularly striking considering the burdensome problems associated with dialysis. Hemodialysis is very costly, it requires attachment to a dialysis machine for 12 hours a week, and unnaturally constrains and dictates the patients lifestyle physically, socially, emotionally, professionally, and sexually.

In 1989 there were 16.1 organ donors per million Americans. African Americans donated 8 percent of the kidneys available for transplantation (11.3 donors per million), but received 23 percent of the available kidneys, almost three times as many kidneys as they donated (3).

Ten years ago, because of a similar situation (1,2,8) and the absence of any prior research on donation among A.A.s, Howard University Hospital sponsored a pilot study to disclose the most salient reasons influencing low Black donorship. The five primary reasons were: 1) lack of transplant awareness; 2) religious myths and superstitions; 3) distrust of the medical community; 4) fear of premature declaration of death after signing an organ donor card; and 5) potential Black donors' preference for assurance of Black receivership (8). Our 2-hour focus sessions provided education on an individual basis which proved to be the key to changing attitudes about donation. Only 10 percent of participants agreed to sign an organ donor card before the interview, while 100 percent signed them at the conclusion of the sessions.

Drawing from the experiences of this pilot study, the District of Columbia Organ Donor Project (DCODP) was developed in 1982. This paper discusses the origin of the DCODP, the first community-based organ/tissue donor program targeted to the Black population, and the development of subsequent initiatives which have been used to eradicate the obstacles to organ and tissue donation and transplantation among A.A.s.

Of vital importance to the success of this project have been the following: 1) an ethnically directed community message, 2) volunteerism, 3) ethnically sensitive and similar messengers, 4) community empowerment, 5) private sector sponsorship and partnership, and 6) coalitions between transplant and community organizations. We propose that the synergistic relationships operating in these programs will significantly increase A. A. donor rates when the National Transplant Educational Program is extended to the Black community. We therefore recommend establishing a National Minority Organ/Tissue Transplant Educational

Program (MOTTEP) coordinated through a national office, with 20 local programs, as an effective national strategy to increase the A. A. organ donor rate per to 16 million by 1993.

### **Methodology and Results**

In 1978, the author was first approached by members of the Southeastern Organ Procurement Foundation (SEOPF) to identify the obstacles to organ donation in the A.A. population and the dichotomy between low Black donorship and high ESRD incidence rates. I have elsewhere described the critical elements of these original efforts (1,2,8,12) but will summarize here the steps which have led to current efforts.

In 1980, the Howard University Organ Donor Pilot Study was organized under the direction of Dr. James A. Bayton. The information yielded from focus session interviews with 40 members of the Black community shaped the concept for the D.C. Organ Donor Project (DCODP). Instituted in August 1982 under the auspices of the National Capital Area's National Kidney Foundation (NKF) and the support of Howard University Hospital, the DCO DP worked with representatives from local members of the medical, political, educational, business, and religious communities.

The key founding members and subcommittee chairpersons included Harvey Silver and Preston Englert, Executive Directors, NKF; Curtis Yeager, Transplant Coordinator Howard University Hospital; Paula Barry, Public School Education Chairman and Curriculum Developer; Donovan Gay, liaison between NKF and Bureau of Motor Vehicles and first Chairman of the Financial Affairs and Grants Subcommittee; D.C. Councilman William Spaulding, First Co-Chairman of DCO DP, who launched the campaign in Ward 5; Dr. Charles Thompson (first dialysis and transplant patient member) former principal and Public Education Subcommittee member; Garrett Stewart, Jr., transplant patient and liaison with funeral directors; Dr. Clive Callender, Transplant Surgeon, President NKF, Co-Chairman DCO DP; Patti Grace Smith, Communication Specialist, First Chairman of the Subcommittee on Media and Community Relations.

The DCO DP steering committee met monthly from 1982 to 1984 to present subcommittee progress reports, propose future initiatives, and discuss strategies to raise funds and disseminate the message into the A.A. community to increase the number of A.A. organ and tissue donors. Funds raised paid for communication materials (video tapes, slide presentations, brochures, books, and posters), the salary of a full-time DCO DP Program Coordinator, and the development of a strategic plan, with committee input, by ethnically sensitive professional planners. This strategic plan led to the development of ethnically sensitive messages and techniques for effectively communicating to the A.A. community the need for more

A.A. organ donors. The DCODP strategic plan implemented in 1985 has been one of the main building blocks of this effort. All presentations now include either ethnically similar or sensitive donors, recipients, transplant candidates, family members, or health care providers whenever possible.

The message delivered to this target community is ethnically sensitive, appropriate, honest, and direct. It allows time for meaningful dialogue and for evolving answers to key questions. The message is structured as follows:

#### **The Problems:**

1. The incidence of all types of kidney disease is highest in A.A. patients.
2. A.A.s with hypertension between ages 25 and 44 are twenty times more likely than Whites to have kidney failure.
3. While A.A.s make up 12 percent of the American population, they constitute 30 percent of kidney patients waiting for transplantation.
4. Kidney transplantation is less successful in A.A.s than in Whites because we have so few A.A. donors.
5. A.A.s are transplanted at a rate of 50 percent less than that of Whites.
6. Twenty percent of A.A.s have transplant genetic markers that are rarely found in Whites, hence, the need for more A.A. donors.

#### **Proposed Solutions:**

1. The patient is the most important member of the health care team and must feed back to the physician all information about side effects when they occur. The physician, in turn, must respond in a sensitive and caring fashion.
2. A.A.s should have semi-annual blood pressure evaluations after the age of 12 (13,14).
3. If a diagnosis of high blood pressure results, a physician should be contacted and treatment started as soon as possible. The earlier the therapy the less likely that medication will be required and the greater the likelihood that stroke, heart attacks, and kidney disease will be prevented.

4. Treatment of hypertension is the critical first step in early prevention of kidney failure. The treatment of hypertension decreases the number of deaths from heart attack and stroke, and is likely to decrease the incidence of kidney failure if the diagnosis is made early enough and treatment is begun promptly.

5. Impotence or decreased sexual libido is a side effect of some anti-hypertensive medications, but many anti-hypertensives do not cause this side effect. If impotence occurs, this information should be shared promptly with the physician, who will adjust or change the medication so that the patient's sex life is not compromised.

6. More compatible A.A. donors are likely to make the success of kidney transplantation in A.A.s equal to the success of kidney transplantation in Whites.

7. The A.A. community is encouraged to start a family tradition: to sign an organ donor card and to have a family discussion about organ donation and transplantation at the dinner table and at family gatherings, and to make this discussion a part of daily living.

These problems and solutions are shared with the medical or lay community as time permits with presentations ranging from 5 - 120 minutes depending on the audience's time frame.

In 1986 representatives of the Dow Chemical Company attended a DCODP presentation at the national meeting of the American Council on Transplantation. They were favorably impressed by the early DCODP results and inquired about possible participation in continuing or expanding this local initiative. That same year, with Dow's support, the Dow Take Initiative Program (Dow-TIP) campaign took the donor education effort on a tour to 22 cities with the largest A.A. populations. This tour was completed in 1989.

The success of these efforts led to the development in 1988 of a joint effort between the National Medical Association (NMA), physicians, and A.A. clergy. This A.A. donor education project was characterized by Black physician and clergy interactions in an attempt to dispel widely held religious myths concerning organ donation. These groups applied the grassroots approach which had proven successful in previous Black donor targeted programs. This effort took place under the direction of Dr. Jesse Barber, Chair of the religious subcommittee and former NMA president, and Dr. Frank Staggers, past NMA president. Subsequent to these experiences, in the summer of 1990 a National Black Physician Education Project was initiated by the NMA and the National Institute for Allergy and Infectious Diseases (NIAID) under the direction of Dr. Vivian Pinn-Wiggins, Immediate Past

President of NMA, to educate as many Black physicians as possible about organ/tissue donation and transplantation.

In the fall of 1989, based upon the previous successes of the DCODP and the Dow- TIP Black Donor Education Programs, the Dow/NAACP Black Donor Education Project was begun in New York City, Saint Louis, Memphis, Detroit, Baltimore, and Houston. These efforts used a successful triad of (1) a voluntary Black community organization, the National Association for the Advancement of Colored People (NAACP) and (2) Regional Organ Procurement Organizations (ROPO) after receiving government-sponsored minority or Black donor targeted educational grants from the Division of Organ Transplantation, and (3) the private sector sponsorship of the Dow Chemical Company which paid for much of the educational materials, public relations and media contacts. This national Black donor targeted educational pilot program (Dow/NAACP) and its early successes are the reason for the creation of the MOTTEP which is proposed as a national strategy to overcome the donor shortages of Black and other minority populations.

### **The National Minority Organ and Tissue Transplant Education Program (MOTTEP)**

#### **MOTTEP Methodology A**

Establish and maintain a national office for overall project direction and coordination.

Develop Organ/Tissue Donor Programs within local communities. Use the successful Washington DCODP as a model.

Develop a strategic plan for reaching minority populations.

Identify key minority spokespersons and the appropriate message for their communities.

Establish a program committee of dedicated minority community workers and volunteers committed to increasing the number of organ and tissue donors.

Create and revise national and regional transplant curriculums for medical, nursing, divinity, and mortuary science schools, predominantly minority undergraduate colleges, and elementary and secondary schools.

**MOTTEP Methodology B**

Build on previous regional and national minority efforts including those of: Dow-TIP, Dow/NAACP, the DOT regional OPO minority grant programs, National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), National Institute of Allergy and Infectious Diseases (NIAID), Office of Minority Health Affairs, Department of Health and Human Services, and the Centers for Disease Control (CDC).

**Proposed Local Programs**

Local programs will be implemented in 20 cities, whose Regional Organ Procurement Organizations (ROPO) have received DOT minority educational grants and Dow/NAACP Black donor targeted Organ Donor Programs (ODP). The following cities are proposed as initial sites:

- |                          |  |
|--------------------------|--|
| New York City - Dow      | Atlanta - ROPO                                   |
| Baltimore - DOW          | Jackson, Mississippi - ROPO                      |
| Philadelphia - OPO       | San Francisco - ROPO                             |
| Washington, D.C. - DCODP | Los Angeles - ROPO                               |
| Detroit - DOW            | Jacksonville, Florida - ROPO                     |
| Houston - DOW            | Miami, Florida - ROPO                            |
| St. Louis - DOW          | Memphis - DOW                                    |
| New Jersey - ROPO        | New Mexico - ROPO                                |
| San Antonio - ROPO       | Arizona - ROPO                                   |
| Chicago - ROPO           | Columbia or Charleston,<br>South Carolina - ROPO |

**Local Program Costs\***

Local program cost per year	\$ 35,000
Local program cost for 20 cities (20 x \$35,000)	\$ 700,000
Total for 20 local programs over 5 years	\$3,500,000

\* costs include local program coordinator salary, consultant fees, equipment and supplies, travel and miscellaneous.

**MOTTEP National Office Operational Activity Costs.\*\***

Total national office operation per year	\$ 142,572
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\*\* Costs include national coordinator, research assistant, consultant fees, office space, equipment, telephone, postage, supplies, travel and miscellaneous.

**MOTTEP National Marketing Costs**

Cost for national office activities, services, and products	\$ 285,000
Three videotapes (production, reproduction, and shipping)	\$ 108,750
Two national slide shows (production, reproduction, and shipping)	\$ 56,525
Three national displays	\$ 15,000
Four national posters	\$ 35,000
National brochure	\$ 15,500
Organ donor cards	In Kind
Revision of National Transplant information Curriculum for elementary and secondary schools (revision, production, and shipping)	\$ 53,000

**Total MOTTEP National Office Costs**

National office operations (\$142,572 per year X 5 years)	\$ 712,860
National Office activities, services and products (\$285,000 per year X 2 years)	\$ 570,000
Local program costs (20 programs for 5 years)	<u>\$3,500,000</u>
Total costs for MOTTEP for 5 years	\$4,782,860

## **Results**

Since the development of the District of Columbia Organ Donor Project in 1982, there have been some outstanding results, including:

1. Development of a list of experts who could be called upon to speak at various organizational groups, and church meetings.
2. Widespread distribution of "A Gift of Life Poster" featuring organ donor cards signed by Black role models, professional basketball star Rick Mahorn, and former Senator Edward Brooke the most recent Black senator.
3. Introduction of a curriculum on kidney disease that has been included since 1985 in the District of Columbia public school system at the high school level.
4. Presentations to hundreds of civic and social groups including sororities, fraternities, neighborhood advisory councils, funeral directors, lodges, women's organizations, and other community-based organizations. Similar presentations have been made to more than 100 of the 1000 Black churches in the Metropolitan D.C. area.
5. Collaboration or cooperative ventures with organ donor programs in Georgia, Florida, Chicago, California, New Jersey, and Pennsylvania. Educational materials produced by the Organ Donor Program have been shared with at least 40 cities and 20 States interested in initiating their own programs.
6. Initiating a program within the District of Columbia Motor Vehicle Administration licensing unit whereby drivers could indicate their intention to become an organ donor. A symbol would be placed on their license as an indication of their intent. This effort increased the number of organ/tissue donor symbols appearing on licenses from 25 per month in 1982 to 750 per month in 1989 (15).
7. Since 1982 the number of Black organ donors and transplant recipients has increased significantly -- locally, regionally, and nationally (15).
8. Seven Black organ donor targeted videos have been produced since 1987 for use in local and national Black organ donor education efforts. These are shown to Black lay and medical groups.
9. The Dow/NAACP Black Donor Education program has been launched in six cities: New York and St. Louis in 1989, and in Memphis, Detroit, Baltimore, and Houston in 1990.

10. Since launching the above program in 1986, information concerning Dow Black Donor Education Media efforts has been featured in more than 275 newspapers and magazines, including USA Today, the St. Louis Post-Dispatch, the Detroit News, the New York Daily News, the Houston Post, Newsweek, Parade, Jet, Ebony and the Journal of the National Medical Association. In addition, information concerning Blacks and organ donation has been included on 60 local and national television broadcasts and 70 local radio stations, generating approximately 300 million media impressions.

11. A Black donor awareness guidebook, based on the DCDP experience was created and copyrighted in 1987 for the Dow/NAACP Black Donor Education Program.

12. A Dow/NAACP Black Donor Question and Answer Brochure was created in 1989 and more than 5,000 copies have been distributed.

13. The publication of Organ Donation: A Minority Dilemma - Howard University Hospital. More than 250 copies have been distributed since 1988.

14. Publication of "Start A Family Tradition", A Black Organ/Tissue donor targeted brochure. More than 10,000 copies have been distributed since 1988.

15. The conduct of the First and Second International Symposia on Renal Failure and Transplantation in Blacks, in Washington, D.C. in 1985 and 1989, respectively. Both symposia were sponsored by the Howard University Hospital and the National Institute of Diabetic and Digestive and Kidney Diseases. The symposium now bears the name of the Samuel L. Kountz Symposium and the third Symposium is scheduled for 1993 in Washington, D.C.

16. The development in 1988 of two slide tapes which are targeted at A.A. audiences: one for the lay community and one for the medical community. Both are available to interested cities.

17. A comparison of the Dow Gallup Polls of 1985 and 1990 demonstrates a heightened awareness in Blacks of the highly successful nature of organ transplantation as well as a tripling of the number of persons signing organ donor cards during that interval. This dramatic increase is at least partially the result of the intensive Black donor education efforts described above.

### Discussion

Between 1983 and 1989, the gap between the supply (donors) and the demand (patients waiting) for organs in the United States has widened from 1,050 to 9,903. Most of this change has occurred since 1986 (16). Furthermore, as of

June 1990, 20,828 people were waiting for organs for transplantation and three people die every day because of this shortage (3). Thus, the scarcity of organs has become the major limiting factor in transplantation today (7). This appears to mandate a priority shift for the transplant community and a critical need for their innovative and creative energies to be directed toward solving this dilemma. This has not yet occurred. In an effort to address this concern, the author has made the shortage of organ and tissue donors one of his highest priorities for the past 10 years. Reasons for low donorship in Black and White communities have been examined and found to be very similar (1,17,18,19,20,21). Thus, efforts successful in the Black community may be successful in communities of other ethnic origins.

Before this pioneering effort, no Black community transplant education effort had been researched or attempted. In addition, efforts to enlist the Black community in solving this problem could not be found in the literature. The solution was therefore approached in a grassroots fashion. The grassroots approach has a unique meaning for the Black population when considering historical factors and present socio-economic conditions. The approach has been unwittingly employed throughout Black history but most prominently during the civil rights movement in the 1960s. It was effective in mobilizing Mississippians to form the Mississippi Freedom Democratic Party and in garnering support for the freedom bus rides throughout Alabama. A sense of community empowerment is generated because organizers discuss the problem, consider the factors surrounding the issue, and most importantly illustrate each individual's ability to effect change (15,22,23,24).

This is particularly important when considering the lack of access to health care and health care professionals as well as the malicious history of health care officials using Blacks as agents of disease states as in the Tuskegee experiment (25). This method clearly is not restricted to the political sphere, but can be applied to the medical problems of the Black community as we have shown here.

The positive results of organ donor campaigns from 2 to 5 years after their initiation is proof that the Black community when appropriately challenged will respond (1,8,12). We attribute this success to grassroots organizing. Whether grassroots organizing is employed in research or education, an atmosphere of reciprocal learning is created which is especially necessary for the interdependency between the medical and the lay communities. Coalitions are developed and ethnically sensitive role models are generated to reach all areas of the A.A. community to help members of the community realize their equally important roles in organ donation. This may be particularly crucial in the A.A. community where a combination of socio-economic factors produces a more pronounced schism or

social distance between the medical and lay communities (22,23,24). Therefore, programs like required request may be ill-fated due to the untrained or insensitive approach of hospital personnel, compounded by the untimely nature of the request (26).

The face-to-face approach utilized by the DCODP was responsible for increasing the number of signed Black organ donor cards from 25 per month, in 1982, to 750 per month in 1989 and the Black organ donor consent rate from 10 percent in 1978 to 40 percent in 1989 (15).

The Dow-TIP, born directly out of the success of the DCODP, utilized several principles of grassroots mobilization at a national level. A media campaign using magazines directed towards the Black community like Ebony, Jet, Essence, Black Enterprise, Black Health and other ethnically oriented community newspapers and national print media played a crucial role in illuminating the urgency and necessity for the Black community's involvement. Such articles, along with TV/radio broadcasts and numerous community discussions, laid the foundation for the increase in Blacks who signed donor cards from 7 percent in 1985 to 24 percent in 1990, and in transplant awareness from 10 percent in 1985 to 32 percent in 1990, as seen in the Dow Gallup Poll of May 1990. No less impressive has been the increase in Black organ donors as shown in the SEOPF, Washington Regional Transplant Consortium (WRTC), HCFA, and Terasaki data (15). The WRTC data demonstrates a marked improvement (10 percent - 1978; 43 percent - 1989) from the 10 percent Black organ donor consent rate which existed in 1978 (15) before these efforts began (1,2,8,11,12). It also reveals for the first time data which depicts highly statistically significant differences between Blacks and Whites in medical unsuitability (9 percent Whites, 30 percent Blacks) and willingness to donate in one locale (15).

A Dow/NAACP coalition formed in October 1989 nurtures the seeds planted by the efforts of the Dow-TIP project. Even though it is too early to quantify its performance, two promising letters have been received, one from the Mid-American Transplant Association and the second from the Wisconsin Organ Procurement Organization. Since the launching of this project, data indicate that Black organ donations in the first 6 months of 1990 jumped to 39 percent from 15 percent for all of 1989. Similarly, the Dow/NAACP initiative was started in Memphis, Tennessee in April 1990. One month later, a person who heard one of the presentations on organ donation experienced a family member's tragic death. The family decided to donate their relative's liver, in part because one family member had learned about the critical need for organs during one of the organ donor talks and concluded they should participate in giving the "gift of life." As a result, a patient in Wisconsin with chronic Hepatitis B, in intensive care, received a successful liver transplant.

The most obvious benefit of these initiatives is an increase in the available organ and tissue pool across the racial spectrum, significantly increasing the likelihood that a Black transplant candidate can be successfully transplanted. A report recently released from the DHHS Office of the Inspector General reveals that Blacks wait twice as long as Whites to receive kidney transplants (10). One of the factors in this discordance is the shortage of Black organ donors. Consequently, an increase in the Black organ donor pool may help reduce long waiting times. Immunogenetic studies have also indicated that mismatches for certain major histocompatibility antigens, such as HLA-DRW6, are found with greater frequency in Blacks than in Whites (27) and have been associated with a decreased kidney graft survival (27,28). Recovering more organs from Black organ donors with similar antigens may therefore be crucial to increasing graft survival in Black transplant recipients (4,5,19,27,28,29).

The message on transplantation and organ donation that we take to the Black community is ethnically sensitive, appropriate, honest, and direct. Moreover, time for meaningful dialogue is allowed because questions and answers are key. As significant as the message is, the author has observed that ethnically similar or sensitive organ donor families, patients awaiting transplantable organs or tissues, and successful transplant recipients are the most effective and credible messengers and we use them as often as possible as the critical members of the messenger team. When possible the messengers should be the same ethnicity as the community addressed. Since transplant coordinators are specially trained to talk with family members and communities about donation and transplantation, when addressing the Black community, Black transplant coordinators are preferable. Since only 5 percent of the transplant coordinators in the United States are Black (16), the expertise of the Black coordinators must be maximized. In their absence, other Black health care providers, such as psychologists, social workers, nurses, physician assistants, etc., must be educated as ethnically similar messengers (which is preferable) or ethnically sensitive non-Black transplant coordinators must be trained to talk with Black families and communities.

When delivered by the appropriate messengers, this message increases awareness about the transplant dilemma and also publicizes the need for frequent blood pressure checks, fulfilling a preventive health community need. As individuals and the lay community realize the significance of their role in giving the gift of life and the control they can exercise over their own health by acts as simple as taking heart medication or having regular BP checks, the schism between the medical and the lay communities should become less pronounced. The impetus for these initiatives must come from public organizations, health care professionals, and the private sector. With impetus from well-informed public and private sectors, volunteer efforts of the community completes the team necessary for the

successful grassroots approach. This team can then help empower communities to actively participate in facilitating their own health care. The approach is economical, appropriate, and feasible.

Below is a schemata which details the evolution of the MOTTEP. This program, based on successful Black donor-targeted community efforts that began in the District of Columbia in 1982, now can be expanded nationally with the support of the private sector: e.g., Dow, Sandoz, Ortho, UpJohn, Burroughs Wellcome, Dupont, etc.; the public sector: e.g., DHHS, Regional Organ Procurement Organizations, CDC, NIH (NIDDK, NIAID), UNOS, the Red Cross, etc.; and Black community volunteer organizations such as the NAACP, the Urban League, Sororities, Fraternities, the Links and Black Women coalitions and organizations including churches. As detailed analyses are performed for each of the six pilot cities in the Dow/NAACP project, the successful correlates should be incorporated into the additional 20 cities targeted for donor education programs. The cost for such a program approximates \$5 to \$10 million over a 5-year period. This is relatively inexpensive when one considers that \$5 billion is spent annually on end stage renal disease and 30 percent of the patients with end-stage renal disease are A.A.

The minority organ/tissue donor program could increase organ donation by 5 per million per year. Because there are 50 million Hispanics and Blacks in the United States (1990 census) this would mean 250 more donors and 1000 more organs (500 kidneys, 250 livers, 250 hearts) per year, and 5,000 organs after 5 years. Translated into socioeconomic impact, this would save 9,230 patient years. Phillip J. Held, Urban Institute health economist, suggests that American society values a life at \$110,000 per year. Thus, a yearly increase of 250 organ donors would, over a 5-year period, save life years valued at over \$1 billion.

Increased organ donation through this program would have an enormous economic impact on Black kidney patients, who, as a group, have the poorest graft survival rate (33 percent lost in the first year, 18 percent lost each year thereafter). Graft life expectancy among Black kidney patients is 26 months; among Whites it is 4 years. The per-patient cost of direct medical care for dialysis and related medical expenses is \$100 per day. The cost of kidney transplantation is \$30 per day per patient. The approximate average cost benefit from this organ donor program therefore, would be \$70 a day per patient (dialysis expenses minus transplantation expenses). If we assume that 2,500 kidney patients in 5 years would receive transplants because of increased organ donation through this program, the total cost savings would be \$43.5 million for Black kidney patients, and \$87 million for White patients. However, if we add the cost-benefits derived from additional transplants (for example, hearts and livers) and the resulting savings of 9,230 patient years, we would realize an additional cost savings of \$1.15 billion.

### **Recommendations:**

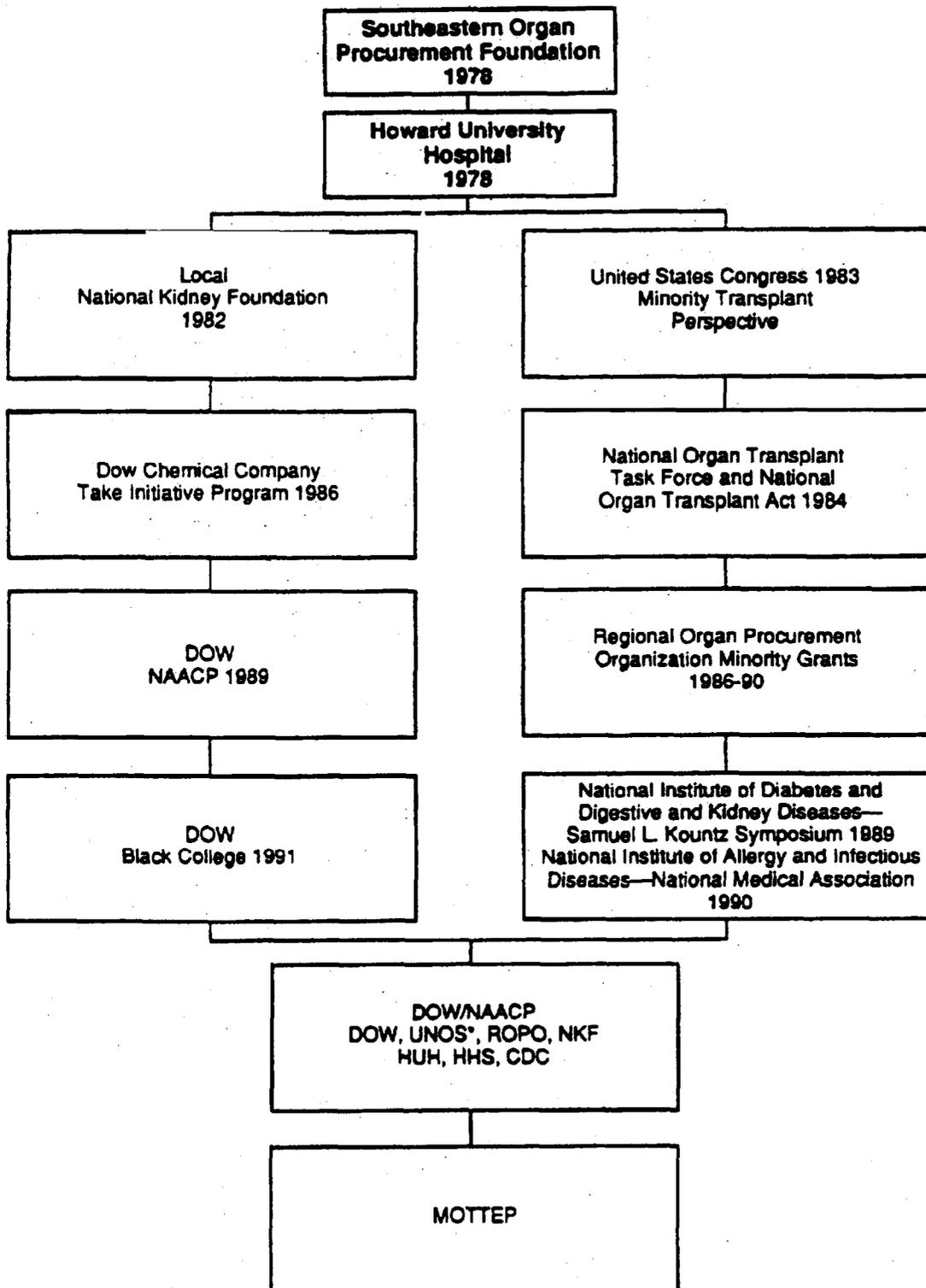
We have described a successful grassroots approach in the African American community which has: 1) heightened transplant awareness, increased the number of A.A.s signing organ/tissue donor cards and increased the number of A.A. organ donors; 2) emphasized a synergistic relationship between the public sector, the private sector and volunteers in the African American community; 3) been successful locally (DCODP), regionally (Dow-TIP), and nationally (Dow-TIP and Dow/NAACP); 4) emphasized the use of ethnically similar and sensitive community role models, ethnically similar organ donor families, successful transplant recipients and patients waiting for organs/tissues for transplantation, as very credible and effective community educators.

### **Conclusions:**

We propose MOTTEP as a program targeted to the minority population which will provide an increase in the number of minority organ donors and a subsequent potential savings to the government of \$43.5 million if Black kidney patients are transplanted and \$86 million if White kidney patients are transplanted. Overall savings resulting from the increased organ donation would extend to the benefits of 9,230 patient years and \$1.2 billion. These benefits would be well worth the \$5 million required for the 5-year, 20 city program.

It is time now for a national expansion of the modus operandi of the DCODP into 20 cities (MOTTEP) taking advantage of the lessons learned from the previous successful efforts. The principles outlined in this report are applicable across the entire racial spectrum of organ donors and may be useful in the resolution of the current acute shortage of transplantable organs and tissues.

# The Evolution of The National Minority Organ and Tissue Transplant Education Program



\* UNOS - The United Network for Organ Sharing

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## **HISPANICS AND ORGAN DONATION: PROSPECTS, OBSTACLES AND RECOMMENDATIONS**

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### **Summary of Main Points**

Hispanics are a large and rapidly growing group with several unique characteristics relevant to health planners and policy makers.

Hispanics are an aggregation of different national origin subgroups with different biological and historical backgrounds and different geographic distributions. Any generalization about Hispanics should be checked to see that it applies across all of the different Hispanic subgroups. The same is true regarding immigrant status, language dominance, and class status.

A few States and several cities contain much of the U.S. Hispanic population.

Latinos are generally younger, poorer, and less well educated than the general population.

There are at least three major segments of Latinos: Spanish-dominant immigrants, English-dominant or bilingual lower class natives, and the English-dominant middle class.

Mexican Americans have a much higher incidence of ESRD than the general population. The incidence of ESRD among non-Mexican Latinos is not known.

The proportion of Hispanics receiving transplants is similar to the proportion on the waiting list.

Hispanics do not have equal access to health care because of cost, language, and lack of insurance coverage.

The strongest objections Hispanics have to organ donation seem to come from lack of access to health care.

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*\*I would like to thank Oscar Salvatierra, Amy Peele, Phylis Weber, Ashley Baquero, David Warner, Mary Ganikos, and the members of the Surgeon General's Advisory Committee for their comments and assistance. I would also like to acknowledge the research support provided by the Elspeth Rostow Centennial Fellowship.*

The method of approaching the next of kin for permission to remove organs for donation can be made sensitive to Hispanic needs and concerns.

Family-oriented Spanish language television might be a good way to raise the issue of organ donation in a context where potential donors could express their sentiments to their family members.

A Hispanic-specific program could and should have a goal of general equity of organ donation and transplantation.

### **Introduction**

Hispanics are one of the largest and fastest growing minority groups in the United States. The 1990 Census enumerated 22.4 million Hispanics comprising about 9 percent of the Nation's total population. In the period between 1980 and 1990, the Hispanic population grew by 53 percent while the U.S. population grew by 10 percent (1). The literature reviewed in this paper indicates that Hispanics have a greater need for organ transplants and that they also have lower rates of organ donation. The size, growth, and relatively youthful age distribution of the Hispanic population, their socio-economic and linguistic characteristics, their medical needs, and their potential contributions to the organ transplant pool make the issue of Hispanic organ donation an appropriate and vital element of any effort to increase the levels of organ donation for transplantation. This paper shall focus on barriers to Hispanic donation and to the principles which might be applied to mount an effective campaign aimed at the Hispanic population.

### **Characteristics of the Hispanic Population**

Hispanics are an aggregation or agglomeration of several distinct national origin subgroups: Mexican, Puerto Rican, Cuban, Central and South American, and Other Hispanics. The term Latino has a growing preference over the use of the term Hispanic. To reflect this and still be consistent with those who continue to use Hispanic, I will use the terms interchangeably (2). The Mexican origin population is by far the largest Latino sub-group, constituting 62 percent of the United States' Hispanic population. The Puerto Rican, Central and South American, and Other Hispanics form a cluster of values at 13 percent, 11 percent, and 9 percent respectively. Cubans make up about 5 percent of the total Hispanic population (3). Among these different subgroups we can find a population variety of different genetic backgrounds, socio-economic characteristics, immigration or generational status, and geographic distributions. If any of these distinctions are pertinent to the specific subject at hand, then the subgroups will be referred to individually. There are also

many instances when Hispanics may or must be referred to as a group. There are many similarities among all or some of the Latino subgroups. Also, the amount known or written about Hispanics and organ donation is very scarce. The literature on this topic which distinguishes between the different subgroups is almost non-existent.

There are distinctive patterns of geographic distribution found among these subgroups. The Mexican origin subgroup is the largest Hispanic group in the Southwestern States and Illinois, Puerto Ricans outnumber other groups in the Northeastern States, and the Cuban origin Hispanics are the largest group in Florida. Large proportions of the Central and South American and Other Hispanics are found in Florida and the Northeast. The observation that large measures of the Hispanic population are concentrated in just a few States is confirmed by the percentages of the national Hispanic population in each State as well as by the cumulative percentages. One State, California, has about one-third of the nation's Hispanics. Three States combined -- California, Texas, and New York -- have about two-thirds of all Latinos in the U.S. Furthermore, the ten metropolitan areas with the largest Latino population contain about 62 percent of all Latinos. In descending order, these are: Los Angeles, New York, Miami, Chicago, San Francisco, Houston, San Antonio, Dallas/Fort Worth, San Diego, and El Paso (4).

Latinos are younger than the non-Latino population. In 1988, the median age for Latinos was less than 26 years; for non-Latinos the median was almost 33 years (5). The younger Latino age structure is reflected in the fact that the Latino proportion of the school age population in many areas exceeds the overall population proportion of Latinos. The higher concentration in younger age groups reflects higher fertility rates and the fact that many immigrants come to the U.S. during their child-bearing years. This demographic characteristic has several implications for an education and outreach program regarding organ donation. First, a program targeted toward youths could have long-term payoffs as these youths are exposed to circumstances over their life course requiring them to make a decision regarding organ donation. The preponderance of Latinos among the youth of many areas requires that a long-term educational program take account of their particular characteristics. The young Latino age structure also has another long-term implication -- as the entire population ages, a large part of the Anglo baby boom population now in their late thirties and early forties will eventually be concentrated in the age groups over 65 from which organ donations are not currently acceptable. The demographic future of the U.S. clearly has a large proportion of Latinos, African Americans, and other minorities in its future work-age population (6).

Many Hispanics are recent immigrants and immigration accounted for about half of the growth during the 1980s. While immigration is a major source of Hispanic population growth and many Hispanics are recent immigrants, many Hispanics are descendants of families which have been U.S. citizens for generations. The distinctions between

immigrant and native-born are often drawn in terms of generational differences. Typically, first generation refers to foreign-born immigrants with foreign-born parents; the second generation consists of a person born in the U.S. with one or two foreign-born parents; and the third generation consists of the U.S.-born children of U.S.-born parents. This last category includes all those who have been in this country for more than three generations as well and could be referred to as the third and third-plus generation. If Puerto Ricans born in the Commonwealth are counted as foreign-born, 58 percent of Latinos between the ages of 25 through 64 residing on the U.S. mainland were first generation; 17 percent were second generation; and, 25 percent were third generation. If the first and second generation are combined, 75 percent of the Hispanics had a direct, or through immigrant parents, indirect, contact with a foreign country, a foreign culture, and a foreign language (7).

The high proportion of immigrants among Latinos explains part of their lower attainment in education, income, and occupation. The poverty rate for Hispanic families was 23.4 percent in 1990, compared with 9.2 percent for non-Hispanic families. The median Hispanic family income was about two-thirds of the median income for non-Hispanics. The Latinos unemployment rate for 1990 was about 60 percent higher, and Hispanics that did have jobs were concentrated in unskilled and semi-skilled occupations (8). A similar report for 1988 showed that half (51 percent) of the adult Latinos had at least a high school education compared to 78 percent of all non-Latinos. The 10 percent of Latinos who had completed 4 or more years of college was about half of the non-Latino proportion of college graduates. Correspondingly, the Latino high school dropout rate was more than twice as high the non-Latino rate (9). Illiteracy is much higher among Hispanics than either Blacks or Anglos (White non-Hispanics) (10). A recent study projected that in 1991, 20 percent of the Spanish language population would be monolingual Spanish speakers, 37 percent would be Spanish-dominant bilinguals, and 43 percent would be English-dominant bilinguals. It appears that the amount of Hispanic immigration in the 1980s has greatly exceeded the level assumed in making these projections. Increased immigration would increase the Spanish-dominant and lower the English-dominant projected proportions. English monolingual Hispanics are not part of the Spanish language population (11).

Immigration, however, does not fully account for the lower attainment levels of Latinos. I have argued elsewhere that the recent historical experience of most second and third generation Hispanics contradicts the claim that they are achieving parity in measures of social or economic attainment with Anglos. There is not even a tendency in that direction. Instead, many educational and economic measures indicate that Latinos are not making progress and some even show relative and absolute declines even among those Hispanics who have been in the U.S. for a number of generations. The relatively small proportion of educationally and occupationally mobile Latinos has many social and cultural attributes of the majority Anglo population. However, there is a large number and proportion of second and third generation Latinos, many of

whom are English-dominant, who have lower income and educational levels and a diffident orientation to many elements of mainstream institutions (12).

### **Segmenting and Reaching Latinos**

The previous description of Latino characteristics and the literature cited imply that it would be useful to divide or segment the Latino population into three major groups. One consists of Spanish-dominant recent immigrants with lower class jobs. This group would be concentrated in cities that had experienced substantial immigration during the 1980s. Many Central American origin Latinos would fall into this category as well as a large number of Mexican immigrants. The second group is composed of English-dominant second, third, and third-plus generation adults with low educational levels and lower or working class occupations. The literature cited above suggests that Mexican Americans and Puerto Ricans would comprise most of this group and that it would be found in high concentrations in the Southwest and Northeast. The third group consists of an English-dominant middle class. This would be a relatively small group. The literature suggests that it would be geographically dispersed and that appeals or advertisements regarding organ donation that were targeted towards the U.S. population as a whole would also reach this group.

Currently, many advertisers believe that all Hispanics should be reached through Spanish language advertisements. The attention paid to the Spanish language population is a recent and well warranted recognition by advertisers of the size and nature of this group. Any health education and outreach program that did not address the Spanish-speaking population would miss a large group with extensive needs. However, not all Latinos are Spanish-dominant. The English-dominant lower and middle class groups have to be addressed as well. Spanish language media will reach some members of this group directly or, through family and friends, indirectly. Areas with large Latino populations may require an English language outreach campaign which targets this group as well. Hernandez and Newman outline elements of an English language campaign that may effectively reach the entire English-speaking audience. Their suggestion is to use an "ethnicized message" emphasizing Latino food, music, language, etc., in a context which will not disaffect the non-Latino audience. One example of this is using and pronouncing Spanish words or names with the correct Spanish pronunciation in an English language message. As another example, they mention a recent television commercial for McDonald's depicting a party for a young girl. To most viewers, the commercial simply depicts a birthday party; for some Hispanics, the commercial depicts or suggests a quincienera, traditional coming-of-age celebration (13). This approach takes advantage of the fact that many Latinos are English-dominant yet identify with elements of Latino culture and tradition. Common sense and empirical research both suggest that Hispanics are best reached in their native language, whether it be English or Spanish (14).

## **Hispanic Organ Transplantation and Donation**

It is surprising to find that there are very few epidemiological studies of Hispanic organ donation or transplantation. It is generally believed that Hispanics, as a group, have a higher rate of end-stage renal disease (ESRD), but this is usually supported by references to a careful study of ESRD in Mexican Americans conducted in San Antonio, Texas. Pugh and her colleagues find that Mexican Americans had an age-adjusted incidence of ESRD three times that of non-Hispanic Whites (15). Another study focusing on Los Angeles found that Hispanics had a slightly lower incidence of ESRD than Whites. Given the large concentration of young Hispanics in California and particularly in Los Angeles, the fact that this study did not make age-specific comparisons between Whites and Hispanics limits the applicability of its findings regarding Hispanic rates (16).

To the degree that the findings from San Antonio are generalizable to the Mexican American population as a whole, and the fact that Mexican Americans comprise 62 percent of all Latinos would tend to give all Hispanics a higher rate of ESRD if only because they dominate the composition of the aggregate group. In part, the high incidence of ESRD in Mexican Americans is tied to the higher incidence of diabetes in this group. The higher incidence of diabetes in Mexican Americans is a genetic heritage from Native Americans combined with the action of a strong environmental factor, presumably diet (17). The genetic heritage of Mexican Americans is probably similar to Central American Hispanics but different than that of Puerto Rican and Cuban Hispanics (18). African Americans also have markedly higher rates of ESRD than do Anglos. To the extent that the increased incidence of ESRD among African Americans is genetic, and to the extent that Puerto Rican and Cuban Hispanics share that genetic heritage, then these groups could also be expected to have higher rates of ESRD (19). At this point, the incidence and causes of ESRD among non-Mexican Hispanics is a matter of conjecture and speculation rather than fact. The statement regarding the genetic component of ESRD in African Americans and Caribbean Latinos should be read as a suggestion for future research on ESRD among Hispanics.

Another area in which the different genetic backgrounds of the Latino subgroups becomes important is that of the distribution of antigens. Whites, Blacks, Native Americans, and Asians have different distributions of ABO [blood group], MHC [major histocompatibility complex] and other antigens (20). To the degree that the antigens among the Latino subgroups reflect their different genetic backgrounds, this could limit the likelihood that organs from different subgroups would match. However, given these differences in the distribution of antigens, it is still possible to match and successfully transplant organs between Hispanics and Anglos. A sample of Hispanics in San Antonio, presumably Mexican Americans, were found to have a much higher rate of transplant survival than Caucasians whether the cadaveric donor was Hispanic or Caucasian. The survival rate of Caucasian kidney

transplants also was not dependent on the ethnicity of the donor. The survival rate of a Caucasian transplant was the same whether the donor was Caucasian or Hispanic. In both cases, the Caucasian survival rates were lower than Hispanic rates regardless of the ethnicity of the donor (21). A similar study of renal transplant survival rates in Caribbean Hispanics found that they also had significantly higher graft survival rates than the North Americans (22).

Kidney transplants are, by far, the most common transplant. However, the frequency of transplantation of other organs is increasing (3). The examination of causes of death might indicate if these advancing technologies have a different impact on Latinos than Anglos. The most prevalent cause of death among Anglos in California was heart disease; the fifth most prevalent cause was chronic obstructive pulmonary disease; and, the seventh was chronic liver disease. Among Mexican origin Latinos heart disease was also the most prevalent cause of death, and cirrhosis and liver disease was the seventh most prevalent cause of death (24). To the degree that death by these causes could potentially have been prevented or deferred by heart, lung, or liver transplants, the crude comparison suggests that Anglos might benefit more from the growth of the transplantation of these organs than would Latinos (25). The information necessary to present a similar comparison among the different Latino subgroups is not available.

Most of the evidence that the rate of Latino organ donation is lower than that of the Anglo population consists of comparing the proportion of Latino donors to the proportion of Latinos in the service area. Such comparisons do not control for differences in age distribution or causes of death, but the differences between the donor and population proportions are often so large that these comparisons probably do not indicate a lower incidence of Latino donation. For example, 52 percent of San Antonio's population is Latino; 80 percent of organ recipients there are also Latino, but Latinos are only 14 percent of organ donors (26). A very informative study of family refusal rates in New York, Miami, and Los Angeles shows that Latinos in all three metropolitan areas have much higher family refusal rates than Anglos. Each of these cities has a predominant concentration of a different major Latino subgroup suggesting that a disinclination to donate may be commonly found among all Latinos (27).

Another issue which remains unresolved is whether Latinos have the same chance of getting a transplant as an Anglo. Several studies have shown that Blacks do have a smaller probability of being the recipients of an organ transplantation even though they experience a much higher incidence of ESRD than Anglos. The lower proportion of minority donors does decrease the probability of matching blood groups and antigens. Several of the studies showing that Blacks have a smaller probability of receiving a kidney transplant also found the same to be true for non-White races. However, none of these studies specified if Hispanics were included in the data for non-White races (28).

Comparing the proportion of Hispanics who have received transplants to those on the waiting lists provides some evidence regarding the probability of Latino transplants. This comparison shows that the proportion of Hispanics receiving transplants was within 2 percent of the proportion of those on the waiting list for four major metropolitan areas. In two cases the transplant proportions were 2 percentage points greater than the waiting list proportions and in two cases the transplantation percentages were 2 percent less than the waiting list. The similarity of the proportions and the existence of positive and negative differences suggest that Latinos are getting transplantations in relation to their frequency on the waiting list. The pattern is very different for African Americans. While they represent a large proportion of the transplant waiting list, the percent of transplants is between 5 to 12 percent less than the proportion on the waiting lists in the same four metropolitan areas (29). While suggestive, this comparison does not control for the availability of matched organs. Moreover, the waiting list does not necessarily reflect the population that could potentially benefit from transplantation. Both individual and institutional factors could limit the placement of minorities on the waiting list (30).

An important element of any appeal for increased organ donation among Latinos is the claim that Latinos have a fair chance of getting an organ transplant if they should need it. This claim is supported by the similarity of proportion of Latinos having received transplants and on waiting lists and the fact that many Latinos receive organs donated by Anglos. However, the unambiguous demonstration of this point would only help an outreach campaign. If careful examination shows that equality of access is not currently the case, the adoption of this goal should be considered as part of the campaign.

### **Barriers to Hispanic Access to the Health Care System**

Hispanics have much less access to health care providers and institutions than any other group in the United States. The factors which limit access are lower rates of coverage by private or public health insurance, lower income levels, language differences, and scarcity of Hispanic health providers.

Much higher proportions of Hispanics are not covered by health insurance than those found among the U.S. population as a whole, or White non-Hispanics in particular. Only 10 percent of the White non-Hispanic population does not have either public or private insurance coverage compared to 37 percent of the Mexican Americans, 20 percent of the Cuban Americans, 20 percent of the African Americans, and 15 percent of the Puerto Ricans. Comparing Hispanics without insurance coverage to those with coverage shows that a much smaller proportion of those without insurance had a regular source of care and reported themselves to

be in excellent or very good health. Conversely, higher proportions of uninsured Hispanics reported never having had a routine physical examination or having seen a physician in the previous year (31).

These results confirm an earlier study which found that insurance and financial considerations were important factors in the number of physician visits by Latino children. In contrast, health perceptions were important determinants of physician utilization by Anglo children (32). A tabulation of responses from the Hispanic Health and Nutrition Examination Survey (HHANES) showed that by far the most prevalent cause of dissatisfaction with access to health care was that it was "too expensive." Other important factors were that the wait for an appointment was too long, the wait in the office was too long, and the long wait would cause loss of work and pay (33). Financial and insurance status and related factors create barriers to health care access by Hispanics. The characteristics of low income and high poverty levels of the Latino population discussed earlier corroborate the salience of these factors. These barriers are most conspicuous among the largest Latino subgroup, Mexican Americans.

Another set of factors creating barriers to health care have a social, cultural, or linguistic basis. Hispanics are extremely underrepresented among health care professionals and this is a cause of some of the problems Latinos have in getting access to health care (34). The ratio between the Latino population and Latino health care providers for California Latinos was more than ten times greater than the population-to-provider ratio for the total population (35).

Some have argued that cultural factors, particularly the utilization of, or credence in, the efficacy of curanderos, herbalistas, or other practitioners of folk medicine were obstacles to the utilization of health services by Latinos in the United States. A recent communication in JAMA even suggested that such practices and beliefs were factors in the lower proportion of Latinos donating organs for transplantation (36). However, only 4.2 percent of the Mexican American respondents in the HHANES data had been treated by a practitioner of traditional rather than scientific techniques. Furthermore, the utilization pattern of medical practitioners by the clients of curanderos was indistinguishable from that of the Latinos who did not use the services of the traditional healers. These facts suggest that the reliance on traditional medicine is not a major obstacle to the use of medical services.

A much more prevalent "cultural" factor which may well generate barriers to health care access is the existence of a large proportion of Spanish-dominant Latinos. The use of, or preference for, Spanish has often been used as an indicator of an attachment or fidelity to traditional culture. However, the Spanish-dominant individual, who represents a large proportion of Latinos, will also be less able to function well in English-dominant medical establishments which have, as noted above, an extreme scarcity of Latino professionals. A cogent article examining this

issue concludes: "[A]bility to speak English increases the extent to which Hispanics can effectively attain institutional access...In sum, regardless of one's level of acculturation on psychological or social dimensions, variation in language preference seems to be a critical determinant of utilization of health services, and is best viewed in terms of accessibility." (37)

A report evaluating methods to expand the number of organ and tissue donors offered three hypotheses to account for the low rate of minority donation: 1) donations may be deterred by cultural elements; 2) donations may be inhibited by socio-political dissension; or 3) health professionals may be reluctant to approach minority families (38). This brief discussion of barriers to better health access for Latinos suggests that the cultural element of belief in traditional medicine is probably not a major factor. Clearly, there are economic constraints to equitable access to the health care system by Latinos as indicated by the prevalent concern with health care costs and lack of insurance coverage. The reluctance to donate organs may in part have an economic component; in some cases, the cost of embalming an organ donor is raised by \$200. The lower rate of insurance coverage among Latinos may also limit the real availability of transplants. The amount of all kidney transplantation costs paid by Medicaid coverage varies from State to State (39). The third hypothesis, the reluctance of physicians to approach minorities, could well be, insofar as it refers to Latinos, the flip side of accessibility limited by language. It could be postulated that economic or linguistic barriers might translate into social or political conflict, thus supporting the second hypothesis, and this might indeed be a factor inhibiting Latino organ donation. However, none of the material reviewed provides direct evidence of social or political conflict. It is simpler and more direct to propose a fourth hypothesis: i.e., economic, insurance status, and linguistic factors create barriers to the complete integration of Latinos into the health care system and these factors directly and, through the consequent decrease in integration, indirectly contribute to the lower rate of organ donation.

### **Hispanic Attitudes Towards Organ Donation**

The amount of information available on Hispanic attitudes towards organ transplantation was greatly increased by the survey of Hispanic households in northern California conducted by The Gallup Organization for Dr. Oscar Salvatierra and his colleagues with the Organ Procurement Organization Transplant Service at the University of California, San Francisco. The survey consisted of telephone interviews of 505 Hispanic household heads conducted early in 1987. The survey questionnaire was designed to measure and evaluate Hispanics' knowledge of and attitudes towards organ donation and related issues.

While 82 percent of the sample felt that they were treated fairly when they go to a hospital, clinic, or doctor, only 68 percent of the foreign-born respondents, 70

percent of the Spanish-dominant respondents, 72 percent of the low income respondents, and 74 percent of the respondents with less than a high school education felt that they were treated fairly. These characteristics are all associated and point to the characteristics of the Hispanics who are going to have the least access to, and be the least integrated with, the health care system. The response to two related questions also indicates a lack of trust in the system and physicians. More than half of the respondents, 55 percent, stated that the belief that "They might do something to me before I am really dead," was a very important (42 percent) or somewhat important (13 percent) reason for not giving permission for organ donation. The second very closely related question indicates who "they" are. The fear that doctors might hasten their death was given as a very important or somewhat important reason for not agreeing to be organ donors by 54 percent of the respondents. Compared to the responses to the same question on a 1984 poll of the U.S. population as a whole, the Hispanics' responses indicating that these fears are factors in the decision not to donate are much higher. They are also sentiments that connect the lack of access and integration with the unwillingness to donate organs.

Most Hispanics, 87 percent, are aware of organ donation and transplantation. Again, the lowest proportions of respondents with awareness of the procedures were found among the lowest income group, 77 percent, and those who were either foreign-born or had less than a high school education, 81 percent of each category. The level of awareness for the U.S. population as a whole in 1984 was 95 percent. Education and outreach could contribute to changing this for all Hispanics, especially for foreign-born, Spanish-speaking, and less well educated Hispanics. Two other elements that should be part of a public education campaign are the fact that Hispanics do have a greater need for organ transplants than non-Hispanics; and, the fact, if it is indeed true, that Hispanics do get their fair share of donated organs. Only 3 percent of the survey respondents thought that Hispanics had a greater need for donated organs and only 28 percent thought that Hispanics got their fair share of organs. On this second issue of equity, 54 percent were not sure that Hispanics did get a fair share. Given the uncertainty on this issue in the professional literature, resolving this point and advertising an affirmative finding would fill a knowledge gap regarding organ transplantation and could influence Latinos' willingness to participate in organ donation.

Another survey response indicates what might be an important justification for, and element of, a public education campaign targeted at Hispanics. Half of the respondents said that the fact that they had never really thought about organ donation was an important reason for not participating in organ donation. This was a higher proportion than in the U.S. population generally.

Religious considerations played a smaller role as an expressed sentiment against donation than the issues discussed above. Only 34 percent of the Latino

respondents said that the belief that organ donation was against their religion was a reason for not donating. Only 8 percent said that their religion forbade donation, but 24 percent did not answer or were not sure. About a third of the respondents listed concerns about having their body intact for resurrection or an afterlife as reasons for not donating organs. The religion-oriented objections are not a factor for a majority of Hispanics, but the proportion of Hispanics who list such responses is greater than for the general U.S. population. This indicates that religious objections are not a major factor among Hispanics but they are relatively more important than for the U.S. population as a whole. Another possible indicator of an orientation towards religious issues was that a priest was third on the list of persons respondents would feel most comfortable talking to about organ donation. The top two choices would be a relative or a doctor.

This survey has additional important information on Latino attitudes towards organ transplantation, including information related to approaching the next of kin and media use. The findings will be discussed in the following sections.

### **Approaching the Next of Kin**

A recent study evaluating methods for increasing organ donation found that the education of the personnel who would approach the next of kin and request permission to retrieve the organs was more effective if it focused on methods for approaching grieving families rather than on technical information (40).

The California Transplant Donor Network has used the results of the San Francisco survey to compile procedures for approaching the next of kin. It can be read as a protocol for approaching families which responds to the suggestions of the evaluation report above. I will briefly summarize it here:

The physician should inform the family of the death of the patient. The concept of "brain death" should not be introduced because it seems to mitigate the finality of the declaration. The request for permission to retrieve organs should be separated from the pronouncement of death and the approach made by a transplant coordinator. The next of kin may want to defer to an elder member of the family in making the final decision. The discussion should include important relatives, English-speaking friends, and a priest. However, it may be advisable to keep the number of people involved to a minimum. The content of the discussion should emphasize the routine nature of the request and the fact that the family might be comforted by knowing that the donation is a gift. Concerns that the survey respondents commonly raised can be allayed by emphasizing that the request is initiated only after the patient is dead; that it is simple to give permission; that the donation can be done confidentially if there is concern that other family

members will object; that most religions, including Catholicism and Protestantism, support donation; and that the procurement procedure is done like other surgery -- the corpse is not simply cut up. The transplant coordinator would preferably be completely fluent in English and Spanish. This individual should remember that many Hispanics prefer to speak English and that some may not be literate (41).

The use of this protocol or one like it could be the basis for starting and maintaining an ongoing evaluation of the different aspects of the organ donation process.

### **Reaching the Hispanic Population**

A public education campaign focused on Latinos should mention that this group has a greater need for kidney donations, that the costs of kidney transplants are covered by Medicare, that there may be associated costs which are not covered, and that Latinos receive their fair share of organ transplants, if further research shows that this is indeed the case. These aspects of organ donation should be mentioned in a context which provides general information about organ donation and transplantation. However, there is another desirable element of a public education campaign -- it should evoke a response whereby members of the audience tell family members that they would like to have their organs donated if they should die in a manner where this is appropriate. The proportion of survey respondents who said that they would give permission for organ donation increased from 54 percent in the case where the respondent had not discussed this issue with the decedent to 94 percent in the cases where the decedent had explicitly expressed a desire to donate organs (42).

One way to make an appeal with this goal in mind would be a family-oriented television show. One example of how this might be done with reference to the Spanish-dominant segment of Hispanics is to place an articulate spokesperson on Sabado Gigante. This is a very popular Spanish language variety show broadcast for 4 hours every Saturday night. The show includes music, contests, games, and at least one segment devoted to a serious, educational topic. A discussion of the importance of organ donation to Latinos seems like an appropriate topic for such a segment. A well-constructed campaign could include an appeal (on this or a similar program) to tell a relative about the desire to donate organs.

The research literature on Latino media use is similar to that on Latino epidemiology or demographics: too often it consists of small-scale local studies from which it is difficult or dangerous to generalize. In addition, studies of media use are even less useful now due to recent changes in Latino immigration and

because they do not present the information necessary to segment or stratify the Latino population in terms of nativity, language dominance, national origin, or class.

Other means of achieving the same goals could include using Spanish and English radio and television public service announcements and organ donation themes in popular television shows, particularly soap operas or novellas, which would emphasize the importance of discussing organ donation with family members (43). The use of different media in different languages will reach different segments of the Latino population. For example, the audience that prefers Spanish language radio differs from the Hispanic audience of English language radio in the following ways: they prefer Spanish television, they prefer speaking Spanish at home, they are less educated, older, listen to the radio during the morning and midday, buy more records, tapes, and soft drinks, and are more likely to be married (44). While none of these characteristics have a conspicuous association with organ transplantation, this type of information could be the start of a knowledge base for effectively educating different segments of the Latino audience on an individual basis. Since it is true that, "Anheuser-Busch pitches differently to Hispanics in Texas and California," a health education campaign probably would be well-advised to follow the same principles (45).

Another way to reach the Latino population is with the cooperation of various non-profit groups or community-based organizations with good connections to various segments of the Latino community.

#### Conclusion: Would an Outreach Campaign Targeting Latinos be Effective or Divisive

Some of my suggestions regarding the components of a campaign to increase Latino organ donation could be seen as divisive. If Latinos do have a higher need for organ transplants, this fact might diminish the willingness of non-Latinos to donate. If it became known that Hispanics are receiving their fair share of organs but African Americans are not, then this too might create inter-group friction rather than cooperation. Since any campaign to increase organ donation will focus increased attention on the subject of equity, it is best to confront the issue directly. Inter-racial equity of transplantation has been a major concern in the scientific literature. Any increase in the attention given to transplantation, whether it specifically focuses on minority donors or not, will call attention to the issues of equity and fairness. The reason to focus on minority donation is because it represents a large group of potential donors who are currently under-represented. The way in which the equity issue should be addressed is to make equity of transplantation and donation for all groups a strongly desired goal. A campaign targeting Hispanics would not be an effort to treat this group differently, but to

recognize their differences so that they may participate equally. Ignoring current inequities will not encourage the minorities who are not completely participating to change their behavior. I suggest that efforts to improve the rate of organ donation adopt two related goals. The first is to develop the information resources necessary to evaluate and monitor the inter-racial equity of organ transplantation. The second goal is to make the attainment of equity a top priority. A commitment and effort of this nature would provide a welcome and appropriate encouragement for minorities to fully participate in the organ transplantation system as recipients and as donors.

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**PLANTING THE SEED:  
ORGAN TRANSPLANTATION EDUCATION  
FOR CHILDREN, YOUTH, AND YOUNG ADULTS**

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Teaching young people about organ transplantation is not notably difficult. Their lives are filled with situations ripe for discussing the topic, from school to church to community activity. The subject is intrinsically interesting, is not difficult to understand, and appeals to youthful altruism. But the organ transplant community has to offer strong inducements for teachers in various settings to take up the task.

Neither members of the organ transplant community nor teachers in schools, colleges, religious organizations, and community youth activity groups seem to want to undertake that task in any great numbers. Education efforts of the transplant community are concentrated on medical professionals and the general public. Few teachers or youth group leaders have been prompted by either their own interest or the suggestion of others to introduce the topic into appropriate situations. Strong, persistent education efforts focused specifically on young people seem comparatively rare.

Directing concerted education efforts to children and young adults would seem of clear value to the organ transplant community. Helping young people understand the facts about transplants early in life increases the chance that they will be sympathetic to the idea of organ donation should the situation arise later in their lives. They will be more willing to designate themselves as organ donors or to give permission for organ donation by next-of-kin should they be faced with such a decision. They are also likely to respond to a teacher's suggestion that they find occasion to discuss the issue with their families or with peers, thus multiplying the educational effect.

And then the possibility exists for that rare occasion when a young person who has been exposed to the subject of organ transplantation and discussed it with his or her family sadly becomes a candidate to donate organs. Exploration of the issues under circumstances free of stress makes it easier for medical professionals to gain consent for donation in the emotional upheaval attendant upon a young person's dying. A recent case in Michigan attests to the fact that such circumstances do arise.<sup>1</sup>

This paper focuses on the opportunities available for reaching school- and college-age people with information about organ transplantation and donation and suggests strategies for gaining access to those avenues of communication. As background and point of comparison for that discussion it considers briefly the reasons why comparatively little education effort has been focused on this age group and samples the efforts that have been mounted to inform young people to see what can be learned from these programs. It concludes with some suggestions about likely educational approaches to children, youth, and young adults.

The approach to these issues is that of an educator. I have had no association with the organ transplant community prior to writing this paper and only a lay person's superficial acquaintance with the topic. But I have spent a professional lifetime in colleges and universities dealing broadly with undergraduate curriculum and instruction and 8 years as a board of education member for a large and sophisticated school system. If my comments seem technically naive to those who work daily with organ transplantation and donation and lack a feeling for the texture of their professional lives, readers will understand why. I can only hope that an "outsider's" approach may suggest some new ways of thinking about a difficult problem.

### Central Problems

The old wheeze about the mule and the 2"x 4" has such staying power because there are so many situations in which "You have to get his attention first." The present topic is one of them. The problem is not that few know about successful organ and tissue transplantation or about the possibility of becoming a donor. The problem is rather that: (a) teachers do not think about the possibilities of organ transplantation as a vehicle for teaching other concepts, and (b) the topic has to compete with many similar ones for a place in the curriculum. In school and college curriculum, school-related activities, and church and community youth group programming, organ and tissue transplantation and donation just does not have the clout of the man with the 2"x 4".

Nor is the topic likely to achieve the preeminence among the concerns of this age group that would dictate its inclusion in education activities as a matter of course. The major medical/social preoccupations related to young people are sex, drugs, and alcohol. These topics are followed, at a considerable distance, by such matters as stress, nutrition, and fitness. The concerns of the transplantation community can be attached to some of these issues, but the spin that might be given organ donation in some of those contexts would not be particularly conducive to the community's message.

If organ transplantation and donation are only one among many interesting but not essential topics for curriculum planners and activity programmers, the topic has quite negative connotation for many young people, particularly late adolescents and young adults. These groups are averse to dealing with any matter that causes them to contemplate their mortality. In putting this paper together I spoke with a university health center director who works with a quite active student health advisory board. When the director asked the board chair about the possibility of the group's taking an interest in organ donation, the response clearly indicated a distaste for the whole topic. If university students most interested in health matters do not want to touch the topic, what must be the attitude of most others?

Thus, those seeking to increase awareness in the school- and college-age population should have as their first goal simply getting on the agenda. Once there, they have to be content with advancing on a broken front, trying a variety of tactics to reach audiences in several different situations, aggressively seeking out and actively creating allies where they can find them.

Given the difficulty of first getting on the agenda and then the likelihood of making only limited progress, it is no wonder that organizations trying to increase the number of organ and tissue donations have concentrated their public information and education efforts on other audiences. Organ Procurement Organizations (OPOs) focus most of their efforts on medical professionals, particularly those in hospitals. Hospital staff members are at the point of contact when the question of organ donation arises in earnest. They are at the most proximate source of potential donations and are legally obliged to ask the appropriate person about willingness to have the dying person's organs or tissues donated. It only makes sense to concentrate education efforts there.

It makes even more sense considering the pressures OPOs are under from Federal regulators. The pressure now is on the bottom line: increasing the number of organ donations immediately. Broader public education, particularly focused on young people, takes time to produce results. The logical conclusion: given limited personnel and funds for education activities, redouble efforts at reaching the proximate source and making efforts more effective.

Education programs for hospital personnel, however, seem for the moment to have achieved as much as they are going to. Indeed, that is why the Surgeon General's Workshop is being held. Organ donations seem to have peaked and the transplant community is looking for ways to increase them. It may be that a substantially different approach with hospital personnel will achieve improved results. It may be that better public education will result in more receptivity to organ donation. But it is quite clear that the present effort to arm hospital personnel with the applicable facts, laws, strategies, and attitudes is not producing the number of organ donations needed and the nets have to be cast more widely.

Associations focused on health issues related to a single organ or type of tissue (e.g., the National Kidney Foundation, the American Heart Association) also conduct extensive public education campaigns. Their efforts, however, focus on a wide variety of issues of which organ donation is only one. (When they do talk about organ donation, however, they tend to talk about donation of all organs and tissues, not just those that are the focus of their association.<sup>2</sup>) The greatest amount of money and effort goes into media campaigns and other activity directed to the general public. The Source Book of the American Council on Transplantation, a compendium of programs for public awareness about organ and tissue transplantation and donation published in 1988, lists fewer programs directed at young people than can be counted on the fingers of one hand.

So just as one wonders about the potential for improved results from the OPOs' educational focus on health care professionals, one has similar doubts about the ability of these associations' public campaigns to increase organ donations. More specifically targeted education programs, among which are activities for children, youth, and young adults, are at least worth considering.

#### **Efforts to Reach Children, Youth, and Young Adults**

Contacts with key members of the organ transplant community nationally and in major population centers have turned up only scattered examples of education materials and programs specifically directed at young people. By far the most prevalent such efforts are presentations for school classrooms and assembly programs.

Typically, the offer to conduct such a program comes from the education section of an OPO or association, although some organizations outside the transplant community, such as the Junior League, have taken a specific interest in organ donation education. The group wishing to present the program sends a request to a school official: superintendent, curriculum supervisor, or principal. Sometimes the request is routed to a teacher who might wish to schedule such a presentation, sometimes it goes in the wastebasket or languishes on the principal's desk. Occasionally a teacher responds and the session is scheduled. Thus, of many seeds sown, only a few germinate.

The more successful programs target teachers, who have the most direct control over the day-to-day content of classroom instruction. The problem is getting names for an accurate mailing list and following up with personal contacts. OPOs and association regional offices cover large areas with many schools and school systems. They have limited staff to devote to identifying the likely targets by name and contacting them in such a way as to maximize the possibility of gaining

entry to the classroom. The best solution has been finding a receptive school system and concentrating efforts there before moving on to another interested system.

Once having achieved a strong position in a school community, the problem is to continue arranging presentations in those schools year after year while expanding the program of classroom presentations to other systems. No organization I located had been carrying out a focused program long enough to have faced that problem.

Prior to initiating contacts with schools and school systems, organ donation educators must decide what part of the school curriculum they wish to target. Would they most wish to present an assembly program or speak to students in a particular course such as health education, driver education, biology, or general science? Do they wish to reach elementary school students or concentrate on the secondary schools? Clearly, different programs are required for different situations: one size does not fit all.

Tailoring the presentation involves knowing how to relate the material to the general purposes of the course and the content of classes immediately preceding and following it. A talk in a driver education class, in which the context is agreeing to sign the organ donor form, should be differently designed than a presentation in a health education course which is part of a unit on organ systems.

These distinctions do not appear to be clearly made. The presenting agencies most frequently have an all-purpose videotape that is the focal point for the presentation. The agency representative introduces and bases comments on the tape. Most such presentations incorporate, if at all possible, an organ recipient or the relative of a recipient, most desirably a person close in age to the audience. Frequently the main presenter is such a person. Sometimes a physician is included in the presentation.

This general format is designed for a one-time, stand alone presentation. It is quite effective in increasing awareness and knowledge about organ transplantation and donation and beginning to dispel myths. The comments of recipients and their families, either on tape or in person, leave a strong impression, but one does not know how long the impression lasts or what specific results it produces. We have only anecdotal information.

Some teachers are perfectly satisfied to have a presentation unattached to the general design of their courses. If some more organic connection needs to be made, they will make it. Conversely, I suspect that at least some of the resistance to presentations on organ donation in health and science classes is due to the perception that it will not work into the flow of the course, that it will be an

interesting but not notably relevant side trip. Teachers need to see how the subject of organ transplantation can be used in connection with a particular topic to illustrate a general point. Understood this way, organ and tissue transplantation could be dealt with in studying the immune system, organ systems, science and public policy, medical ethics, or social psychology.

This same tendency to treat organ transplantation and donation as an unrelated topic is manifested in the curriculum materials that various groups have produced and distributed. Even when the materials have been designed for use in a particular course, the assumption seems to be that the teacher is to treat the subject on its own terms rather than as a specific case of a more general issue. For example, a unit on "Donating and Transplanting Organs and Tissues" designed for eighth grade health education classes lists these objectives:

- Students will develop an understanding of issues concerning the donation and transplantation of human organs and tissues.
- Students will identify which parts of the human body may be donated to promote the improving and/or saving of another individual's life.
- Students will identify at least three common misconceptions surrounding the issue of donating human body parts.

These objectives, or for that matter any other part of the unit, give no clue as to why the student ought to be learning this material, or to what other aspects of the students' personal or educational experience this knowledge might attach.

The few curriculum guides I have been able to locate and classroom materials, such as coloring books, I have seen are not a reasonable basis on which to generalize about other instructional supports that may be available, if indeed any exist. Two guides are clearly expected to be used in specific situations, one for driver education classes, one in a religious education context. The driver education guide, except for its emphasis on the Uniform Anatomical Gift Act and the Uniform Donor Card, could be used in any situation. So could the materials designed for a religious setting. They are not sectarian and differ from the public school materials only in their greater emphasis on altruistic motives and empathic responses.

All the curriculum guides focus on mastering the vocabulary of anatomy and organ transplantation at a level appropriate to students' ages and to provide some exemplary cases through which to understand processes and issues. Sample word games and coloring books are provided for younger children, model tests and discussion topics for older ones. All seem designed to persuade students to adopt certain attitudes or, in the case of older students, sign a donor card. All could be strengthened to some degree by less tendentiousness and, in the case of older students, more emphasis on ideas to discuss and less on producing right answers. When a teacher's guide is provided, it offers far less information than instructors

are likely to need and employs some technical vocabulary which teachers should not be expected to know. In short, these curriculum guides offer some useful ideas and materials, but as the controlling documents for a unit are rather a mixed bag.

Apart from the standard approaches to curriculum and instruction offered by these guides, some unusual programs and resources are worth attention:

**"Debbie Donor Doll"** is produced by Soft Sculptured Dolls of Dallas, Texas. "She" is a child-sized soft doll who can be zipped open to reveal removable cloth organs and tissues attached by Velcro tabs. Children can see where the organs are located and can "transplant" healthy organs and tissues.

**"The Kids on the Block"** is a program designed originally to help young children understand the problems of their differently-abled peers. The "Kids" are large puppets worked by trained performers. Ideas are communicated by and through the puppets. The program has been extended to deal with such problems as sexual abuse and substance abuse. Recently, Tennessee Donor Services contracted with The Kids on the Block, Inc. to develop an organ donation and transplantation program which is now available to any OPO.

**"Teens for Transplants"** is a program of the American Organ Transplant Association (AOTA) working with the High School for Health Professions in Houston, Texas, LifeGift Organ Donation Center, and the Texas Medical Center. The 40 students involved are all considering careers in the health professions. Through the program they get a sense of the possibilities their future work might offer by providing one-on-one peer support for young transplant patients at the Medical Center, engaging in donor awareness programs focused on minority communities, and learning what it is like to do organ transplant work as a health professional. AOTA has formed a new division to propagate the program.

Use of **The Kids on the Block** represents a good example of getting organ and tissue donation into the curriculum by using the topic to serve a larger purpose. The puppets teach responsible social behavior by providing young children with an avenue for discussing their social attitudes. The strategy encourages honest expression of feelings and reduces the risk of such expression. The general goal of encouraging empathic response, surely an important purpose of early elementary schooling, can be approached through a variety of subjects, of which organ and tissue donation is one. Thus the topic gets attention in a way integral to the curriculum.

Teens for Transplants is a fine example of using extracurricular activities as a way to reach young people. To be sure, siting the activity at a high school whose program is designed for future health professionals gives it a chance for success rarely duplicated, but such an activity does not require such a setting. All sorts of service-oriented clubs and activities find fertile soil in high schools, appealing to many teenagers' altruistic instincts. Indeed, organ and tissue donation organizations may find their time better spent in approaching students through the extracurriculum than through the curriculum. At both high schools and colleges, service clubs and student government groups are looking for suitable projects. Donor awareness activities within the school or the community meet their needs well and give the organ transplant community an opportunity to educate a group of students in a setting providing more receptivity than the classroom.

Transplant education agencies should be aware, however, that sustaining such activities over a number of years requires a lot of effort. Teens for Transplants chapters have a good chance of lasting because they are focused on a single concern in much the same way as Students Against Drunk Driving.

If, however, the leadership of a student government association or service club gets excited about organ donation and mounts an excellent effort in that area, there is no guarantee that the effort will ever be repeated. Student organization leadership changes every year and the next year's leaders may have other enthusiasms or less ability. The University of Pittsburgh chapter of Mortar Board, a national undergraduate service honorary, involved four Pittsburgh area colleges in a highly successful organ and tissue donor awareness program in 1985. Different leaders the next year had other interests or less energy and the effort has never been repeated despite the excellent project documentation the graduated leaders left behind.

The only college and university program at the national level is an activity program for National Organ and Tissue Donor Awareness Week put together by the American College Health Association, a group comprised principally of health center directors. The Association put together a packet of educational materials, suggestions for publicizing the Donor Awareness Week, and ideas for activities. These materials were made available at no cost to campus groups interested in using the occasion to increase public awareness.

Apart from this program, any attention paid on college campuses to organ and tissue transplantation and donation appears to be a matter of the interest of individual faculty members. A number of social scientists have research interests in this area. The research subjects are frequently college and university students. In their involvement in these experiments, which deal with attitudes toward transplantation, students may end up learning a good deal about the issue.<sup>3</sup>

Information about the efforts of student organizations on college and university campuses is likely to be fugitive. No information exists about OPOs or associations directing their efforts toward postsecondary education and individual campus efforts are probably scattered and short-lived. There may be a fertile field there, but no one seems to have plowed it.

## Conclusions

Efforts specifically directed at informing children, youth, and young adults about tissue and organ transplantation are scattered and of variable sophistication. In few cases are they the principal focus of someone's job. The programs brought into schools and the materials made available to teachers, approach transplantation and donation from the point of view of the transplant community rather than that of the curriculum. The most imaginative and successful programs reflect an understanding that transplantation stands a better chance of becoming a subject of instruction as an illustrative example of a more general topic than as a topic in and of itself.

The possibility of reaching young people through extracurricular and community activities remains largely unexplored. Despite the difficulty of sustaining programs once they are successfully begun, the possibility of payoffs from young people's altruistically motivated volunteerism would appear to make the effort worthwhile.

Reasons for transplant educators' marginal efforts to mount programs specifically directed at the school- and college-age population are quite understandable. Education activities are the concomitant rather than the focus of OPOs' activities. They have comparatively little funding and staff for education and must devote most of their attention to hospital personnel. General public education comes second, with programs targeted at specific populations third. Only now is the realization growing that targeted campaigns may produce better results than broader efforts. But they are also more expensive of staff time.

OPOs now find themselves in a particular squeeze. Newly proposed Medicare regulations make immediate increases in organ procurement a necessity for survival. Education programs aimed at young people produce most of their results over the long run. OPOs feel the need to focus their efforts in areas that will produce the most immediate results.

As the number of OPOs decreases, the geographic area assigned to any one OPO increases. That enlargement of the service area makes it all the harder to maintain the personal contact with individuals in schools and colleges whose interest and cooperation is essential to a successful program for students.

The associations, on the other hand, are in the business of education, but transplantation is only part of that business. They are concerned about health maintenance, support for research, and treatments short of transplantation before they get to the transplantation issue itself. The associations, too, are beginning to think more about education programs for particular groups, but they still rely mostly on public service announcements, posters, bookmarks and national awareness days and weeks.

Even with time and determination, schools and colleges are difficult to penetrate. No curricular priority creates a reason for classroom discussion of organ transplantation and donation any more than dozens of other scientific, medical, or public policy matters. Requests for the schools' curricular attention are overwhelming. One health education curriculum coordinator reports 400 solicitations a year for adoption of particular texts, inclusion of units of study, and purchase of teaching materials. Only occasionally does an item that comes in over the transom get adopted.

The main focus of programs in schools is one-time presentations in assembly programs and health and driver education classes. All-school assemblies are the best setting for the kind of presentation transplant organizations are prepared to make, but fewer and fewer schools even have such events.

Driver education classes, too, are a fading feature of school life, but talk about organ donation has a clearly identifiable place in such courses. Even though curriculum materials for the most part conveniently neglect the fact that a signed organ donor card is for practical purposes meaningless as a form of consent to donating one's organs, discussion of donation and the signing of the Uniform Donor Card is valuable. The discussion itself raises awareness. If students then introduce the discussion at home, the matter comes to the attention of their parents, most of whom are in the age range that produces the most donors. Most important of all, signing the donor card is for many students one of the first acts of assuming adult responsibility for the general welfare.

Health education and biology classes in the secondary school and the science curriculum in the elementary school would seem the most logical place for discussion of transplantation. However, the approach to the inclusion of units on transplantation here is far too limited and educators have shown very little imagination about exploring other curricular areas in which to embed their message.

Penetrating the college curriculum requires more effort than the result would justify. Decisions about course content at the level at which transplantation discussions might occur is entirely in the hands of individual faculty members. Trying to identify the few who might find that organ transplantation or donation

provides a good vehicle for illustrating a point they would like to make is not a good investment of time.

The best entry to post-secondary institutions is through student groups: fraternities and sororities, service organizations, honorary societies in various disciplines. This approach through the extracurriculum holds promise for high schools as well. Organ donor education groups must, however, be prepared to deal with the problem of sustaining effort. Either they must accept the fact that a program successful one year may die the next or be willing to provide the kind of organizational support that will keep the program intact through periods of weak or uninterested student leadership.

While the lives of most young people center on their schools and, for half the 18-21-year-olds, on colleges, people in this age group are also involved in community activities: church groups, boys' and girls' clubs, scouting, 4H Clubs, Little League baseball and its equivalent in other sports, youth auxiliaries of adult organizations, and so on. Focused efforts to reach the African American community have used churches as a vehicle. In recent years the Boy Scouts offered an opportunity, now discontinued, to earn a merit badge in organ and tissue donation awareness. Otherwise the transplant community seems to have ignored the possibility of reaching young people through their community activities and concentrated instead on the schools.

Despite the major pitfalls and the investment of staff time necessary to mounting a successful education program aimed at young people, the potential payoff is worth the effort. Current strategies have brought organ and tissue donation to a steady state. Moving to the next quantum level requires new strategies. Young people are a large group whose characteristically sympathetic response to others' needs makes them a receptive audience for the transplant community's message. In the classroom setting they are also, to put it bluntly, a captive audience. But if the message can be carried by an appropriately designed vehicle, the topic of organ transplantation is of sufficient inherent interest to engage their attention. They then become a conduit for discussion of organ donation at home, producing, ideally, a multiplier effect. And as they mature and are perhaps called upon to make decisions about the donation of others' organs, they stand a good chance of being more receptive to the notion, having better factual knowledge.

Those young people who find the matter of organ donation particularly compelling are a prime source of volunteers. They have time, energy, and commitment which can easily be put to use by regional associations, OPOs, and the like. If only as a means of recruiting volunteers, the efforts to reach children, youth, and young adults may be worth the time.

To succeed in these efforts, educators in the transplant community need to mount persistent and coordinated efforts. Such efforts may not be possible for regional organizations whose attention is pulled in many different directions and whose funding is unstable. Coordinated efforts beyond the regional level and funding targeted for specific education efforts would be helpful. It is clear that the current level of effort which with rare exception is occasional, casual, and unsystematic will not begin to tap the enormous potential that young people hold for increasing the level of organ donation.

### **Recommendations**

In making recommendations, I am tempted to suggest that the organ transplant community try all the avenues that seem plausible to reach young people. Since so little has been tried and the efficacy of so much of that has yet to be demonstrated, it is hard to know what will work.

Many of the following recommendations are suggestions about practical matters of procedure on the local scene rather than matters of policy or practice on a larger scale. The focus on particular practices grows from a perception that, at least for the time being, education programs will be carried out by regional groups and by people largely unfamiliar with the way schools and colleges work. Thus my first desire is to help avoid wheel spinning.

#### **A. Curriculum**

**(1) Design curriculum guides and classroom presentations as an integral part of the course of study rather than as stand alone segments.** Organ transplantation and donation as a topic in and of itself really has no natural place in the curriculum except perhaps in driver education. As a specific case of a general principle, however, it fits in countless places. For example, the topic can be introduced in studying the immune system in biology, anatomy, and physiology courses; in studying human anatomy in a health course; as a public policy issue in a political science or current events course; or as a science and ethics issue in a general science or philosophy course. Any good teacher, unless he or she has a personal interest in the topic, will want the curricular materials or presentation tailored to the purposes of the course.

**(2) Curricula and presentations should acknowledge some of the complexities surrounding organ transplantation and donation, as is appropriate to the understanding of students of the age for which the materials are designed.** Too much of the material suggests that if all the myths were dispelled, organ transplantation as it is currently practiced would be seen as an unmixed blessing. Questions about such matters as organ sharing among OPOs, who gets organs,

and cost-benefit issues should be introduced and discussed. While one does not expect elementary school students to raise such questions, older students are not so naive and need to have these issues dealt with honestly.

If a major purpose of donation and transplant awareness activities in schools and colleges is to get the issue discussed around the dinner table, then **(3) all programs and curricula should include strategies students can use in introducing the topic at home.** Even in the most structured situations students cannot absolutely be required to raise the issue, but they can be strongly urged and helped to do so.

#### B. Dealing with schools

**(4) Focus efforts on people who are the real decision makers about curriculum.** Superintendents and principals almost never make decisions about particular items of curriculum. Those decisions are, to all intents and purposes, made by curriculum coordinators at the system level and individual teachers at the school level. Except in rare instances when the superintendent has a strong personal interest in seeing that organ and tissue transplantation gets some curricular attention and wants to do something throughout the school system, he or she will not want to get into the matter at all. Even working through the curriculum coordinator, the best likely result at the system level is introduction of an optional unit for teacher consideration. The best way to get on the agenda is to work with individual teachers.

Given these facts of curricular politics, writing letters about available programs or curriculum materials to superintendents and principals is not cost effective. Even writing to individual teachers will yield no better results than one might expect from a direct mail campaign. **(5) Contact the relevant decision makers personally,** presenting to them options for materials and presentations that are specifically geared to topics with which the curriculum for that course deals. That strategy requires a lot more preparation than offering a canned program and probably requires a representative of the organ donation agency who knows something about curriculum. **(6) Where possible, agencies should employ a staff person with a good knowledge of school curriculum.** As I have frequently suggested, the transplant community may more effectively get its message into schools through student clubs and organizations than through the classroom. **(7) Organ transplant educators should try enlisting student organizations such as service clubs, student government associations, Students Against Drunk Driving, or peer counseling groups in their efforts.** An active, carefully guided donor awareness effort by a student government can educate a whole generation of students and perhaps produce some volunteers for the OPO or organ association in the process. Even if the program is not picked up by the organization in the following year an advantage has been gained.

More likely to have staying power are organizations like Teens for Transplants. Such an organization has donor awareness and volunteer work with patients as its purpose for existence. A charismatic advisor can get such a program well established and give it a strong basis for longevity. **(8) The organ transplant community should support the efforts of the American Organ Transplant Association to establish Teens for Transplants organizations in high schools.** Student organizations do not generally exist on the elementary school level. Other than the classroom, the best point of entry for elementary schools is the PTA. **(9) OPOs and association chapters should work with PTAs to design programs suitable for their meetings.** PTAs are always looking for topics for programs. Organ transplantation and donation is an interesting topic with some personal relevance to individuals in almost any community. If a central purpose of getting organ and tissue transplantation into the school curriculum is to get the topic discussed in the family, PTA programs would seem a more direct way to achieve that result.

All of these strategies are easier to implement if one is dealing with school people who have a prior interest in organ and tissue donation. People who have themselves been organ or tissue recipients or close relatives of recipients are natural allies. But one may also create allies by enlisting them in the cause.

**(10) Agencies should establish education advisory committees composed of people influential in the local education community.** A curriculum coordinator, a PTA president, a science department head at the local university, an influential teacher can provide useful advice on designing programs directed at young people and can become active players in facilitating their adoption. Although the care and feeding of such a committee takes some time and thought, members' support for the agency's education activities can be well worth the effort.

### C. Postsecondary Institutions

In postsecondary institutions, the best approach is through student organizations. Fraternities and sororities are always looking for public interest projects. While some efforts are short-lived, others may go on for years and become part of the life and character of the organization. Service honoraries are often similarly at a loss for services to provide. Since they turn over their membership completely every year, getting an activity rooted is more difficult, but encouraging a one-time effort, if it is substantial, may be worthwhile. **(11) Donor awareness groups should work with undergraduate organizations to mount donor awareness projects.** Opportunity may even exist to create an analog of the Teens for Transplants program on college campuses, using pre-medical or health education students as its basis.

#### D. In the Community

Many untested opportunities exist for reaching young people through the community. The only particular model that has been used often enough to suggest some promise is using religious schools and youth groups as an avenue for education. **(12) Donor awareness groups should work with churches and synagogues to identify opportunities for youth education and service activities.** Beyond the religious groups, a variety of youth organizations offer possibilities. **(13) Donor awareness groups should make an informal inventory of youth groups in their service areas to determine which offer structures conducive to awareness activities and have supportive adult sponsors.**

#### E. Research and Funding

Of 29 awards made in 1988 and 1989 under the Division of Organ Transplantation's grant program for OPOs, only two were for education activities directed at children and youth. Given the disincentives for addressing this population, substantial activity will require far more support and specifically targeted funds. **(14) The Division of Organ Transplantation (DOT) should seek funds to establish a grant program to encourage donor awareness programs designed for children, youth, and young adults.**

Such a grant program could be included in the activities of a Donor Education Network with the responsibilities recommended by the American Council on Transplantation (ACT).<sup>4</sup> This Network's purpose would be "to coordinate the many separate public education initiatives conducted by transplant-specific, transplant-related organizations, and organizations that are interested in the cause of organ and tissue donation and transplantation on a project-oriented basis." Developing materials for education programs of many different kinds and to address many different audiences is clearly much more than any single organization can take on. There is not even a good mechanism for sharing ideas or collaborating on program and materials development. A coordinating body could facilitate development of more sophisticated materials and strategies geared to a variety of audiences. **(15) The DOT and the organ and tissue transplantation community should take steps to create a Donor Education Network.**

The Network, among other tasks, could foster research on the effectiveness of education activities. The ACT found that nearly half of public education programs incorporate no evaluation.<sup>5</sup> The summaries of the DOT grants indicated no provision for evaluation. Clearly research on the effectiveness of these programs is necessary. **(16) The DOT should use part of its 1 percent evaluation funds to assist grantees in evaluating their programs.**

## **In Conclusion**

Organ and tissue transplantation and donation education programs for children, youth, and young adults are in an early stage of development. Substantial efforts are few and time and money for them are limited. Most are not very sophisticated in the way they approach schools and school curriculum. The range of types of programs is narrow and the avenues of approach to young people have not been widely explored.

Scattered examples of reasonably successful programs exist, though some of them have been short lived. These programs can form a basis for expanding activity if funding and the regulatory climate will allow. But the effort needs a boost of both national attention and funding if it is to get off the ground.

*1. Letter from Eleanor Forlenza, Administrator, Transplant and Health Policy Center, Ann Arbor, MI, to Judith B. Braslow, Director, Division of Organ Transplantation, March 13, 1991.*

*2. American Council on Transplantation, "Executive Summary" of "An Assessment of Public Awareness Initiatives Promoting Organ/Tissue Donation and Transplantation: Findings and Recommendations," 1990, p. vi.*

*3. Several reports of behavioral science research on attitudes and behaviors with regard to transplantation, using college students as subjects, are reported in Organ Donation and Transplantation: Psychological and Behavioral Factors, ed. James Shanteau and Richard Jackson Harris (Washington, DC: American Psychological Association), 1990.*

*4. Executive Summary, p. iii.*

*5. ibid., p. vi.*

## SOURCES

*This topic calls for a listing of the sources of helpful, practical information. The listings that follow are partial, reflecting only what the author was able to discover in the course of writing this paper.*

### Books

*American Council on Transplantation, The Source Book 1988: A Master Reference to Increasing Public Awareness About Organ and Tissue Donation and Transplantation (1988).*

*Organ Donation and Transplantation: Psychological and Behavioral Factors, ed. James Shanteau and Richard Jackson Harris (1990), American Psychological Association.*

### Reports

*American Council on Transplantation, "An Assessment of Public Awareness Initiatives Promoting Organ/Tissue Donation and Transplantation: Findings and Recommendations" (1989).*

*Task Force on Organ Transplantation, Organ Transplantation: Issues and Recommendations (1986), U. S. Department of Health and Human Services, Health Resources and Services Administration.*

### Curricula and Teaching Materials

*National Kidney Foundation of Eastern Missouri & Metro East, St. Louis, MO, "Giving and Receiving the Gift of Life." (Materials designed for use in a religious education environment. Separate curricula and materials for K-3, 4-6, Junior High School and High School).*

*Transplant and Health Policy Center, Ann Arbor, MI, "Donating and Transplanting Organs and Tissues: An Eighth Grade Module."*

*Transplant Recipients International Organization (TRIO). Various classroom handouts and instructional activities.*

*The Virginia Transplant Council, Richmond, VA, "Organ and Tissue Donation Curriculum Guide." Both a general purpose guide and one designed specifically for driver education classes.*

### Programs of Interest

*American College Health Association, Organ Donor Awareness Week materials for use on college campuses. Contact: Richard Fasano, Southern Illinois University, Carbondale, IL.*

*American Organ Transplant Association, Missouri City, TX, "Teens for Transplants."*

*Junior League of Baltimore, "Second Chance."*

*Junior League of Pittsburgh, "Organ Transplant Outreach Project."*

*Mid-America Transplant Association, St. Louis, MO. Schools outreach project. Contact: Theresa Parks-Thomas.*

*Tennessee Donor Services, Nashville, TN, "The Kids on the Block, Inc." Contact: Elizabeth S. Nuckolls, BSN.*

***Teaching Aid***

*"Debbie Donor Doll," available from Soft Sculptured Dolls, Dallas, TX.*

## INCREASING ORGAN AND TISSUE DONATION:

### WHAT ARE THE OBSTACLES, WHAT ARE OUR OPTIONS?\*

*Arthur Caplan, Ph.D., University of Minnesota*  
*Laura Siminoff, Ph.D., University of Pittsburgh*  
*Robert Arnold, M.D., University of Pittsburgh*  
*Beth Virnig, M.P.H., University of Minnesota*

#### **The Procurement of Organs and Tissues in the United States: Grappling with Scarcity**

Inadequacy in the supply of organs and tissues has been a constant and frustrating reality in the field of transplantation for more than a decade. While no reliable statistics existed as to the number of Americans waiting for solid organs until 1987, and no precise numbers exist now as to how many Americans are waiting for tissues, scarcity has long been a fact of life for those in need of transplants.

At the end of 1987, the United Network for Organ Sharing (UNOS) waiting list for solid organs showed 13,396 names. In 1989 there were 19,173 names. At the end of 1990, there were 22,008 names on the list, an increase of more than 40 percent from the previous year. The list has been growing despite the fact that a record number of solid organ transplants, 15,162, were performed in 1990, a significant increase over the 13,176 organ transplants done in 1989.

Two thousand new patients are added to the list of those waiting for organs each month. Between a third to a half of all Americans on transplant waiting lists for hearts, livers, lungs, and heart and lungs die before a transplantable organ is found. Some experts estimate that a new name is added to the list of those waiting for organ transplants every 30 minutes.

As of March 11, 1991 the number of persons on the UNOS waiting list were:

Kidney	18,205	Heart/lung	181
Lung	410	Pancreas	524
Liver	1,311	Heart	1,899

*\* work for this paper supported in part by a grant from the Agency for Health Care Policy and Research (AHCPR) No. 5R01-HS06579-020*

**Between 2,500 and 4,000 Americans are on waiting lists for cornea transplants during any given month. Tens of thousands more await transplants of skin, bone, ligament, joints, dural matter, heart valves, and bone marrow.**

**The shortage of organs for newborns and very young children is especially acute. Twenty five percent of those waiting for liver transplants are children less than 10 years of age. In 1990, nearly 400 infants born with congenital defects of the heart died because there were no donor hearts available for them.**

**There are many reasons to believe that the demand for organs and tissues will continue to increase at a rapid rate. There have been major improvements in the efficacy rates associated with all forms of transplantation. The shift in the demographics of our nation's citizenry toward an older population means that more individuals are likely to need transplants. Improvements in immunosuppressive drugs combined with a better understanding of the genetics of the immune system, provided by knowledge acquired through the human genome project, hold out the promise of continuing improvements in efficacy rates and for increasing the number of potential recipients of transplants. And, there are more and more centers capable of performing transplants.**

**In the past two decades there has been an explosion in the number of medical centers performing both tissue and organ transplants (Russell, 1986). Whereas only a decade ago a mere handful of medical centers were capable of even attempting bone marrow transplants, today dozens of centers have done so. In 1985 one center had done pediatric heart transplants. In 1990, 35 medical centers reported experience with at least one pediatric heart transplant. In 1991, 20 more medical centers had indicated to the International Heart Transplant Registry that they intended to perform pediatric heart transplants (personal communication, 1991). Rapid increases in the number of centers capable of performing liver, lung, pancreas, intestinal, and heart transplants means that there will be increased demand for these solid organs. Similarly, the number of medical centers willing to undertake non-related bone marrow transplants has been growing at a very rapid pace.**

**As transplant surgeons begin to fully master the techniques of transplantation and as newer forms of immunosuppressive drugs become available, the eligibility standards for potential recipients are expanding. Broader standards of candidacy promise to fuel a continued demand for organs and tissues (Caplan, 1989). Age limits of 55 for heart and liver transplants that prevailed in the 1970s have long since been broken. Diabetes is no longer an absolute contraindication for kidney transplantation. Persons suffering liver failure resulting from alcohol abuse have been successfully transplanted. Fetus to fetus bone marrow transplantation has been attempted for various metabolic disorders.**

All of these factors contribute to what will be an inevitable increase in the demand for organs and tissues. Improvements in techniques for 'bridging' those in need of transplants, new forms of cellular transplantation such as myoblast transplants for those with muscular disorders, and the modification of the immune system of donor and recipient through genetic engineering will only add to the demand. Scarcity is the single greatest challenge facing those in need of transplants and those who wish to help them and will be so for the foreseeable future. The challenge facing our nation is to understand the organizational, legal, moral, regulatory, educational, and financial factors that currently underpin organ and tissue procurement in order to see whether there are any changes that can be made which will help bridge the gap between supply and demand in transplantation.

### **The History of Public Policy and Ethics Regarding Procurement**

Organs and tissues have historically been obtained almost exclusively from human sources. The primary source of organs and tissues in the United States has been cadavers. While living donors have been used to obtain kidneys, bone marrow, and, in recent years, segments of pancreas, lobes of lung and liver, cadaver donation is the single most important source of transplantable organs and tissues. Yet, because of the particular way in which transplantation techniques have evolved over the past four decades, public policy, law, and morality regarding cadaver donation has been strongly influenced by policies that were formulated primarily in response to the practice of using living donors.

#### **Voluntary Choice**

The first organ transplants were attempted in the early 1950s. These early efforts involved kidneys from living donors. Since there were no reliable methods for overcoming immunological differences between donors and recipients, no techniques for preserving organs outside the body, or for artificially maintaining bodily functions in cadavers, the only possible donors and recipients of kidneys were twins or biological siblings.

Law, religion, and public policy viewed the early days of transplantation with apprehension. Kidney transplants were seen as highly experimental. Some religious leaders worried that organ donation involved the mutilation of the body solely for the benefit of another and, as such, constituted an immoral act (Vatican, 1960, Meyers, 1990). Still other religious groups were concerned that God's gift of stewardship over one's body might not permit organ donation (May, 1985).

Those asked to provide donor kidneys were seen as requiring the protection of the state and the legal system so that neither coercion or ignorance were allowed to

play roles in efforts to secure organs. Since the outcome of kidney transplantation was not known, American courts would only permit the use of living sources if organs were voluntarily donated. Donors had to give informed consent knowing that their sacrifice might not eventuate in success. Courts held surgeons responsible for making sure that no one served as a donor as a result of coercive pressure from the potential recipient or other family members.

American courts and State legislatures generally held that incompetent persons such as children or persons who were either severely mentally ill or retarded could only donate organs if surrogate consent was provided by family members or guardians. The imposition of risk on incompetent persons was only allowed under the presupposition that the decision to donate is one that the incompetent person would have made were they to suddenly become competent (substituted judgement) or that the prospective donor could be harmed by the knowledge that a sibling had died because an organ was not available (best interest) (Meyers, 1990). The norm of voluntary choice is amply reflected in a long series of state court decisions to allow incompetents to donate based upon the doctrine of substituted judgement (Scott, 1982).

The emphasis on voluntary choice as the moral basis for permitting donors to assume risks in the face of uncertain benefits was carried over to cadaver donation. The concern about informed consent grew when it was discovered that during the 1960s some physicians had surreptitiously removed pituitary glands from cadavers in order to obtain growth hormone to help children born with congenital dwarfism (Caplan, 1984). Public and Congressional outrage over the removal of tissues from bodies without consent was so overwhelming that it resulted in an effort by health care professionals, government officials, and lawyers to create a means wherein voluntary choice could be guaranteed as a condition of cadaver organ or tissue procurement (Sadler and Sadler, 1984).

In the 1960s a flood of new technologies including respirators, heart-lung bypass machines, and artificial feeding tubes swept into medicine. These technologies allow physicians and nurses to keep organs functioning in individuals in whom no brain functions can be detected. This led physicians to call for a modification in the definition of death to include not only the traditional definition of the cessation of cardiac and respiratory function but also the complete and irreversible cessation of all brain function. Various model statutes were advanced proposing a brain death standard in the late 1960s (Capron and Kass, 1972) and had been adopted by more than 30 State legislatures by 1975.

As the concept of brain death gained acceptance in medical and nursing circles, it became clear that a mechanism was needed to allow individuals who wanted to donate organs or tissues upon their deaths to do so. The concern about the need for voluntary consent and the deeply held conviction that removing organs or

tissues from a cadaver without consent was manifestly immoral and repugnant led to the idea of an advance written directive for donation--the donor card (Sadler, Sadler and Stason, 1968).

### **Altruism**

By the late 1960s transplantation had made great progress. Kidney transplantation could be successfully accomplished using cadaver sources. Techniques had emerged for preserving and shipping kidneys and other solid organs. Surgeons were experimenting with transplantation of the liver and heart. Cornea transplantation had become a well-established therapy.

This progress led to a good deal of public debate about whether public policy should be changed with respect to organ and tissue procurement. Some analysts argued that the success of transplantation justified abandoning the prerequisite of informed consent in favor of laws and public policies which would permit the routine salvaging of cadaver organs (Dukeminier and Sanders, 1968, Columbia Law Review, 1969). Others argued that, rather than abandon informed consent, the time had come to consider permitting financial rewards to those willing to make organs and tissues available after their deaths (Michigan Law Review, 1974).

Neither of these proposals to change the moral and legal foundation of organ and tissue procurement was successful. Critics of presumed consent and routine salvaging argued that it was unfair to imperil the rights of those opposed to organ and tissue donation on religious grounds (Ramsey, 1970). Others were concerned that public policies which allowed either the routine removal of organs and tissues from cadavers or financial incentives to encourage making organs available would corrode social attitudes toward the dignity of the body and the sanctity and worth of the individual (May, 1973). The argument that prevailed was that public policy and law should favor both voluntary choice and altruism because these moral values were consistent with the desire of Americans to respect individual autonomy and liberty and that public policies based on these values might permit an adequate supply of organs and tissues to be obtained from cadaver sources if adequate efforts were made to encourage public altruism (Caplan and Bayer, 1985)

These moral values, informed choice and altruism, still constitute the ethical foundations of organ and tissue procurement in the United States today. One option that exists to increase the supply of organs and tissues from either cadaver or living sources is to institute laws and public policies that are not grounded by these values. Any assessment of the desirability of pursuing such strategies requires some understanding of the nature of existing State and Federal laws.

## **State and Federal Laws Pertaining to Donation**

The concern that the donation of organs and tissues be voluntary and altruistic was reflected in the earliest national legislation dealing with donation. In 1968, the National Conference of Commissioners on Uniform State Laws adopted the Uniform Anatomical Gift Act (UAGA). By 1972, versions of this law had been passed in all 50 States. The Act specifies who may execute an anatomical gift and how individuals may do so--by signing a donor card. State laws recognized a signed card as, in and of itself, completely sufficient for donation. There was and remains no need for next-of-kin to be approached or to consent when a donor card exists. Health care professionals who make a good faith effort to locate next-of-kin prior to relying on a donor card to remove organs and tissues are immune from legal action. To ensure that decisions to donate were autonomously and altruistically made, subsequent State and Federal legislation, the National Organ Transplant Act of 1984, explicitly prohibited the sale of organs.

If a deceased person has not completed a donor card then the UAGA permits donation based on the consent of relatives or guardians. In such circumstances family members are given the right to veto a donation. The law clearly recognizes that family members have a legitimate interest in the fate of the cadaver, but does not recognize a property interest.

Initial efforts to increase organ and tissue procurement were tied to this legislation. Public education campaigns encouraged persons to sign organ donor cards. These early campaigns appealed to altruistic motivations to encourage donation. People were encouraged to "Make the Gift of Life". Many States enacted laws allowing a modification of their driver's license applications to permit the indication of a willingness to serve as an organ or tissue donor.

In the 1980s two major legislative changes were introduced in an effort to increase procurement. One set of changes aimed at increasing the efficiency and proficiency of organ procurement organizations. The other aimed at encouraging greater awareness of the option of donation and more opportunities for donation to occur.

The National Organ Transplant Act of 1984 established a grant program whereby the Secretary of the Department of Health and Human Services could make grants for the establishment, initial operation, and expansion of qualified organ procurement organizations. These organizations were to establish procurement agreements with hospitals and health care professionals regarding donations. Later legislation, including the Omnibus Budget Reconciliation Act of 1986 and the Health Omnibus Act of 1988, attempted to further increase OPO efficiency and power by setting minimal standards for procurement performance. Tissue procurement organizations were not affected by these laws.

Legislation was also enacted requiring that request for donations be made of family members at the time of death. Initially, required request laws were enacted by States. Both Oregon and New York passed such legislation in 1985. By 1988, 44 States and the District of Columbia had enacted some form of "required request" legislation governing both organs and tissues from cadaver sources.

Two types of required request laws were passed. Twenty-six states and the District of Columbia have "strong" required request laws. These laws require health care professionals to document in writing on the death certificate that a request was made and the outcome of the request. The remaining States have "weak" laws which simply require that hospitals develop protocols to ensure that family members are made aware of the options of organ and tissue donations.

In 1986, the United States Congress enacted legislation requiring hospitals to institute weak required request policies. The Health Care Financing Administration issued regulations on July 31, 1987 and made the existence of protocols for informing families of the option of donations a prerequisite for Medicare reimbursement eligibility. These regulations went into effect on March 31, 1988. Shortly thereafter, the Joint Commission on Accreditation of Health Care Organizations established a policy of weak required request for hospital accreditation. It is important to note that the National Organ Transplant Act explicitly affirmed the prohibition on the sale of organs and some tissues. The Act was modified in 1988 to include a ban on the sale of fetal organs. Numerous States have also acted to ban the sale of organs and some tissues. Exceptions to these policies have been made for certain types of replenishable tissues such as plasma and sperm.

It is interesting (and an exception to the general voluntarism and altruism of procurement policy) that 10 States and a small number of cities have enacted legislation granting authority to medical examiners and coroners' offices to procure organs and tissues from unclaimed bodies undergoing autopsy. For example, Louisiana, Florida, Ohio, San Francisco, and Denver permit procurement from bodies under the control of medical examiners when no family members can be found and there is no reason to assume any prior objection to procurement.

#### **Public Support for Organ and Tissue Donation: Surveys, Polls and Studies**

There are a variety of ways of measuring public opinion on organ and tissue donation. One strategy is to see how well informed members of the general public are about various aspects of donation and transplantation. Another indicator is determining how willing individuals say they are to donate their own organs, or assessing the reported willingness of the public to donate the organs of their family members. In addition to prospective attitudinal studies, actual donation rates can

be determined as can the percentage of people carrying organ donor cards. These indicators offer somewhat inconsistent findings about public support for organ and tissue donation.

According to numerous public opinion surveys and polls conducted over more than 10 years, public education campaigns undertaken by various organ and tissue procurement organizations, community groups, government agencies, and private foundations have been quite effective in increasing public awareness regarding transplantation (American Council on Transplantation, 1985; Caplan and Bayer, 1985; Task Force on Organ Transplantation, 1986). Recent polls show that 98.7 percent of Americans are aware of transplantation (Evans and Manninen, 1988). Over 78 percent of adults say their overall feeling about being an organ donor is favorable. A majority accept the idea that being an organ donor helps other people and is the "right thing to do."

Various public opinion polls have indicated that between one-half and three-quarters of those polled would want to donate their own organs after death (Caplan and Bayer, 1985). People are more likely to report being willing to donate their loved ones organs than their own (62.5 percent vs. 49.3 percent in Evans and Manninen, 1988)

Some studies in the early 1980s showed consent to donation rates as high as 80 percent being obtained by some OPOs (Prottas, 1984). But more recent studies indicate that there may be a serious gap between hypothetical responses and real world behavior. Health care professionals report that roughly three-quarters of all families they approach are very likely or likely to refuse (Caplan and Virnig, 1990). Some States report consent rates at 15 percent or less (Edwards, Ohio Department of Health, 1991).

The disparities reflect inaccuracies inherent in asking questions about hypothetical behavior. For example, a frequently cited reason for the disparity between willingness to donate their loved ones' organs and their own is based on the fear that their families will allow their organs to be removed before they are 'really dead' (Caplan, 1992).

Some of the disparity between the small proportion of people who report carrying donor cards and the larger proportion who report being willing to donate their organs can be attributed to uncertainty about the donation process (Manninen and Evans, 1988). Some people, while sympathetic to transplantation, appear not to have actually thought about the donation process (Nolan, 1989).

Among families who have actually donated a relative's organs surveys reveal that they overwhelmingly did so from the belief that something positive would come out of a tragedy. They also felt that donating helped them in their grieving process

and they were motivated by the hope that someone else might live. Of the families who have donated, 89 percent report they would do so again (Prottas and Batten, 1986).

Questions of allocation are important to the public--black and white alike. Evans and Manninen (1988) report that over 88 percent of those surveyed were concerned that 'organs be distributed fairly and equally,' and over 81 percent reported that 'medical need, not social or economic factors should be the only criterion used to select transplant recipients.' Likewise, Watts (1991) reports that participation in organ donation programs is inhibited by doubts about fairness in the allocation of organs and tissues.

Public opinion polls support the hypothesis that blacks are less supportive of donation than whites (Callender, 1989; Watts, 1991). There are several possible explanations for this cultural difference. One study suggests that there may be a tendency for white health care professionals to be less willing to ask black families to donate (Maximus, Inc., 1985). Callender (1989) suggests that blacks are less likely to donate because of a lack of awareness about transplantation, religious fears, distrust of the medical community, fear that donors will be declared dead prematurely, racism (blacks do not want to give their organs to non-blacks). Interestingly, similar reasons are cited in explaining low donation rates generally (Basu, 1989, Watts, 1991). Among the reasons cited for a lack of willingness to donate are: religious objections (Watts, 1991), a fear that they will be allowed to die prematurely, (Nolan, 1989; Watts, 1991), a desire to bury the body intact (Nolan, 1989) and uncertainty about whether anyone will really benefit from donation or that everyone has a fair chance of benefitting (Watts, 1991).

In recent years, social scientists have studied the factors influencing people's views regarding organ donation and their decisions to sign (or not sign) an organ donor card. These studies show that:

1. Persons of color are somewhat less enthusiastic about transplantation and are less likely to sign donor cards than are whites. In a recent survey (Gallup, 1991 for Partnership for Organ Donation) 76 percent of whites and 45 percent of blacks say they would be likely to donate.
2. Favorable attitudes toward donation are also more common among women, persons with a higher socio-economic status, greater education, and serious health problems. A variety of psychometric studies show that people who are more materialistic view their organs as more central to their sense of self. Interestingly, some studies suggest that patients are more likely to donate when told about the benefits to themselves rather than emphasizing the benefits to others.

3. Despite the generally positive public opinion toward transplantation and donation, at most only a quarter of the public has signed an organ donor card. This rate is especially low among teenagers and young adults. A variety of explanations for this relatively low percentage have been offered including:
- a) People do not fill out organ donor cards because to do so would make them aware of their own mortality (Watts, 1991).
  - b) People's positive views regarding donation are outweighed by their fears concerning organ donation. The most common concerns are being declared dead prematurely so that organs may be procured for others and the fear of mutilation. One study found that two facts about death - the attitude toward death and the fear of being declared dead too soon - are predictive of organ donation behavior with respect to carrying a donor card.
  - c) There is growing evidence that people's concern regarding the fairness of organ distribution adversely affects the decision to sign donor cards (Watts, 1991).
  - d) Donor cards are not where the public wants them. A recent public opinion poll found that a substantial minority did not know where to obtain donor cards; they are not available in health care facilities where the public expects to find them (Watts, 1991).

Empirical inquiry via polls, surveys, and studies reveals high levels of public understanding about transplantation and relatively high levels of general support for transplantation. On the other hand, respondents to surveys are more likely to say they would be willing to consent to the donation of an organ by a relative than they would be to donating their own organs or tissues. There are many fears and doubts about the process of donation which seem to trouble large numbers of Americans. Most importantly, the hypothetical levels of support are not born out in practice either with respect to the number of Americans who have donor cards or with respect to the number of families who actually give their consent to donation when a death occurs.

### **Organ Donor Cards**

Forty-five States allow people to indicate organ donor status on their drivers licenses (Overcast, 1984). The proportion of persons reported in the literature as carrying a donor card varies, ranging from less than 8 percent (Bermel, 1984) to

over 37 percent (Basu, 1989). Data consistently indicate that more highly educated people are likely to report carrying a donor card (Simmons, Bruce, Bienvenue and Fulton, 1974; Manninen and Evans, 1985; Basu, 1989). Some studies have also found that younger people and women are more likely to carry donor cards (Simmons, 1974; Lewis, 1986).

The actual value of organ donor cards in obtaining organs is unclear. Some suggest that their primary value is encouraging discussion with families, rather than as an indicator of patient's wishes at the time of death (Prottas, 1983; Caplan, 1984). Others have noted that physicians and nurses very rarely look for donor cards prior to making requests of families, and that the presence or absence of a donor card is not overly influential to health care professionals (Caplan, 1984; Overcast, 1987).

There are other important limitations to donor cards' ability to increase donation. The most important limitation is that most organ procurement agencies will not procure organs without family consent, regardless of the presence of a donor card. Overcast et al., (1984) surveyed OPO and district attorney offices in all 50 States and the District of Columbia to determine the extent to which donor cards were effective in obtaining organs. Few donors were known by hospital personnel to be carrying cards at the time of death. Caplan informally polled groups of OPO and tissue bank personnel in 1984 and 1985 and found no reported instance in which an organ or tissue had been procured solely on the basis of a donor card. Despite the legal sufficiency of donor cards, misunderstanding of existing State laws plus the fear of adverse publicity has led hospitals to de facto require family consent prior to donation.

Cards do not seem to be effective as a means to facilitate donation. However, they may play a pivotal role in influencing the attitudes of family members if they are approached about donation.

### **The Performance of the Current System for Obtaining Organs and Tissues**

There are many steps in the process of procuring organs. These include:

1. a traumatic injury or accident occurs
2. resuscitation efforts are made
3. transfer to hospital
4. treatment attempts
5. recognition of the inevitability of death
6. recognition of potential donor status
7. decision to cease treatment efforts
8. discussion with family of imminence of death

9. diagnosis and declaration of death
  10. discussion with family concerning donation
  11. request to family for donation
  12. consent
  13. establishment of donor suitability
  14. notification of OPO for procurement
- (adapted from Waltzer, 1983)

All of these steps must occur in the order described for procurement to happen under the laws, regulations, and practices that currently control cadaver organ procurement. Tissues differ in that the sequence begins with the pronouncement of death. Modifications can be attempted at any one of a number of points in this sequence in the attempt to elicit increases in organ and tissue procurement. We will only focus on four especially crucial stages in the sequence: identification of donors, discussion of donation with donor families, obtaining consent, and the procurement of organs concurrent with OPO identification.

#### Identification of donors

The donation of internal organs such as liver, heart, kidney, and lung is restricted largely to brain dead, heart beating cadavers. Thus, most organ donors are found in hospital Intensive Care Units (ICUs), having suffered an acute catastrophe such as a car or gunshot accident, a drug overdose, or a cardiac arrest. Tissues, such as cornea, bone, and skin, can be obtained within 6-24 hours of a cardiac arrest. In many cases those who could not donate organs may be eligible to donate tissues since organs are currently taken only from those pronounced brain dead.

There is some disagreement about the frequency with which organ donors are distributed in acute care hospitals. Some studies indicate that the majority of prospective organ donors cluster in hospitals which handle high volumes of trauma (Partnership for Organ Donation, 1990; Garrison, et. al. in press). Other studies indicate a much broader distribution of prospective organ donors (Nathan, et. al., 1991) throughout various sizes and types of hospitals. Potential tissue donors are generally thought to be widely distributed throughout the acute care hospital system.

A recent study of the size of the potential donor pool in a large eastern State showed that the number of donors was between 38 and 55 per million population (Nathan, et. al., 1991). This was estimated to be about three times the rate currently procured nationwide. Other research suggests that patients admitted because of traumatic intracranial injury were identified as possible donors most frequently while patients suffering vascular or anoxic catastrophes were identified less frequently. Unidentified donors had been admitted to three major services

(neurosurgery, neurology, and internal medicine). The percentage of 'missed' potential donors was highest among internists.

Unrecognized donors tended to be older and had longer hospital stays. Interestingly, there was no clear influence of hospital size, trauma center designation, or the number of ICU beds on the number of missed potential donors.

Health care professionals fail to identify medically suitable donors for a variety of reasons (Toole, 1983). Failure may result from the lack of a comprehensible hospital policy clearly designating the health care professionals responsible for assessing patient's medical suitability. Some hospitals require that attending physicians or their designees carry out this task, but make little effort to educate physicians.

Health care professionals' lack of knowledge may decrease their ability to identify eligible donors. Some doctors and nurses have trouble understanding or accepting the concept of brain death. In one study only 35 percent of 195 physicians likely to be involved in procurement correctly identified the legal and medical criteria for brain death (Youngner, 1989). Some ICU nurses and physicians are uncertain about the validity of brain death (Martyn, Wright and Clark, 1988). OPO directors claim that in roughly 12 percent of cases, brain death is either unrecognized or recognized but not declared.

Other studies have documented a more general lack of knowledge regarding procurement criteria (Diamond, Campion and Mussoline, 1987). In one study roughly one-half of ICU nurses said that doctors were unaware of donor eligibility criteria and one-third said that nurses were unsure (Prottas and Batten, 1988).

Problems of donor identification may relate less to a lack of knowledge or responsibility than to lack of time or interest. Other responsibilities may be more salient to health care professionals than determining donor eligibility (Robinette, 1985). Nurses are especially likely to feel too overburdened with other responsibilities to spend a great deal of time identifying potential organ donors (Caplan and Virnig, 1990).

#### **Discussion of donation with families**

Numerous studies over the past decade show that a relatively small percentage of hospitals were responsible for supplying a large percentage of organs and tissues. For example, one small study found out that one-third of 105 hospital patient deaths were eligible to donate corneas, but that families were approached in only 16 percent of cases. In a recent survey of neurosurgeons, over two-thirds were hesitant to cooperate with organ procurement because they feared speaking with families.

A study of organ procurement in a trauma population in Vanderbilt Hospital from 1984 through 1987 revealed that 23 percent of eligible donors were not asked to donate. Why is there such resistance to approaching family members to discuss donation?

First, in many hospitals no person or group of persons is clearly responsible for talking with families about organ and tissue donation (Caplan and Virnig, 1990). Consequently, families may never be approached about donation.

Second, health care professionals who do discuss procurement with families may be uneasy about performing this task or lack training as to how to do so. One study found that 50 percent of health professionals reported that their fear of upsetting a grieving family inhibited their initiating discussions. Other health professionals were concerned about the amount of time such discussions require (Robinette, 1985). Another study found that 20 percent of ICU nurses had strongly ambivalent feelings about the organ procurement process which may interfere with their ability to discuss donation (Sophie, 1983). In some instances physicians and nurses are reluctant to approach families when they feel a sense of guilt or responsibility for the death of their patient. This is especially so in the case of children and newborns. Finally, concern regarding legal liability is common among physicians and may also affect discussions regarding donation (Protas and Batten, 1988).

### **Consent**

Although, as noted earlier, numerous public opinion polls report that families are willing to donate their relatives' organs, these polls and surveys do not provide accurate predictions of actual behavior. As Manninen and Evans (1985) note, people are likely to want to respond positively to a hypothetical question about donation because of the high value our society places on voluntarism and altruism.

In fact, family refusal to donate is a key reason procurement efforts failure. Nathan, et al. (1991) found that between 29 and 39 percent of the unrealized potential donors were attributable to family refusal. Studies which have directly examined potential donor families' willingness to donate find that between 23 percent and 63 percent of families consented to donation. According to a 1989 survey of OPO Directors, 38 percent of donors are lost due to family's refusal to consent--the most frequent barrier to procurement.

Fewer studies have examined the situational factors affecting the procurement of tissue and organs. These include the surroundings in which the request takes place and the attitudes of hospital personnel approaching the family. Anecdotal accounts claim that a brusque approach or one that consists of nothing more than the mere invocation of a State or Federal requirement are unsuccessful in obtaining

consent (Perkins, 1987). Others feel that confusion and equivocation regarding the declaration of death is likely to result in confusion regarding the patient's condition, decreasing the likelihood that the family will donate (Caplan, 1988; Wikler and Weisbard, 1990). Asking in the presence of family and friends or in an informal, quiet, private setting also appear to be associated with higher rates of family consent (Simmons, 1987).

Recent data suggest that an especially critical determinant of consent is the timing of a request relative to the pronouncement of death. There is reason to think that there is a real need to delay requests for donation until after the family has acknowledged the death of their loved one. In a retrospective study, University of Kentucky researchers found that 53 of 93 families agreed to donate if they had clearly understood that their loved one was dead before they were asked. When the request for donation accompanied the notification of death only 11 of 62 families consented to donation (Garrison, et. al., forthcoming).

The identity of the person who interacts with the family may also be important. Researchers at Vanderbilt Medical Center found that families were more receptive to donation requests when they were asked by health care professionals with whom they had a good rapport. Pre-existing factors such as the requestor's professional background and training, race, and personal characteristics may also influence the effectiveness of requests for donation.

Some have argued that organ procurement agency personnel, because of their greater expertise and interest, are more likely to obtain family consent (Prottas, 1990). Others feel that the most important determinants of consent are social demographic factors or the circumstances surrounding the patient's death. Unfortunately, there is no systematic data concerning the factors associated with family consent.

Little is known about why families refuse to donate. Their refusal may reflect a conscious rejection of altruism and voluntarism. On the other hand, families' refusal may be the result of inadequate communication and misunderstanding. There is some evidence that many families who refused, when approached long after the patient's death, had changed their minds and wish they had donated.

#### **Procurement of organs and OPO contacts**

After the family consents to donation, care must be taken to support the heart beating cadaver until solid organs can be retrieved. A recent British study revealed that a significant percentage of organs were lost because the patient's heart stopped before organs could be procured. It is not clear what factors, financial or otherwise, influence a hospital's decision to institute a brain death protocol.

There are currently 69 HCFA-certified organ procurement organizations in the United States. Individual OPO rates of cadaver organ procurement range from a low of 5.6 donors per million to a high of 32.5 per million. There is little explanation for these differences in OPO performance (Nathan and Jarrell, 1991).

There is some evidence available that hospital personnel historically have been uncertain about exactly which OPO to contact regarding procurement. As the number of OPOs has consolidated, this problem is decreasing at least in some parts of the country. However, hospital personnel still report confusion in deciding who to contact among organ, cornea, skin, and other kinds of tissue banks. Moreover, their confusion is increased by variations in the eligibility standards used by these agencies. In some parts of the United States agencies do not do a good job of referring potential donors among themselves.

Another source of complaint by hospital personnel and some donor families is that OPOs and tissue banks do not always do a good job of follow-up to report on what happened to donated organs and tissues. While many OPOs and tissue banks insist that letters and other contacts are made to let those involved in donor identification and maintenance know the results of their efforts there is at least a groundswell of anecdotal reporting that says these attempts are not effective.

Clearly, each of the steps in the donation sequence can be impeded or derailed by many different factors. While the opportunities for change are numerous, the risk of unintentionally harming or compromising the requisite sequence of events is high.

### The Impact of Required Request/Routine Inquiry Legislation

One of the most significant attempts to modify public policy on organ and tissue donation during the past 10 years has been the creation of State and Federal laws mandating hospital personnel to make requests. This policy, while respectful of the value base of donation, decreases the autonomy and freedom afforded health care professionals in the hope that by asking for organs and tissue more voluntarism and altruism will be forthcoming.

Unfortunately, little data exist documenting the effect of this public policy on the procurement process. In part this is a function of the fact that organ and tissue procurement do not exist in a vacuum. A variety of other changes including shifts in the organization and number of organ procurement agencies, changes in laws governing drinking and seatbelt use, gun control measures, the proliferation of emergency services, and the rise of the AIDS epidemic makes it difficult to analyze the specific impact of a required request policy. In part, the lack of study is a

function of the fact that the laws are so new that it will take time to see their impact.

Caplan and Welvang (1989) polled health departments, eye banks, organ procurement agencies, and hospitals in the first 10 States to pass required request laws. While most reported increases of 20 percent or more in the number of cornea, skin, and bone donors since the enactment of required request laws, the increase was still substantially less than might have been expected based on the estimates of eligible donors. Organ donation increased 10 to 20 percent in four States surveyed, while in the remainder, the number of donors was constant or decreased. The reasons for this disappointing response varied from poor compliance, to the absence of formal training programs, to problems in developing a workable method to monitor requests and donations.

Data from individual States on the impact of required request policies is quite varied. New York has some information available because its law required the State health department to report to the legislature on the effects of required request by July 1987. In 1986, heart donations increased by 94 percent, livers by 96 percent, and kidneys by 23 percent (Miller, 1991). There was a 58 percent increase in eye donors and skin availability increased by 180 percent (Miller, 1991). Oregon also reported dramatic increases in cornea, bone, and skin donors and a slight increase in organ donors during this same period.

The State of Ohio has attempted to monitor the impact of its required request law. Organ donation in Ohio increased nearly 50 percent during the first 6 months the law was in effect. However in subsequent years donation levels remained stagnant. In 1989, the third year of required request, a serious effort by the health department to enforce compliance by hospitals resulted in a 24 percent increase in the number of livers, a 30 percent increase in kidneys, and a 74 percent increase in cornea donors (Edwards, 1991).

In other areas the data is more discouraging. Both Los Angeles and San Francisco reported temporary increases in referral following the passage of required request laws but the number of donors stayed the same. In Tennessee, the total donor referrals increased in the year following implementation of required request laws but fell to pre-required request levels over the next year. New Jersey's enactment of a strong required request law did not result in a statistically significant change in organ procurement. Although there was a large increase in the number of referrals, the number of families consenting to donation decreased. Minnesota saw a rapid increase in cornea and skin donors in the month in which the State's required request laws went into effect, but a negligible impact on organs.

The reasons required request laws have not fulfilled expectations are not well understood. With rare exceptions, the majority of studies have not empirically

examined the problems of donor procurement as a process constituting several steps, each of which is affected by structural and organizational variables as well as by health care professionals' attitudes. Assessments of the policy have tended to focus almost exclusively on organ donations to the exclusion of tissue donations.

Probably the critical factor behind the failure to obtain an immediate response to the creation of State and Federal laws was the poor record of hospital compliance with those laws (Caplan and Welvang, 1989; Caplan and Virnig, 1990). In the past year there is some evidence that more hospitals are beginning to comply with the new public policy and that more health care professionals are asking about donation. This is born out by the latest figures from the AOPO and UNOS which show significant increases in the number of organs available during the past year (Caplan, 1991).

### **Localism**

Some transplant surgeons and OPO officials argue against creating a single national list for allocating tissues and organs, claiming that people donate with the intent that the donation will benefit someone from their region or State (Edwards, 1991). A preference for localism and regionalism is often cited by transplant surgeons and procurement personnel from States which are net exporters of organs and tissues on the grounds that a 'neighbors first' policy is of concern to donors. Yet there is little empirical evidence to support the claim that localism, while important to transplant centers, is important to donors or donor families.

### **OPOs and tissue banks**

Since organ procurement agencies began to operate on a large scale about 15 years ago, there have been two distinct organizational forms: hospital-based and independent. For most of the history of organ procurement, hospital-based OPOs have predominated. As late as 1982, two-thirds of OPOs were hospital-based. These hospital-based OPOs are usually located in a Department of Surgery, or Division of Transplantation, are generally under the direct supervision of the transplant surgeon, and are often staffed by nurses previously employed at the hospital's transplant service. Hospital-based OPOs generally tend to serve only the transplant hospitals in which they are located whereas, free-standing OPOs are separately incorporated entities providing only procurement services. They also serve several hospitals. Independent OPOs are larger than hospital-based ones and have more full-time as opposed to part-time employees. They have been a more effective segment of the organ procurement system (Protas, 1989).

Nonetheless, larger does not necessarily mean more efficient. The 16 largest OPOs, servicing 85 million people, had retrieval rates of less than 5 donors per

million and 13 other OPOs covering 4 million inhabitants had retrieval rates of 10 donors per million. The national average donor retrieval rate was 16 donors per million. The most successful procurement organizations in the nation had retrieval rates of 30 to 35 donors per million (Nathan and Jarrell, 1991). These were generally small OPOs covering populations of a few million people, and operating almost exclusively at the local community level in close contact with their transplant centers (Rapaport and Anaise, 1991).

The National Organ Transplant Act of 1984 was the first Federal legislation designed to organize, control, and establish accountability in organ donation and transplantation. This legislation mandated the formation of the Organ Procurement and Transplantation Network (OPTN). A Task Force was commissioned to examine and report on pressing issues in the field of transplantation, such as networking for organ sharing, education, procurement, research, and patient access to transplant services (Rogers, 1989). The Act established a grant program for the establishment, initial operation, and expansion of qualified organ procurement organizations. The Act requires OPOs to establish procurement agreements with hospitals located within their service areas. Professional responsibilities of OPOs include public and professional education, procurement, and preservation of donated organs, allocation of donated organs according to established protocol, and coordination of activity with other transplant programs (Rodgers, 1989).

The United States operates the largest organ procurement system in the world. Medicare has been the main source of financing for OPOs since the passage of the End-stage Renal Disease Act in 1972. There are currently 69 federally funded, HCFA-certified organ procurement organizations, a significantly smaller number than the 90 which existed in 1985. Fifty OPOs are independent free-standing organizations; the rest are hospital-based. All OPOs are non-profit organizations or part of not-for-profit organizations or hospitals. With minor exceptions, every region in the United States is served by an OPO (Abt Associates, 1990) since there are OPO arrangements with over 4500 community hospitals. In 1988, the number of procurement organizations decreased for the first time as a result of Federal pressure to consolidate a number of these agencies. Many of these OPOs have been restructured as free-standing entities (Prottas, 1989).

Federal law does not mandate the relationships which should exist among hospitals and health care professionals and procurement organizations, namely, OPOs, tissue banks, and eye banks. Although no formal survey has ever been conducted that systematically examines this question, anecdotal evidence supports the claim that the structure and nature of these relationships varies geographically.

The Omnibus Budget Reconciliation Act of 1986 (OBRA) was another step in the process of institutionalizing, refining, and regulating organ donation and transplantation, including the relationship between the potential source of body

parts (i.e., the hospitals) and the agents of procurement and distribution (i.e., the OPOs). OBRA, institutionalizing required request, mandated that hospital's receiving Medicare and Medicaid must establish written protocols that reasonably assured that families of potential donors will be offered the option of donation, and that the appropriate regional OPO will be notified of all potential donors.

Moreover, institutions that perform transplant procedures must participate in and abide by the rules of UNOS, a private, nonprofit, national organ sharing organization authorized by the OPTN to facilitate the equitable distribution of organs. For OPOs to receive reimbursement for costs associated with organ recovery, the organization must be certified as qualified by the Secretary of Health and Human Services. Thus, OPOs are required to participate in UNOS and to abide by its policies. Only one OPO per service area is designated by the secretary. Failure to comply with the statute means revocation of Medicare funding (Rodgers, 1989). This has encouraged hospitals and OPOs to work together to procure solid organs.

During the late 1970s and early 1980s, concern increased over the allocation policies used to distribute donated organs. UNOS was awarded the contract to fulfill the goals of OPTN, and today, develops the national policies of organ distribution. All potential organ recipients must be listed on the UNOS computer. Organs are shared based upon a point system. The potential recipient with the highest point rating will receive an available organ. The current point system tends to emphasize the importance of need and medical urgency over prognosis post-transplant.

There is no evidence that the general public is aware of the standardization of allocation policies. This is a serious problem given the frequent concerns of prospective donors and the general public about the degree to which the allocation of organs and tissues is fair.

One significant difference between organ and tissue procurement organizations is that the latter may be for-profit. The National Organ Transplant Act requires that OPOs receiving Medicare funding be non-profits. The Act prohibits the sale of any human organs but does not address tissue.

Most for-profit tissue banks are involved in the preparation, storage, and shipping of bone implants or heart valve implants. The preparation of bone for medical use requires expensive equipment and highly trained personnel and such tissue banks require considerable capital outlay. Non-profit agencies are less able to provide these services. As a result they are more likely to have to compete for these particular tissues with for-profit organizations. With the exception of bone marrow, Congress is not extending Medicare funding to tissue banking activities. As a result, for-profit tissue banks face little competition (Rodgers, 1989).

Much of the controversy surrounding for-profit tissue banking is ethical in nature. Donors and donor families voluntarily give their anatomical gifts. Most are stimulated by altruistic feelings, the belief that a part of them lives on or the death of a loved one is not in vain. It is questionable how these individuals would accept the knowledge that their gift was resold at a profit to somebody else. Public anger over stories (Gaul, 1990) detailing the ways in which voluntarily donated whole blood is resold and reprocessed into saleable products suggest that the reaction would not generally be positive.

However, until non-profit organizations provide equal services, for-profit tissue banks seem secure, provided they do not violate the Federal prohibition on the purchase of organs or any applicable State laws dealing with the sale of organs. The reality is that hospitals and surgeons demand these tissues in treating their patients and, to date, the for-profit sector of tissue banking has been the only sector capable of meeting the demand.

It is also true that organ distribution remains heavily controlled by the individual transplant centers. Only a few years ago, transplant centers that could not use an organ they retrieved would, on the basis of private conversations, send that organ to another center. That center might be in the same State, another State, or for that matter, in another country. Local discretion over distribution of organs is no longer allowed. The OPTN requires that centers and OPOs have formally stated criteria governing the distribution of organs and that OPOs use the national organ center for distributing any organs they cannot use within their own service areas.

Through the OPTN's local use policy, the 250 transplant centers are allowed to retain almost all the organs they have retrieved. They enter into cooperative agreements with an OPO or other centers only at their own volition. If they wish, they can make arrangements concerning the distribution of organs with the donor hospital and/or an OPO in other service areas. The distribution system is also localized in the sense that most organs procured in a service area never leave that area. These arrangements represent institutional agreements between hospitals and OPOs. However, we know little about the key relationship; that is, the interface between OPOs and the health care professionals upon whom the OPOs depend to identify potential donors.

Many OPOs make themselves visible to hospital personnel through providing educational "in-services" with hospital staff, especially nurses. Many hospitals now have standing committees or designated staff who are specially trained to deal with donation issues. To make all hospital personnel aware of the OPOs' activities, hospitals often post stickers, posters and incorporate information about the donation process into their procedural manuals. Hospitals also often enter into voluntary agreements with OPO staff. For example, some hospitals have volunteered to inform their local OPOs about every hospital death. The OBRA Act

of 1986 and the passage of State laws which required that hospitals formulate and carry out a required request protocol have no doubt acted as catalysts for these agreements.

Communication among OPOs, tissue banks, and eye banks varies according to locale. There is very little communication between those involved in the newly created National Marrow Donor Program and other organ and tissue organizations.

In certain regions, there are close relationships between OPOs and tissue banks, with the organizations working as a team. For instance, a central office might take all calls concerning donation and advise on eligibility for solid organs, tissues, and corneas. In other regions, these organizations are more atomized. Hospitals may find themselves dealing with three, and sometimes more, organizations. The advantages or disadvantages of a unitary vs. individual procurement system are unknown.

#### **Experience of Other Nations with Organ and Tissue Donation.**

Most nations in the western world have made a strong commitment to the same moral foundation of cadaver organ transplantation, voluntarism and altruism, as has the United States. The system of donation in Canada, Holland, the United Kingdom, Australia and nearly all of Central and South America is very similar to that which exists in the United States.

Some nations which operate with a voluntaristic, altruistic values foundation and an opt-in, donor card approach to cadaver donation have resisted the formal recognition of brain death, i.e., Japan, Denmark. However some others with similar dominant value frameworks have recently enacted brain death laws or witnessed their courts affirm this definition i.e., Israel, Sweden.

Some nations have decided to pursue an opt-out policy of routine salvage or presumed consent. France enacted a presumed consent law in 1976. Austria has had what amounts to a routine salvage policy for nearly 100 years with a reaffirmation of this policy taking place in 1988. Belgium moved to institute a presumed consent policy in 1988. Also in 1988, Singapore instituted a donation policy wherein those willing to serve as donors would receive priority of access to transplants as against those who were not, for whatever reason, willing to list themselves as potential cadaver donors.

Following enactment of its presumed consent law, France saw a small increase in kidney donation but most of the increase has been used to decrease the number of kidney transplants involving living donors so there has been no overall increase in transplant rates. Austria saw a significant increase in kidney availability in the year

following enactment of its law but organ availability fell significantly in 1990 (Eurotransplant, 1991).

A few nations permit financial incentives for living donors including India, the Philippines, and Brazil. No nation appears to allow financial rewards with respect to cadaver donation though there have been recent reports of payment for both live and cadaver kidneys emanating from China, Haiti, and Hong Kong (Crosette, New York Times, 1991).

Distribution of organs and some tissues is handled on a regional basis in Europe. The Benelux countries and Germany cooperate with one another through the Eurotransplant Foundation. A similar regional group exists for Scandinavia.

Most European countries do not have specialized personnel serving as organ or tissue procurement specialists (Prottas, 1984). But this may be changing as at least some countries, i.e., Sweden, are moving toward the creation of organ and tissue procurement specialists.

### **Conclusions and Options**

#### **Increasing Public Knowledge and Encouraging Altruism**

Polls indicate many Americans still have reservations about the effect of organ and tissue donation on a cadaver. Public education efforts could be mounted which specifically address concerns about mutilation and destruction of the cadaver. Similarly, educational campaigns could be undertaken to assuage public concerns that prospective donors will not receive aggressive treatment and that organs and tissues are fairly and equitably distributed among those in need. These efforts need to involve the mass media which, in recent years, has conveyed erroneous and frightening images to the public about organ donation in a number of prime time, popular television programs and movies. And continuing efforts need to be undertaken to inform the public about the brain death standard and the tests used to establish that brain death has occurred.

#### **Donor Cards**

A variety of strategies are available for trying to increase the percentage of Americans who carry donor cards. All persons applying for licenses could be required to select a donor status as a condition of licensure. Or all persons admitted to hospitals or nursing homes could routinely be asked about their donor status as part of the Patient Self Determination Act of 1990. State provisions requiring two witnesses to validate a donor card could be modified. Videotapes

and educational materials could be created which target high school and college age persons about the importance of donor cards.

### **OPO and Tissue Banks**

Efforts could be made to help consolidate the relationships that exist between procurement organizations and hospitals. If a multiplicity of procurement organizations proves confusing to hospital personnel in terms of understanding donor eligibility or whom to call for help, then OPOs could be encouraged to create 'one stop' hot lines for contacting all procurement organizations through a single telephone number. The need for clear, unambiguous, current and uniform national eligibility standards must be addressed to see whether uncertainty and confusion about OPO and tissue bank standards can be reduced.

There is some evidence available (Caplan and Virnig, 1990) that hospital administrators are poorly informed about organ and tissue donation laws, regulations, and policies. Moreover, administrative responsibility for monitoring institutional performance with respect to donation is not always clearly assigned and is not routinely a part of licensure and accreditation requirements in many areas.

It is important that competition among organ and tissue banks and between tissue banks be kept to a minimum. Continuing attention needs to be paid to the domain of tissue procurement especially in light of the tension that exists in some parts of the country between profit and not-for profit tissue banks.

OPOs and tissue banks need to be encouraged to focus their educational efforts on donor identification and the proper techniques for making requests. In their educational efforts, some OPOs and tissue banks do not attend to the early stages of identification, eligibility, and requests to families in ways that reflect current empirical studies about how best to handle these issues.

OPOs and tissue banks need to understand the importance of adequate feedback to both hospital personnel, administrators, and donor families. These organizations must also realize that the general public does not distinguish between tissue and organ transplantation (they are seen as the same) so that inappropriate or negligent behavior on the part of one procurement organization adversely reflects upon all others.

### **Expanding the Pool of Cadaver Donors**

One possible strategy for increasing the number of organs and tissues available is to increase the size of the cadaver donor pool. This could be done by instituting efforts to improve the identification of brain dead patients. A variety of studies

show that between a third and two-thirds of eligible patients either are not identified as eligible, or their families are not approached for donation. Strenuous educational efforts as well as monitoring could be instituted in certain key hospitals in order to make sure that all potential brain dead donors are identified.

Efforts could be made to identify institutions where brain dead patients are likely to be. There is still much controversy over which hospitals and trauma centers are likely to see the largest number of potential donors. Similarly it is not known which sorts of institutions are most likely to have potential tissue donors. Identifying such institutions would help focus educational and training efforts concerning donor identification, interactions with families, and contacts with OPOs and tissue banks.

Unrealized potential donors are disproportionately admitted to internal medical services, have long lengths of stay, and tend to be older. These facts emphasize the importance of educating internists regarding eligibility as well as neurologists and neurosurgeons.

A recent study by a team of Welsh physicians suggests that it may be advisable to think about the elective use of mechanical ventilation solely to permit organ donation in persons who otherwise would have died. In persons dying from cerebrovascular accidents where life-support has not been used it would be possible to institute a policy to ask families for their consent to the use of mechanical ventilation in order to make organ donation possible.

Another strategy for expanding the cadaver donor pool would be to support research on allowing the use of organs from persons who arrive at hospitals DOA. It may be possible to develop preservation techniques that allow organs to be salvaged in vivo. It will also be necessary to develop appropriate public policy and consent procedures to accompany this sort of strategy.

It may be possible to make more efficient use of the cadaver donor pool than is currently the case. For example, if waiting list allocation rules were to place less emphasis on severity of illness and waiting time and more on likely prognosis, the same number of cadaver organs might be able to save more lives. Similarly, if more selective criteria were used in determining eligibility for transplants including discouraging or prohibiting retransplantation or, in some cases, the use of assist devices and bridging technologies, overall survival rates post-transplant might be increased.

### **Improving Consent Rates**

During the last 2 years there has been increasing evidence that families frequently refuse health care professionals' requests to donate. Despite public opinion polls

showing widespread support for organ donation, family refusal is a barrier to procurement. It is not clear whether this is a failure of voluntarism or a result of health care professionals insensitively or inadequate explanations of the reasons for organ donation. Without adequate empirical information, it is impossible to determine whether the appropriate public policy response is more training for health care professionals, more public education, changes in the timing, setting or identity of those making requests, or abandoning voluntarism in favor of a policy that is more responsive to self-interest.

Recent revisions in the UAGA suggest that hospitals ask all patients upon admission about their organ donor status. Some States have enacted this requirement into law. The Patient Self Determination Act of 1990 mandates that all prospective patients be appraised of the importance of having a living will and many of the standard forms of this document contain a provision regarding organ donation. These steps may increase consent rates but there is some fear among organ and tissue procurement professionals that asking at the time of hospital admission is as likely to produce refusals as it is prior consent (personal communication, 1991).

Health care professionals' attitudes about organ and tissue transplantation as well as brain death need to be assessed and, if necessary, enhanced. This may facilitate more enthusiastic compliance with existing State and Federal laws regarding requests. Stronger efforts are needed to ensure compliance with existing routine inquiry and required request laws prior to concluding that existing policies are inadequate. Unfortunately, most State laws contain neither provisions nor monies to assure adequate compliance. Developing adequate methods of quality assurance is an essential aspect of any public policy. We are quite encouraged by efforts such as Nathan et al. to develop a computerized program which allows OPOs to track hospital performance, identify outliers, and then investigate the reasons for procurement problems.

Without clear data about the impediments to procurement, one cannot be absolutely confident which changes will improve the system. To date, studies of donation have been piecemeal, focusing on only one part of the entire process. Most studies have relied strictly on chart review or public opinion polls. The few reports about actual consents or refusals rely on nonsystematic observations or anecdotal reports. Only systematic data regarding the organizations, health care professionals, and situational factors affecting organ/tissue donation will provide the information necessary to improve the procurement process. It is essential that further research be conducted on families who did and did not agree to donation to better understand their motives, knowledge, fears, and feelings.

### **Policy Changes--required referral**

Prottas and others have suggested requiring that OPOs be called about all deaths. This might increase identification of eligible donors and ensure that the health care professionals who discuss the issues are adequately trained to do so. Information regarding how such a proposal would work or evidence regarding its feasibility should be required prior to this proposal's adoption. Would the organ procurement agencies be called about all patients admitted to the hospital? To an intensive care unit? Who would do the calling? What role should OPOs have in managing the care of the "near brain-dead?" Would such a screening process be cost or time effective?

### **The Use of Financial Incentives to Encourage Donations**

There are a host of ideas about the ways in which families might be encouraged to donate by appeals to self-interest. These include the payment of funeral expenses, direct cash payments, discounts on estate taxes, or tax deductions to surviving family members (Cohen, 1990, Peters, 1991). All such proposals need to be closely evaluated on both empirical and philosophical grounds. Putting aside the ethical concerns that financial incentives may raise (Pellegrino, 1991), there is no empirical evidence that families will be more willing to donate if offered incentives such as burial cost. Post hoc surveys of families who have agreed to donate or nation-wide Gallup polls of what people say they will do in the abstract are not predictive of what families will actually do when faced with these decisions. Nor is there any empirical evidence to support the claim that a significant segment of the American public either wants or expects financial incentives as a condition of donation.

Prior to accepting any new proposals the Federal government could evaluate their likely impact on donation through demonstration projects. Before changing our deeply entrenched, national public policy regarding cadaver procurement, strong empirical evidence is needed to show that these proposals will increase the number of transplantable organs.

### **Presumed Consent and Routine Salvage**

It may be possible to persuade Americans that it is more reasonable to presume a willingness to donate and subsequently to construct public policy so that the burden of proof falls upon those who wish to 'opt out' of this presumption. However, it is important to keep in mind that the nations which have moved toward this type of public policy have encountered strong resistance from health care professionals who are reluctant to take organs without routinely asking the family about their willingness to donate. It is also important to keep in mind that

the increases in organ donation as reflected in kidney donations, have not been especially impressive in France or Austria--two nations with long-standing public policies of presumed consent.

### **Alternative Sources of Organs and Tissues to Cadavers**

The demand for transplants will outstrip our ability to procure cadaver organs. The number of heart beating cadavers is limited. Given the increasing success of organ transplantation, it is likely that the number of organs needed will always be greater than the number of potentially or even possibly available cadavers. It is therefore imperative that the transplant community and public officials begin discussing alternatives to cadaver donation.

There has been some discussion of broadening the definition of, or the criteria used to determine, death. For example, some have suggested permitting the use of different criteria for determining brain death in anencephalic infants in order to facilitate their use as organ donors (Kaufman, 1988). Others suggest that the concept of donor be expanded to include persons in permanent vegetative states (Cranford, 1989).

Increased reliance on living donors may be one way to respond to the shortage of cadaver organs. Nearly one-third of all kidneys transplanted in the United States are obtained from living donors. Some programs have turned to unrelated persons as possible sources of kidneys. Transplant surgeons have also obtained bone marrow, lobes of liver and lung, and segments of pancreas from living donors. The use of living donors, especially those not capable of giving informed consent, raises many complex ethical questions that will have to be addressed if live donation is to expand as an alternative to cadaver sources.

Another strategy to increase the pool of organs and tissues available is to turn to animal sources. There are obvious ethical, psychosocial, and public policy issues involved in pursuing this alternative. Many Americans believe that it would be immoral to kill animals, particularly primates, for the sole purpose of harvesting their organs. Others note that the use of animals is currently so experimental that informed consent procedures must be especially rigorous and peer review exceedingly conscientious before any potential recipients can be recruited.

## **CONCLUSION**

The scarce supply of transplantable organs and tissues is the greatest challenge facing transplantation professionals as well as those in need of transplants. Unfortunately, changes in public policy or public education are not going to solve the problem of donor scarcity. For the foreseeable future, modest increases in the supply of human cadaver organs and tissues will not meet increases in the demand.

However, we must continue efforts directed toward increasing the number of cadaver organs and tissues that are available for transplant. Much public and professional attention has, in recent years, focused on the prospects for dramatically changing existing public policy on obtaining organs and tissues. Some believe that the United States either ought to permit a market of some sort in body parts or should move toward a system of presumed consent where those who do not wish to make their organs and tissues available would have to make their objections known. However, public support and trust in the system of procurement and distribution of organs and tissues plus deeply held values within American society make radical change unlikely. Refusal rates to requests to donate are in the 60 to 70 percent range or worse, and many major religious groups insist that cadaver donation be based on altruistic choice. These realities show that the prospect is poor for a shift to a public policy which has as its sole moral concern an increase in the supply of cadaver organs and tissues.

Moreover, many aspects of the existing policy (permitting cadaver donation only by a voluntary written directive from the deceased or consent of their next of kin or guardian) can and should be examined before there is any attempt to drastically alter that policy. The public needs more education concerning the concept of brain death and the realities of organ distribution in order to persuade more persons to donate. Health care professionals need to exert greater efforts to routinely identify prospective donors and to make requests of their families. Medical examiners, coroners, and funeral directors need to become more actively involved in matters pertaining to donation. Organ and tissue procurement agencies must try to more closely coordinate their efforts in both education and procurement. Government and professional societies need to make sure that health care professionals understand their obligations and responsibilities with respect to offering the option of donation and in making sure that those gifts which are obtained are acknowledged and handled with respect and fairness.

Scarcity is likely to be a reality in transplantation for the rest of this century. The steps that are taken to minimize the problem must be consistent with the values of autonomy, altruism, and voluntarism which have dominated American attitudes toward the procurement of cadaver organs and tissues since the beginning of this century.

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## **INCREASING DONATION BY FOCUSING ON THE HEALTH CARE ENVIRONMENT: PROFESSIONAL EDUCATION**

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### **Introduction**

The past two decades have seen remarkable advances in the field of organ transplantation in the United States and world-wide. For example, data for the United States show that heart transplants increased from a total of 103 in 1982 to 2085 in 1990; liver transplants increased from 62 to 2656 and pancreas transplants increased from 38 to 549 during the same time period. Kidney transplants, which have a much longer history, increased from 5358 in 1982 to 9560 in 1990 (1).

In addition to increasing numbers of transplant procedures, the patient and graft survival rates are increasing with improved methods of organ preservation, matching procedures, and immunosuppressive therapy, particularly Cyclosporine. For example, 1-year graft survival following a heart transplant in the pre-Cyclosporine era was 62 percent whereas in 1989 the 1-year graft survival was 82 percent (2). Even greater increases in survival have been experienced in liver transplantation.

Clearly, organ transplantation has increased not only the length of life, but also the quality and productivity of life for many individuals. Yet the limiting factor in organ transplantation is the dearth of donor organs. As of March 1991, 18,200 patients were waiting for kidney transplants, 1960 were awaiting heart transplants, 1340 were awaiting liver transplants, and over 500 were awaiting pancreas transplants (3).

To get a sense of the potential donor pool, approximately 2.5 million people die annually in the United States, and of this number, an estimated 20,000 would qualify as medically appropriate donors (4). Yet, in 1990, only 4300 of these deaths actually resulted in organ donation (1). In the previous 3 years, the number of actual donors appeared to plateau at 4000. At the same time, approximately 25 percent of those patients waiting for extra-renal transplants die because an appropriate donor is never identified. Close to 50 percent of children waiting for extra-renal transplants die while waiting.

Increased traffic safety statutes (i.e., required helmets for motorcyclists, required seat belts, and child restraints), reduced number of alcohol impaired traffic fatalities, and the HIV epidemic have been suggested as potential contributors to

the plateau in numbers of donor organs experienced in the late 1980s. Still, there is a large discrepancy between the potential and actual donors in any given year.

Significant efforts have been made over the past several years to educate the public as to the significance of organ transplantation. Gallup polls (5,6,7) indicate that the majority of the public are aware of organ donation, but there has not been a concomitant increase in organ donors.

An effective organ donation system relies upon a broad based alliance of health care professionals and the general public. A positive attitude toward organ donation among health care professionals will promote a supportive hospital environment for organ donation; an informed public who have discussed organ donation with family members will be more likely to respond positively when approached about organ donation.

This paper will focus on the necessity of increasing the involvement of health care professionals in the donation process: what role they should play; how their personal attitudes influence organ donation; and what are possible methods of eliciting greater support for organ donation. This is an area where little literature has been published to date. However, what has been published provides us with some guidance to certain interventions which may contribute to the enhancement of organ donation rates.

The matter of organ donation raises complex emotional reactions for non-medical people and for medically trained people as well. Dealing with the issue of donation of organs forces us, as individuals, to confront our mortality, which is difficult for most of us. For health care professionals, the situation is complicated by other issues such as perceived liability considerations and a general discomfort with the notion of approaching the family of a brain dead individual to encourage organ donation (8).

There appear to be three main groups of health care professionals who may be involved at some level with organ donation. First, there are those who are already members of the transplant community, such as transplant physicians and surgeons, clinical transplant coordinators, and organ procurement coordinators. Of these health care professionals, the role of the organ procurement organizations' (OPOs) staff, specifically the organ procurement coordinator, deserves particular mention. These individuals receive specialized training in promoting organ donation through public and professional education; approaching families of potential donors about organ donation; managing the donor prior to organ recovery; and assisting with the surgical removal of donated organs. These coordinators are employed by federally designated organ procurement organizations which in all areas of the country provide the link between transplant centers and hospitals which have identified potential organ donors. Along with transplant surgeons and physicians,

these health care professionals form the front line of transplantation. Unfortunately, with the exception of the transplant literature, there are few references in medical literature about the services the organ procurement organizations and their staffs provide for donor families and the staffs of hospitals which refer potential donors. Generally, it is the role of these health care professionals to provide education about organ donation to key individuals within the hospitals; to assist with hospital review, revision, and execution of policies and procedures regarding organ donation; and to respond appropriately to hospital initiated donor referral calls.

At the second tier are those professionals whose roles bring them into direct contact with the transplant community. These include social workers, critical care physicians and nurses, trauma physicians, neurosurgeons and neurologists. These individuals, through increased knowledge and positive attitudes toward organ donation and transplantation, could have a significant impact upon the rate of organ donation. To encourage physician and nursing education and support, some suggest that credentialing boards for the various medical and nursing specialties should include questions related to organ donation and transplantation in their written examinations as a means of raising the importance of the issue. Others suggest that undergraduate medical and nursing curricula should include issues related to organ donation and transplantation (9).

There appears to be some agreement in the literature that the attitudes and behaviors of physicians have great importance in influencing the rate of organ donation (8,10). Yet there are a number of factors which cause physicians to be less aggressive in seeking organ donations (8,10). Nurses, in general, tend to be more willing to actively participate in the process of seeking organ donations, although there is a reluctance on their part to do so without the explicit support of physicians (10).

The third group of professionals include clergy, morticians, medical examiners, coroners, and attorneys whose roles, though not directly related to the organ donation and transplantation process, place them in positions to significantly influence individuals' attitudes and decisions related to organ donation.

How can we most effectively provide training to these myriad professional groups which will better prepare them to use their respective roles to positively influence the rate of organ donation? Clearly, each professional category requires an approach which is tailored to its respective role in the process. It also must be determined at which point and where or when in professional training the subject should be introduced, or whether there should be a continuum of training activities. How can we assess the effectiveness of this training by immediate and more long term measures? Are there key issues that must be addressed? Are they constant or do they vary from group to group?

One thing which appears to be true is that health professionals' attitudes are not unrelated to public attitudes. Therefore, we would expect that the greater the awareness of the importance of organ donation and transplantation on the part of the general public, the greater will be the interest on the part of the various related professionals. Professional education cannot, therefore, be totally separated from public education.

In the pages which follow, we examine the current literature related to professional education and training in organ donation and transplantation. We look at what is now being done, what has been done in the past, and what various investigators have suggested for future directions. From this analysis, we attempt to identify the key issues in professional education related to organ donation and transplantation, and to formulate some proposed recommendations for consideration.

### **Current State of the Art**

Research efforts by transplant professionals have focused primarily on issues such as management of immunosuppression, outcomes of transplants, etc. Some studies have estimated the actual organ donor potential in the United States (11,12). Continuing work is vital since it may provide a clearer picture of the discrepancy between actual and potential organ donors. Closer examination of this gap in similar settings may lead to further delineation of the specific barriers to organ donation (11).

Several studies have been undertaken to examine personal attitudes and knowledge about organ donation among health care professionals; attempts have been made to correlate these attitudes and knowledge to successful organ donation requests (13-15). Similar works have identified barriers in the organ donation process and have made recommendations to correct these deficiencies (8,16). These surveys begin to tell the story of the correlation between attitudes and commitment and successful organ donation.

While these studies are important, little specific information exists regarding successful components of professional education programs. Two unpublished surveys, one by Warmbrodt (17) for the National Task Force on Organ Transplantation and another by Politoski (18) for the National Kidney Foundation, have briefly summarized past activities related to professional education. In 1985, the National Task Force studying the status of organ donation and transplantation in the United States conducted a survey to determine ongoing professional education efforts. Distributed to OPOs, voluntary health organizations, professional associations that might be involved in organ donation and transplantation, and professional transplant organizations, the results from the respondents showed that almost all education about organ donation in the

professional community was being done by organ procurement organizations. The OPOs which responded indicated that informal inservice education, combined with occasional structured workshops and seminars, were the types of education they most frequently employed. Only 7 percent of the OPOs specifically mentioned medical staff presentations or grand rounds.

Sixty-seven percent of the OPOs surveyed indicated that they believed that physicians (particularly neuroscience physicians) were the audience least receptive to their educational efforts. When queried as to how education efforts were directed to a group that was not receptive, respondents were almost unanimous in stating that only a physician, particularly a transplant surgeon, could enlist the interest and cooperation of another physician. One-on-one physician meetings seemed to be the most useful forum for education.

Conversely, responding OPOs indicated that nurses were the most receptive audience for professional education programs and, as assessed by the OPOs, were already more knowledgeable about organ donation than other health care professionals. Yet 81 percent of the OPOs' education programs were presented to nurses, perhaps indicating that OPOs spend a great deal of time and effort "preaching to the choir."

Only 18 percent of the professional education programs had measurable goals and objectives. There was basically no consensus as to how to evaluate the success of the programs, although an increase in hospital referrals following the programs was mentioned frequently (17).

The National Kidney Foundation (NKF) study was conducted at the annual convention of the American Association of Critical Care Nurses in 1988. This study of fifty randomly selected nurses attempted to determine the effectiveness of existing training programs and to look at particular ways in which the National Kidney Foundation could effectively motivate nurses to become involved in organ donation. Seventy percent of the respondents of the NFK study had personally participated in approaching families about organ donation. Of those who had approached a family, 83 percent had received formal training related to donation prior to their participation. Classroom instruction had been received by 46 percent of all respondents; 83 percent of the training was conducted by an organ procurement coordinator. Components of training programs were varied and included at least one of the following: lecture, film/tape, discussion, literature, and role-playing. Although most nurses who had participated in training programs felt confident in being able to discuss donation with families, they related feelings of apprehension and discomfort in this role (18). These findings suggest that current education programs lack key components that would enable nurses to effectively influence organ donation. Further investigation of these programs is warranted.

Pervasive in the literature is an acute lack of knowledge of issues related to organ donation and transplantation among health care professionals (9,16,19,20). In a statement presented to the National Kidney and Urologic Diseases Advisory Board, Dr. Patricia Adams stated that "in an era of remarkable public awareness and unparalleled medical success, the medical profession itself is relatively uneducated about the essentials and successes of this new therapy (organ transplantation) and feels little general professional responsibility to procure organs" (21).

In a 1986-87 joint SEOPF-UNOS Survey of Professional Attitudes Toward Organ Donation and Transplantation (15) sent to professional staff at 176 transplanting hospitals in the United States, medical professionals manifested a positive attitude toward organ donation. However, they demonstrated a striking lack of knowledge about social issues and epidemiologic facts of transplantation. Twenty-four percent were unsure how brain death related to cardiopulmonary arrest, and 19 percent thought that withdrawal of support from a brain dead patient constituted mercy killing. Less than 20 percent knew the current graft survival rates for kidney, heart, or liver transplant, and only 8 percent could approximate the number of heart transplants performed in this country in 1985 (15).

Younger and associates (13) interviewed a sample of 195 physicians and nurses likely to be involved in organ procurement in an effort to determine their knowledge, personal concepts, and attitudes concerning brain death and organ donation. Only 35 percent of the respondents correctly identified the legal and medical criteria for determining death. Most respondents (58 percent) did not consistently use a clear description of brain death. Physicians in decision-making roles tended to be much more knowledgeable about these issues than other health care professionals, but the professionals' confusion about brain death criteria has tremendous implications for their involvement with organ donation. One-third of the participants in this survey had participated in transplant education programs. These individuals tended to be more knowledgeable about clinical and legal matters, but their level of understanding about brain death did not correlate with their having participated in such education programs.

A survey of medical and surgical residents at two large teaching hospitals regarding their knowledge, attitudes, practices, and experience with organ donation was conducted by Spital in 1989 (9). Thirty six percent of the respondents were not sure how to recognize a potential donor and 34 percent were not sure who to contact if a donor was identified.

In another survey of family practice residents from five midwestern training centers (19) nearly one-half of the respondents stated that they knew very little about organ donation and would not know how to initiate the process. There were concerns related to premature declaration of death, concern for family feelings, and the cost-benefit ratio of transplantation. A majority of the respondents in both

surveys indicated strong personal support for organ donation. Lack of knowledge of donation criteria, and other issues expressed here, need to be addressed in order to gain commitment from an already supportive population.

A large scale survey of ICU staff complemented by public and professional opinion polls was conducted in England in 1987 (22). Like Gallup Polls conducted in the United States, the majority of the public were supportive of organ donation. When queried as to whether the topic of organ donation had been discussed with their general practitioner, only 2 percent responded positively, but over 50 percent indicated willingness to donate organs. There was also overwhelming support for organ donation among physicians, with no difference in attitudes between general practitioners and hospital based specialists. Physician groups also agreed that organ donation and transplantation should be given considerable prominence in undergraduate medical training (22).

In this same survey, the intensive care staff were asked to indicate which of nine different factors limited organ donation. These factors included dislike of increasing a relative's distress; reservations about brain death criteria; lack of experienced clinicians familiar with brain death criteria; resentment about the time, effort, and cost involved; lack of training in approaching families; adverse media publicity; unfortunate experiences with transplant team members; lack of written policies; and general distaste for procedures involving organ recovery. While no one factor was unanimously identified, the possibility of increasing a relative's distress and lack of training in the approach to families both rated highly as disincentives to organ donation. Nurses in particular felt that lack of training in approaching families and lack of written policies hindered donation (22).

Malecki and Hoffman (14) examined the level of discomfort regarding organ donation among intensive care nurses and its effect on obtaining consent for organ donation. Of 124 nurses who responded, 93 percent indicated that they were aware of criteria for organ donation. Only 33 percent said they had ever been in a position to approach a family for consent, and of these, only 29 percent actually did approach a family. Of families who were approached by a nurse who had a self-perception of confidence, 84 percent said yes, while 100 percent of the families approached by "uncomfortable" nurses declined to donate.

A 1990 survey performed by Stark (20) to look at how attitudes of nurses affect organ donation found that nurses were frequently the first health care professionals to recognize potential donors, but only 65 percent of those surveyed could correctly identify clear cut instances where patients were suitable potential organ donors. Both physicians and nurses were overwhelmingly supportive of donation, and families who were initially unsure of their decision eventually

consented to donation when the nurses and physicians appeared to favor it. In this study of 26 potential donors, six families were not approached about donation, with the main reason cited as "physician reluctance caused by fear of liability"

A recent study by Bidigare and Oermann (23) examined ICU nurses' attitudes toward organ donation and the nurses' knowledge of organ donor protocols. As in previous studies, the majority (94 percent) of nurses were supporters of organ donation. However, only 51 percent had made provisions to donate their own organs, and only 67 percent would encourage family members to do so. Race seemed to correlate with nurses' attitudes, with Black and Asian nurses being less supportive of organ donation than White nurses. However, the small numbers in the survey made it impossible to draw any firm conclusions.

In this same study (23), nurses who had higher knowledge levels were more positive toward organ donation as evidenced by their personal decisions, their willingness to influence families, and the degree to which they would choose to participate in an organ recovery. The survey indicated that the nurses' knowledge base increased with participation in the care of an organ donor and that this expanded knowledge base enhanced positive attitudes toward donation (23).

Perhaps the most extensive look at attitudes of health care professionals was a study performed by Prottas and Batten (8). Neurosurgeons, intensive care unit nurses, directors of nursing, and hospital administrators were surveyed in order to determine their level of commitment to donation, to identify how the groups differed in their level of commitment, and to examine the sources of those differences. While neurosurgeons nearly unanimously indicated support for donation on a personal level and said they were confident of the criteria to determine brain death, nearly 60 percent said that there could be a conflict between treating a patient whom they believe is dying and protecting organs which could be transplanted. Many expressed reluctance to approach families about donation; they were concerned about the time involved in the process and potential legal liability. Neurosurgeons who believe that organ procurement is a professional responsibility are less concerned about interactions with families, time demands, and the threat of legal liability.

ICU nurses surveyed in this study (8) expressed support of organ donation with a strong conviction that organ donation helps families through the grieving process. Nurses expressed two areas of particular concern -- their lack of confidence in physicians' awareness of accurate criteria needed for the determination of brain death and the potential conflict between treating a dying patient and management of organ donation. The most supportive groups of ICU nurses were those found in large ICUs in teaching hospitals. Many of these nurses who had been involved with potential organ donors perceived physicians to be very supportive of donation.

Combining physician support with nurses' belief that organ donation is a professional responsibility tended to minimize apprehensions and conflicts of nurses surveyed in this study.

Prottas and Batten found hospital administrators supportive of organ donation in general and most supportive when they believe the physicians in the hospital are supportive. Directors of nursing demonstrated attitudes similar to nurses and other hospital administrators (8).

### **Summary and Conclusions of Existing Studies**

Almost exclusively, the responsibility for identification and referral of potential organ donors falls to health care professionals employed in a hospital setting. Surveys of these groups bear striking similarities. They are personally strong advocates for organ donation, but the level of their commitment in this process is quite dependent on their attitude of professional responsibility, the measure of support for organ donation they perceive from their peers and other health care professionals, and their knowledge of the process. Unfortunately, survey data indicate that knowledge of the process is sorely lacking. Health care professionals are relatively unaware of criteria for organ donation and how to make a referral (9, 19). They have significant concerns regarding potential conflicts of interest, liability issues (20), family responses to requests for organ donation, cost-benefit considerations (19), and perceived commitment of personal time and energy required of them during the donation process (8). Among all groups, physician support for organ donation appears to be the most critical factor, so these issues most certainly need to be addressed in professional education in order to elicit greater cooperation and commitment to organ donation.

#### **Current Practices**

##### **Organ Procurement Organizations**

Organ procurement organizations recruit employees who for the most part have health care professional backgrounds. Most are nurses with critical care experience but who frequently come to the organization without prior experience in organ donation. In addition to on-the-job training, many organ procurement organizations send new employees to a 1-week training program conducted twice a year by the North American Transplant Coordinators Organization (NATCO). Another 4-day workshop on developing skills to approach families about donation, and teaching these skills to others is also highly recommended by many organ procurement organizations. This particular workshop has been conducted at least annually by Margaret Verble and Judy Worth.

Organ procurement organizations' staff spend considerable time providing public and health care professional education about donation. Again, little data is

available regarding the successful components of these programs, specific content, to whom they are directed, or how to measure their effectiveness.

In an attempt to systematically solve the organ donor shortage, a 2-year research-based demonstration project has been initiated with four organ procurement organizations. The project is directed by the Partnership for Organ Donation. It is the belief of the Partnership, shared by the four organ procurement organization sites, that organ donation will increase when better donation processes are implemented within hospitals and the public becomes more committed to donation through effective public education programs.

The Partnership's strategy for improving donation within the hospitals is threefold: first, to focus on the key hospitals which have the greatest potential for organ donation; second, to identify key individuals within the hospital who are most likely to be involved with donation and to develop with them a team approach to donation; third, to focus on the families' needs in the critical care unit and to insure that the approach to families about organ donation is not initiated until the family members show clear indication that they understand their loved one has died (24). Research done as part of the Kentucky Organ Donor Affiliates (KODA) pilot project suggested that this approach to families had a significant effect on consent rates (11).

### **Health Care Professionals Within the Hospital Setting**

Brain death is central to organ recovery, so within the context of their work, neurosurgeons' support may be a critical component of a successful organ donation program. From survey data it appears that neurosurgeons' concerns about organ donation are mitigated by the feeling that involvement in seeking organ donation is a professional responsibility (8). Therefore, transplant professionals, in collaboration with the United Network for Organ Sharing (UNOS), have begun to work with national associations representing neurosurgeons. To date, an 8-minute video portraying the clinical assessment of brain death and a "neuro ruler" detailing criteria for organ donation have been made available to neurosurgeons. Resolutions supporting organ donation have been adopted and published by the Congress of Neurological Surgeons and the American Association of Neurological Surgeons. It remains unclear how these resolutions translate into action on the part of the individual health care professional.

All physician groups surveyed expressed some lack of knowledge or concern about some aspect of organ donation. If they are not confident of their knowledge or if their concerns are not addressed, then asking them to initiate organ donation poses a significant problem. Many of these concerns seem to be of a psycho-social nature, such as dealing with death and dying and how the discussion of organ donation affects a grieving family. Expectations that physicians are skilled in

dealing with dying patients and their families may be unfounded. Medical school education about death and dying is relatively new in the United States (25), and there is little consensus on teaching methods and course content. In a 1989 survey of medical schools, 51 of 111 respondents replied that death and dying was taught only as a module of a larger course; 30 respondents provided only one or two lectures on these issues during the first 2-years of medical school.

Hospital staffs are very comfortable with pursuing organ donation when the request is initiated by the family of the deceased. Taking this the next step, it could be hypothesized that if medical professionals perceive public acceptance and support for organ donation, they will be more inclined to participate. Aggressive public education campaigns may subtly influence health care professionals as well as the public. There is a body of literature which holds that individuals adopt behaviors which are congruent with what they perceive to be the norms of society. One might suggest, therefore, that if the norm of society is perceived by health professionals as a willingness to consent to organ donation, then there would be a greater willingness on the part of health care professionals to approach the families of brain dead individuals.

Reservations about approaching a grieving family about donation may result from a perceived conflict of interest. Tolle (26) states that primary care physicians must serve as advocates for their patients; but the role of requesting organ donation serves another patient -- the transplant recipient. She suggests that the solution is to have the formal request made by personnel not directly responsible for the clinical care of the potential donor. If this is in fact a true barrier, then the organ procurement community must reinforce their willingness, sensitivity, and experience to participate in this process. Physicians willing to initiate the donation discussion with families must be given adequate information and training in order to perform this task as comfortably and as confidently as possible. How this information and training are best imparted is not clear and needs further investigation.

Each physician must be clear about his or her role in organ donation. Like advanced directives, prior discussion with patients about organ donation from a supportive physician may have great influence on family decision-making. Information about donation should be readily accessible to all physicians, yet there is a paucity of information in the literature addressing the role of primary care physicians in organ donation.

Knowledge about criteria for donation, access to the organ procurement system, and successes of transplantation are details that can easily be provided by the organ procurement organizations at staff meetings, grand rounds, or one-on-one interaction. Greatest receptivity of this material may be achieved by introducing the topic through peer organizations. Transplant surgeons and physicians are often

effective educators in this area. The extent of legal exposure for physicians must be addressed through authoritative channels such as eminent judges or local bar associations. To ameliorate the heavy emotional toll which the organ procurement process exacts on those involved, feedback should be provided from transplant recipients as well as donor families.

Organ donation and transplantation ought to be addressed at every level of medical training. It should begin in medical school and be reinforced during house staff training. The UNOS education committee is currently completing a modular curriculum to be used by medical and nursing schools. Hopefully the importance of the subject matter will be reinforced by the inclusion of questions on credentialing examinations.

From the previous studies, nurses appear to be the strongest supporters of organ donation (8,14,20). Many have discussed donation with their families, and they sign organ donor cards in higher proportions than the general public (23). Most nurses feel that involvement in organ donation is a professional responsibility (8). To enhance the participation of nurses in the organ donation process, the National Kidney Foundation has developed a 1-day program "Making the Critical Difference" designed primarily for critical care nurses. The program recognizes critical care nurses as highly trained professionals whose feelings and attitudes affect their willingness to participate in the organ donation process. It addresses their concerns and allows them to discover the roles they can play in the process. The success of this program will be tracked over a 2-year period. To better understand the nurse's role in the organ donation process and to identify a profile of nurses most likely to participate in the process, a survey will be administered prior to the beginning of each workshop and at 6 and 12 months following the program. This information may prove very useful in identifying the training needs of nurses working in critical care areas.

Perceived support for organ donation among peer groups and other health care professionals appears to correlate strongly with willingness to participate in the organ donation process, and most health care professionals surveyed believe that physicians are the most critical link (8). Apparently a strong and consistent perception on the part of nurses is that physicians are not supportive of organ donation, despite numerous surveys that suggest the reverse. While nurses may perceive their role as one of facilitator in the donation process, they appear reluctant to do so without physician support. Other health care professionals such as hospital administrators and directors of nursing express strong support for the process if physicians are known supporters.

Believing that professional cooperation, especially among physicians, is vitally important to successful outcome of an organ recovery, a number of hospitals have created multi-disciplinary teams consisting of hospital administration, nursing

representatives, neuroscientists, trauma physicians, chaplains, and social workers to formulate mechanisms for identifying potential donors and notifying organ procurement organizations, to insure that families of potential donors are informed of their options regarding organ donation, and to provide adequate training for those involved in the request process (27-29). All hospitals indicated an increase in organ donation after initiation of such programs. A secondary outcome was the perception that the hospital staff are better informed about organ donation issues.

### **Role of Other Professionals**

Supportive roles of other professionals in organ donation need to be more closely examined. Surveys indicate that the public is frequently unaware of their religion's stand on organ donation (7). Active participation of the clergy in addressing this problem requires that they also receive accurate and timely information about organ donation.

Attorneys and funeral directors frequently counsel individuals about health care directives, and pre-need funeral arrangements. How can they best be encouraged to support organ donation?

### **Critical Issues and Questions**

We have identified a number of critical issues related to the roles of health care professionals in increasing organ donation, and educational efforts needed to enhance organ donation. Out of these statements, we will propose some recommendations for consideration.

**ISSUE I:** All of the studies which have been conducted to date suggest that the attitudes and behaviors of physicians are of crucial importance to the success of organ donation programs. Although nursing staff in hospital settings have demonstrated their willingness to approach families of potential donors, there is evidence that without the support and leadership of physicians, there is less willingness on the part of nursing staff to take an aggressive role in this regard. Therefore, it is suggested that training resources should selectively target physicians.

**Discussion:** Given that we know about the importance of physician attitudes in the process of organ procurement, a number of questions are raised and need to be answered. These include:

- Which specialists are most important to target? Studies point to the importance of targeting neurosurgeons, neurologists, intensive care

physicians, trauma physicians, and in certain cases, family practitioners, since these individuals are most often found to be caring for patients who are potential donors.

- Who should most appropriately conduct the training of physicians? What role should organ procurement organizations, national associations of OPOs, UNOS, etc., play in the training process? It has been shown that physicians respond better to training which is done by peers rather than by individuals who are non-physicians.
- At which point in medical training would such training be most effective: undergraduate level, graduate medical education, in-service education for practicing physicians, or all of the above? If at the undergraduate level, then in which parts of the curriculum should it be included (i.e., medical ethics, public health, critical care rotations, etc.)? Are there model programs that can be emulated?
- Should there be questions included on board examinations related to organ procurement and transplantation, or should the maintenance of licensure and/or board certification rely in part upon certification that there is a minimum level of knowledge related to organ procurement and transplantation?

Clearly an indepth discussion of each of these questions may give rise to a number of recommendations, and a variety of organizations or groups of individuals might logically be assigned responsibility for the implementation of such recommendations.

**ISSUE II:** The roles of the various professionals who are involved in the coordination of organ procurement and transplantation are not well defined, understood, or agreed upon by the transplant community, and by the medical community in general.

**Discussion:** Organ Procurement Coordinators are skilled in assisting with the process of requesting organ donation when a potential donor presents. These individuals, who often come from a nursing or physician's assistant background, are trained in the skills required to approach families of potential organ donors seeking permission for organ donation, and in the management of the donor prior to organ recovery. On the other hand, there are the critical care nurses, trauma care physicians, intensive care physicians, neurosurgeons, and neurologists who are providing care for the individuals who often become potential organ donors. It appears, in many cases, that identifying the respective roles of these professionals and promoting a team approach to organ donation may facilitate the process of organ donation and transplantation.

**ISSUE III:** Training and sensitivity as to the importance of approaching the families of potential organ donors must be institution wide, in addition to targeting individual health care professionals.

**Discussion:** Although, as noted above, the attitudes and behaviors of physicians related to organ procurement seem to play a key role in assuring positive outcomes, it is equally important that institutions, namely hospitals and their administrative structures, and related national organizations be sensitive to the importance of organ procurement. This calls for special efforts on the part of organ procurement organizations and others responsible for training, to target hospital administrators and boards of directors. Such training can be approached through increased liaison with hospital associations at the national and State levels. This would involve working with the American Hospital Association, and State hospital associations, in addition to individual hospitals. Questions which are raised in this regard include:

- What are the most effective ways to train boards of directors and hospital administrators?
- Who are the people who are most appropriate to conduct such training?

**ISSUE IV:** Federal and State policy makers who are involved in the formulation of public policy related to organ procurement and transplantation, many of whom are themselves trained as health care professionals, need to also be aware of the issues related to organ procurement.

**Discussion:** Federal and State policy makers are required to view issues from the perspective of fiscal, statutory, and regulatory considerations. As such, it is natural for these officials to view their roles as "guardians of the gates" rather than as facilitators. What can sometimes be short changed in the considerations of policy makers are the human dimensions of the problem and how it might be possible to creatively overcome barriers to the achievement of the desired objectives. Therefore, the organ transplant community must be mindful of the need to design strategies which will promote a high level of awareness on the part of policy makers as to the practical dimensions of implementing legislation in such a way as to result in effective organ procurement and transplantation programs. Again, the question as to how best to accomplish this training and sensitization arises. Also, who are the public officials and policy makers who should be most appropriately targeted in such training? One potential model for such training might be the series of State legislative workshops which were convened around the country in the late 1980s by the National Center for Health Services Research in which they assembled select legislators and high level government policy makers from a number of States to address issues involved in the response to the HIV epidemic.

**ISSUE V:** There are too few good studies which can serve to illuminate the subject of the shortage of organ donors to provide us with specific guidance as to the best approaches to professional training related to organ procurement.

**Discussion:** Further data accumulation and studies are needed before we can answer some of the key questions related to professional training in issues of organ procurement and transplantation. These include such questions as:

- How do professional attitudes and knowledge compare with public attitudes and knowledge related to organ donation and transplantation?
- Are there any comparisons that can be made of various approaches which have been taken to train undergraduate medical students in issues relating to organ donation and transplantation, and the relative effectiveness of these approaches?
- Are there certain OPOs whose professional training programs have succeeded in increasing the rate of organ donation within their respective regions, and if so, can we identify the elements which are responsible for this?

If these, and other questions could be answered, we would be in a better position to design appropriate and effective training modalities targeting health care professionals.

**ISSUE VI:** Issues of legal liability are often cited as reasons why health professionals, particularly physicians, fail to be more active in seeking permission for organ donation. Such questions as "who owns the donated organ?", "is the donor card valid?", "has brain death been properly diagnosed?", etc., are raised as being responsible for physicians' hesitancy.

**Discussion:** Since issues of legal liability appear, at least anecdotally, to be of real concern to health care providers, it may be important to look at actual experience to see if the perception is supported. It is important that the legal issues be addressed carefully and objectively so that there are factual answers for the above concerns. It may be necessary to design a study which would specifically determine the frequency with which litigation has been brought against physicians and other health care professionals in cases related to organ donation. Having answered this question with actual data, it would be possible either to support the perception or refute it.

**ISSUE VII:** Early studies suggest a number of attitudinal impediments on the part of physicians which deter the optimal recovery of organs. These include perceived conflict of interest, fear of liability, lack of current information about the process,

reluctance to spend the time necessary to work with the family of a potential donor, and the high cost of transplantation.

**Discussion:** Each of these attitudinal issues can contribute to the relatively low rate of organ procurement. Any recommendations for training, especially of physicians, must address each of these issues so that, where possible, these attitudes can be influenced in a direction which will succeed in improving the rate of organ donation. In terms of the issues of cost, for example, we must evaluate the cost of maintaining patients with end-stage organ failure as opposed to the cost of a transplant, with subsequent restored physical function.

**ISSUE VIII:** Perhaps OPOs should establish realistic annual goals for organ recovery based upon an accurate assessment of donor availability within their service area. This assessment and goal setting would also allow for evaluation of the success of professional education efforts.

**Discussion:** If such goals were set, it could serve as a rallying point for organ procurement organizations, and some of their professional training efforts could be built around these goals. Of course, there is a fine line between approaching such an effort in a humane and sensitive way on the one hand, and having it appear distasteful on the other. Such goal setting would have to be done with the greatest of care. However, there may be some justification for considering this since we know that there is significant organ wastage.

**ISSUE IX:** Increasing organ donation from among ethnic minority communities requires specific training for requestors which will enable them to approach the families of potential donors in a manner which will be culturally sensitive and appropriate.

**Discussion:** Among individuals needing organ transplants, there is a disproportionately high representation of individuals from ethnic minority groups and yet there is a lower than average rate of organ donation from members of racial and ethnic minority groups (30). The skills required in approaching an African American family, a Latino family, or Asian families from various national and religious backgrounds are different from the skills in approaching a Caucasian family. Therefore, the training of requestors must be tailored to developing the specific sensitivities which are required in approaching families from a variety of racial and ethnic backgrounds. In certain centers it may also be appropriate to recruit requestors from specific racial and ethnic backgrounds in an effort to improve the effectiveness of organ requests from ethnic minority groups.

## **Proposed Recommendations**

The authors would like to propose the following recommendations to the participants of the Surgeon General's Workshop on Organ Donation.

- 1.** That the Division of Organ Transplantation, with advice from the transplant community, prepare a plan for a national strategy to incorporate issues related to organ procurement and transplantation at all levels of physician, nursing, and allied health professions training programs. The preparation of this plan should enlist the participation of all relevant national associations of health professional training and relevant credentialing boards. The plan should address not only action steps, but also organizations and individuals who will be responsible for carrying out the action steps.
- 2.** That the Division of Organ Transplantation design studies which will seek to answer, among others, the following questions:
  - How do professionals' attitudes and knowledge correlate with public attitudes and knowledge as it relates to organ donation and transplantation, and what interventions might effectively influence perceived societal norms related to attitudes regarding organ donation and transplantation?
  - What comparisons can be made of the relative success of various modalities of training undergraduate medical students in issues related to organ donation and transplantation?
  - Which organ procurement organizations have been most successful in mobilizing the efforts of health professionals and are there any identifiable variables which can account for this success?
- 3.** That the Division of Organ Transplantation, calling upon other Federal Agencies and private sector organizations, design a program which will train key policy makers and elected officials at the State and national levels in the importance of increasing organ donation.
- 4.** That the Division of Organ Transplantation convene a working group of interested parties to consider better ways of "marketing" the services of OPOs and organ transplant coordinators to the health professional and hospital communities at large.
- 5.** That a study be conducted to determine the frequency and nature of litigation which has been brought against health care professionals in cases related to organ procurement and transplantation. The results of such a study could serve to allay

fears, or could provide useful guidance as to how to better fashion statutes in order to protect health care professionals.

6. That the Division of Organ Transplantation study the rates of organ procurement and the organ demand within the regions served by the OPOs, and develop realistic goals for organ procurement within these respective regions so that these goals can serve as rallying points for institutions and health care professionals within those regions.

7. That the Division of Organ Transplantation develop a contract request for proposals which will seek to identify attitudinal impediments among the various health care professionals to optimal organ donor procurement. This effort should also seek to propose means of overcoming these impediments through various training modalities.

8. That the organ transplant community explore improved means of training health professionals in the skills necessary to approach families of various racial and ethnic minority groups requesting organ donation.

9. That forums be sought to provide training in organ donation issues for the various professional groups not directly involved in organ donation, but whose roles place them in situations where they could influence organ donation, such as morticians, attorneys, medical examiners, and others.

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## RE-EVALUATION OF DONOR CRITERIA: CADAVERIC DONORS

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### INTRODUCTION

#### Present, Actual, and Potential Cadaveric Donor Pool

Organ donation in the United States has remained static for the last 3 years. In 1988, there were 4,069 cadaveric donors; in 1989, 3,923; and in 1990, 4,357. The apparent increase of 11 percent in organ donation between 1989 and 1990 (Fig. 1) does not represent a significant increase in recovery from the historic donor pool. Analyzed by age alone, there were 3,866 donors below the age of 56 in 1988, 3,765 in 1989, and 3,822 in 1990, an actual decrease since 1988. Conversely, the number of donors 56 years of age and older increased from 231 in 1988 to 276 in 1989 and 388 in 1990, a rise of 70 percent in 2 years which also represents an increase from 5.6 percent to 9.2 percent of all donors (Fig. 2). At the same time, the percentage of donors from which organs were taken but not used grew from 2.6 percent to 3.2 percent in donors aged 55 or less, compared to 9.5 percent to 14.5 percent in donors aged 56 or greater (Fig. 3). Thus, organ donation has increased only slightly during the last 4 years, and this gain is entirely due to increased utilization of older donors.

There are numerous reasons why organ donation has not increased. These include societal and medical factors, professional disincentives, personal disincentives for donation, and a lack of willingness to donate. Among the societal or medical factors are enactment and enforcement of laws that decrease the accidental death rate among the traditional potential donor population, including laws that increase the penalty for drunk driving, laws which resulted in a growing use of passive restraint devices and seat belts, laws for reduced speed limits, laws for child restraint devices, helmet laws, and an increase in the drinking age. In addition, improved highway design and vehicle design, public education directed to preventing accidental injury, enactment and enforcement of laws to ensure a safe working environment, and improved medical care which has decreased the mortality from traumatized victims, have all contributed to a decrease in the historic potential donor pool. Perhaps even more significant is the AIDS crisis and newly introduced tests which exclude potential donors (e.g., HTLV-1 and hepatitis C) that together have been estimated to have reduced the historic potential donor pool by as much as 10 percent.

Among the professional disincentives which persist are a lack of adequate information concerning brain death, a lack of compensation for professional time and effort, malpractice concerns, fear of alienating an already stressed family, emotional distaste for the procurement process, and the consumption of personnel and medical resources which is accentuated by a nursing shortage. In some, but not all areas of the country, there is a lack of cooperation by medical examiners due to fear of interference of due process of law. There are important disincentives for dissuading organ donation from potential cadaveric donors. These include prolongation of the death process and potential emotional turmoil for the donor family, increased funeral costs (e.g., embalming) which are often passed to the donor family, and increased costs of hospitalization including additional tests to determine death and prolongation of care of patients to establish donor status. These are particularly problematic in patients without full coverage of private insurance.

Indirectly related to the organ donor shortage are disincentives for living donations. These include lack of compensation for time off work, fear of pain and disfigurement, lack of provision for child care (where appropriate) during hospitalization and recovery, lack of provision for compensation in the event of potential disability that may occur as a result of the donation process, and lack of provision for compensation in the event of death.

Perhaps the most serious problem related to the donor shortage is a lack of willingness to donate. In various opinion polls, more than one-half of individuals in the country indicate that they are unwilling to donate their own organs at the time of death. The reasons for this are numerous but include a general distrust of the health care system and transplantation in particular, a fear of hastened death to achieve organ retrieval (believed by almost one-third of the population) (1), unwillingness to consider one's own mortality, fear of desecration of the body, personal religious beliefs, misconceptions and superstitions, and racial and socioeconomic issues.

The potential donor pool has been estimated by a number of surveys to be about 50-55 potential donors per million population (2-4). At the present time, approximately one-third of the potential donors are used for transplantation, one-third are lost as potential donors because of a lack of willingness of the family to donate organs, and one-third are lost because of inefficiency of the organ procurement system. Some feel that the maximal achievable number of cadaveric donors in the United States approximates 8,000 per year. This can be accomplished only by addressing each of the issues discussed above in concert with an increased utilization of "marginal" donors.

## **Present and Projected Needs**

The number of patients on the waiting list has increased dramatically, by 18.6 percent per year since 1988, reaching 21,982 by January 1, 1991 (Fig. 4). The rate of increase during the last 4 years has been approximately steady. With increasing success rate with transplantation, especially the introduction of new immunosuppressive modalities, it is anticipated that larger numbers of patients will become candidates for transplantation who are currently felt to be poorly suited. Certainly, changes in practice in the last two decades have resulted in a marked increase in the transplantation of patients over the age of 55 and those with diabetes. It is quite conceivable that within the next few years, as many as one-half or more of the patients developing end-stage renal disease will be candidates for transplantation. With more uniform success rates, the numbers of patients who are potential candidates for liver and heart transplants will also increase significantly.

It is tragic that the number of patients that die while waiting for an organ has increased even more dramatically than the numbers of patients on the waiting list, an increase from 1,628 in 1988 to 2,206 in 1990, or 19.3 percent during the last year (Fig. 5).

### **Economic and Medical Costs of Organ Shortage**

Dr. Paul Eggers, Chief of the Program Evaluation Branch of the Office of Research for HCFA, estimated in 1990 that for every 2,000 cadaveric kidney transplants, \$68,000,000 could be saved over the next 10 years (personal communication). This would represent an increase of only 1,000 cadaveric donors, 25 percent of the current number of donors being taken, or approximately 12 percent of the remaining potential donors in the United States. These cost estimates include only direct costs to HCFA and do not include indirect costs or the economic benefits of return of patients to the work force and improved rehabilitation. In reviewing local data of the country's largest renal transplant center, the University of Alabama, Phillips and Diethelm have estimated that at 10 years each single donor would result in a savings of approximately \$70,000, which is consistent with Egger's estimates (5). However, other estimates have not been as conservative.

## **CRITICAL ISSUES IN USING MARGINAL DONORS**

### **Results of a Survey of Actual Practice by the Organ Donor Center**

In 1990, the UNOS Organ Center conducted a survey by mail to all kidney transplant centers to determine the individual center's criteria of acceptability of kidneys for transplantation (6). Seventy eight percent of the 184 centers indicated

they would use a donor aged 65, 58 centers indicated they would accept a kidney from a donor up to age 70, and only fifteen centers (8 percent of respondents) indicated that a donor over the age of 70 would be considered. In contrast, only 35 centers would utilize a single kidney from a donor less than 2 years of age for transplantation into an adult recipient; an additional 49 centers would utilize a single kidney from a donor aged 5 or less, and 49 centers would require that the donor be older than 5 when used for an adult. Only slightly more relaxed criteria were expressed for acceptability of minimum donor age for a single kidney transplant to a pediatric recipient; only 33 of 160 centers would utilize a kidney from a donor in the first year of life for transplantation to a child. More centers than not would accept enblock kidneys from donors of the age of 3 or less. One hundred thirty six of 179 kidney transplant centers would accept a kidney from a donor with a past medical history of hypertension when the donor was compliant with medications or was not taking medications. However, only 84 of 183 kidney transplant centers would use a kidney from a non-compliant hypertensive donor. Surprisingly, 25 centers would use a kidney from an HIV seronegative active drug abuser, and approximately two-thirds of the centers would use a kidney from a seronegative former drug user. Only a few centers would use a kidney with a creatinine over 3.0 mg/dl whether it was rising or falling. More than one-half (94 of 186 kidney transplant centers) would use a kidney from a donor with a past history of insulin dependent diabetes mellitus. There was great variation in the practice of transplant centers from different regions of the country indicating at the very least, a lack of a vigorous and judicious approach to solving the crisis of organ shortage.

### **Absolute Medical Contraindications for Organ Donation**

There are basically only three absolute medical contraindications for organ donation. These are: 1) when the donor has a potentially transmissible infectious disease that could adversely affect outcome in the recipient to a significant degree; 2) when the donor has an active, potentially transmissible cancer; and 3) when it is anticipated that the organ will not work. The presence of a transmissible disease does not necessarily provide an absolute medical contraindication for organ donation. As an example, organs are frequently transplanted from CMV positive to CMV negative recipients with the anticipation that many patients will develop CMV disease and some may even die from the disease. The same may be true for some donors with potential bacteremia from remote infections, such as those with lobar pneumonia. However, the risk of death from certain infections makes use of certain donors absolutely contraindicated. These include the presence of AIDS, active viral hepatitis, Jakob-Creutzfeldt's Disease, malaria, or disseminated tuberculosis.

It has been demonstrated repeatedly that metastatic malignant cells in a transplanted organ can grow in the recipient, escape from immune regulation,

metastasize, and even cause death of the recipient. The risk to the recipient is sufficiently great to contraindicate donation in patients where a specific cancer is known to metastasize to the organ being considered for transplantation, and the patient has an active cancer. A past history of a "surgically cured" cancer is not necessarily a contraindication for organ donation with the possible exception of melanomas treated at a stage where there is an anticipated poor survival rate.

The final absolute medical contraindication for organ donation is when it is anticipated that the organ will not function when transplanted. There are numerous gray areas requiring judgment calls.

### **Balance of Risk Versus Benefit**

There are obviously risks to using non-perfect donors. These include an increase in the cost of hospital care, disability and disfigurement of the recipient, physical and emotional suffering, utilization of expensive medical resources, and possibly even death. However, these must be balanced against the death of more than 6 percent of patients waiting for kidney transplant, and almost one-half of patients waiting for liver or heart transplant due to lack of a suitable organ. The cost benefits of transplantation of liver and heart are felt to be positive although exact figures are not available. However, as previously indicated, a minimum of \$34,000,000 could be saved each year to the Medicare program if the number of kidney transplants were increased by only 1,000 per year. To achieve a balance between the potential risk versus benefit, it will be necessary to use increased numbers of marginal donors, closely monitor their outcome, and determine which marginal donors are acceptable and which are not acceptable, achieving a balance between risk and benefit. It is obvious at the present time that numerous patients are dying on the waiting list because marginal donors are not being used. The real problem is to determine the precise points when marginal donors provide more benefit than harm. For example, use of organs from marginal donors that provide results no more than 10 percent worse than organs from ideal donors would generate an overall benefit.

There is a potential backlash from using marginal donors, both related to public opinion and the potential for litigation against members of the transplantation team. If transplant surgeons are successfully sued for trying to provide an overall medical benefit by using a marginal donor which results in damage to a specific individual, the use of marginal donors will cease and many more people will die of organ failure. Because of this specter, it is believed that the recipient should be informed not only of the potential risks but also the potential benefits of not accepting a specific organ. Another real problem with the use of marginal donors is that there may be a perceptible decrease in the overall organ survival rate, at least as compared to the use of organs from only ideal donors. There is considerable pressure by the public, the Federal government, and the insurance

agencies to achieve high survival rates. However, in doing so by excluding marginal donors, many patients are denied access to transplantation because few transplant centers will extend the use of marginal donors if they know their results might be inferior to other centers and result in decreased patient referral, lack of certification, and public scorn. It is important that in making information concerning results available to the public from specific transplant centers, the results of marginal donors be included so that rational and informed decisions can be made concerning the center's degree of competence.

### **WAYS TO EXPAND THE DONOR POOL**

As mentioned in the introduction, the "traditional donor pool" seems to be decreasing rather than increasing. The use of older donors has accounted for almost all of the increase in the organ donation rate during 1990 as compared to 1989. The use of marginal donors has, however, been incompletely explored and could be expanded by the following:

#### **Expand Age Limits**

Currently, many centers will exclude donors categorically because of "unacceptable" age. If an organ is anatomically normal and has normal function, there is no reason why it should not be used for transplantation regardless of age (7,8; reference 8 has additional review).

#### **Use of Diabetic Donors**

The presence of insulin-dependent diabetes has traditionally been a contraindication to donation. However, many of these patients have perfectly normal organs, including the heart, liver, kidney, and lungs. Specific tests to examine organ function and vascular anatomy can be performed in these particular patients. If organ function is normal and there is no vascular disease, there is no reason they should not be used for transplantation into non-diabetic recipients (9). However, there is concern that the development of secondary diabetic complications in transplanted organs may occur at an accelerated rate in diabetic recipients.

#### **Use of Hypertensive Donors**

Increasing numbers of hypertensive donors have been used, but follow-up data have been insufficient to determine which of these are unacceptable. Biopsy of the organ before transplantation, when appropriate, and careful examination of the major vessels, may be important determinants.

### **Use of Hypotensive Donors**

Shock may or may not have an adverse effect on ultimate organ function. Prospective data should be collected to determine the limits of acceptability of donors who have been hypotensive and of the effects of the use of pressor agents.

### **Use of Infected Donors**

Currently most potential donors with suspected systemic infection or a recent history of septicemia are excluded. However, there is actually scant evidence that many infectious diseases would be transmitted under the coverage of specific antibiotic therapy. Often, donors are even excluded with a positive RPR test for syphilis. Even if the donor did have syphilis, it is unlikely that the recipient would develop syphilis under the coverage of penicillin therapy. The problem is not infrequently encountered regarding the use of kidneys from donors with positive urine cultures.

### **Use of Non-Heart-Beating Donors**

Even without good methods for organ preservation, non-heart-beating donors were used for kidney transplantation on a routine basis prior to the introduction of brain death legislation. Numerous potential donors are lost because of the requirement by some centers that only donors with brain death can be used. Actually, the kidney can tolerate up to 30 minutes or perhaps longer of warm ischemia with a very high success rate. Protocols should be developed for core cooling of potential recipients before permission can be granted or where there is a delay between cardiac arrest and organ harvest, and for the testing of viability of organs removed from non-heart-beating donors.

### **Use of Donors with Abnormal Organ Function**

The results of the recent UNOS Organ Center survey emphasizes the wide variation in the practice of centers with regard to the maximum acceptability for the level of serum creatinine (6). Levels of acceptability should be more universally defined and adopted. Other tests, such as the MEGX test for liver function, should be more carefully documented to determine limits of acceptability.

### **Use of Donors at High Risk of Viral Infection**

The exclusion of many high risk categories from organ donation presents a serious problem which relates primarily to high risk groups, e.g., IV drug abusers who have a negative serology for HIV and hepatitis C. If highly sensitive and decisive tests,

such as the polymerase chain reaction (PCR) test, could be developed for a routine screening of donors, it would allow the use of subjects from the high risk categories as long as they were negative by these highly sensitive tests.

### **Use of Donors with Past History of Malignancy**

Arbitrary limits have been set regarding the use of donors with a past history of malignancy (e.g., 2 to 5 years after removal of a breast carcinoma with no evidence of recurrence or metastatic disease). Whether these arbitrary limits are correct or not needs to be further defined by careful data analysis after judicious expansion of this potential pool.

### **Conclusion and Recommendations**

Every transplant center strives to achieve the best possible results for its patients, and it has been historically appropriate to exclude donors that might cause disease or disability in the recipient or failure of the transplanted organ, or at least a higher probability thereof. However, with the indications for solid organ transplantation continually expanding to an ever increasing population base, and with an even more rapidly expanding death rate of patients on the waiting list because suitable transplantable organs are lacking, all possible ways to achieve an expanded donor pool need to be explored. Even with extensive programs for public education and incentive programs for donation, the number of donors will be insufficient to meet the needs. Therefore, expansion of the donor pool to include marginal donors is timely and appropriate as long as the use of such donors continues to provide more overall benefit than risk. It is not known exactly how much the donor pool can be increased by using marginal donors, but the author's best estimate would be at least 1,000 donors per year, or an increase of 25 percent in addition to what can be achieved by other means.

The following recommendations are made to maximize the safe use of marginal donors:

- 1) Development of acceptable limits for each organ to be used as a national standard.
- 2) Collection and analysis of data on a yearly basis with redefinition of the acceptable limits on a periodic basis, based on analysis of hard data.
- 3) A standard of acceptability for success rate with marginal organs should be set for each condition. This could be as high as 15 percent less than the success rate for ideal organs.
- 4) Provision of legal protection for the use of marginal donors.

- 5) Inclusion of the need for the use of marginal organ donors in public and professional educational programs.
- 6) Development of UNOS policies to establish donor criteria and mandate offering of organs that meet national rather than local standards.
- 7) Government funding of trials specifically designed to determine the limits of acceptability of donation from marginal donors.

# ORGAN DONATION -- UNITED STATES (Cadavers)

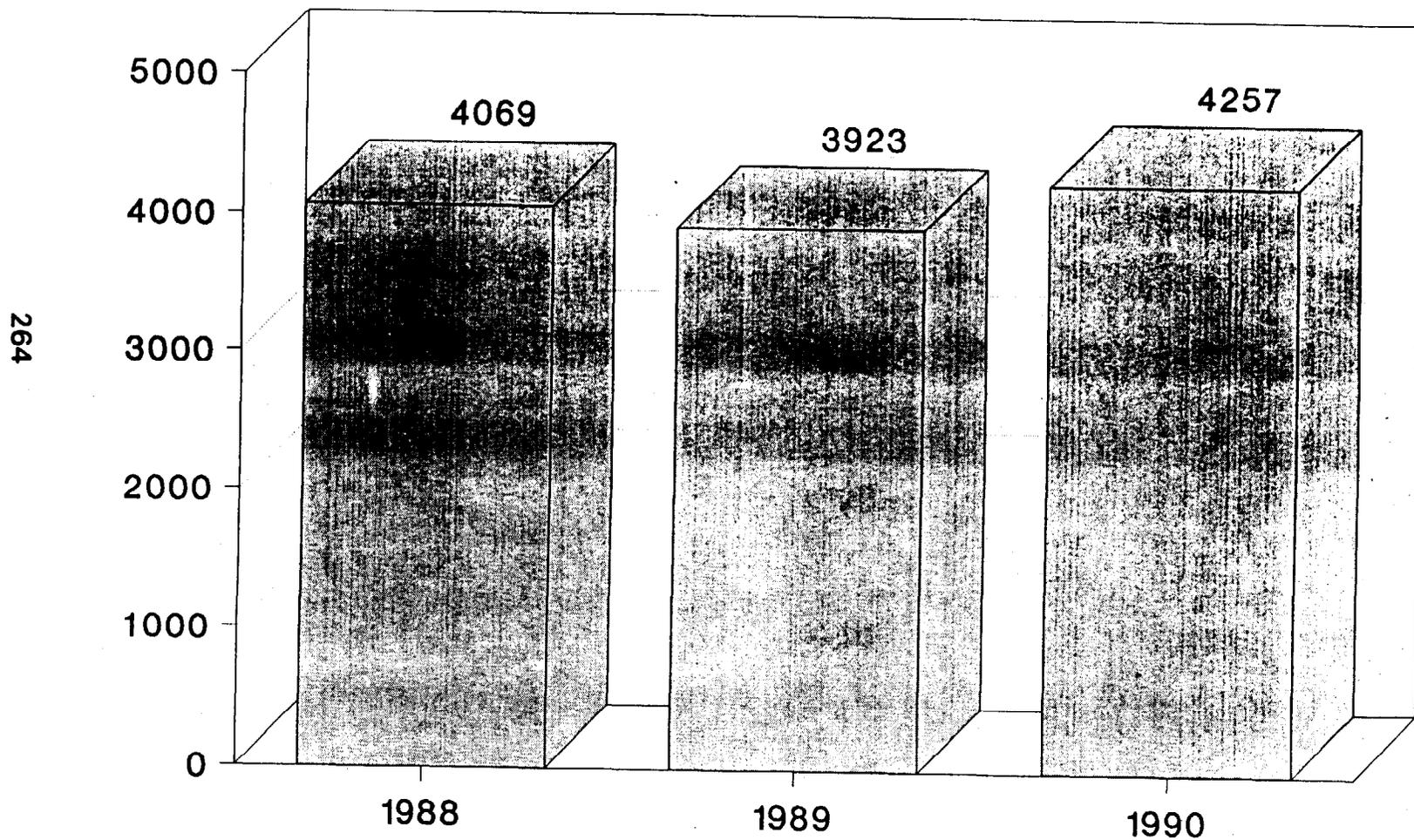
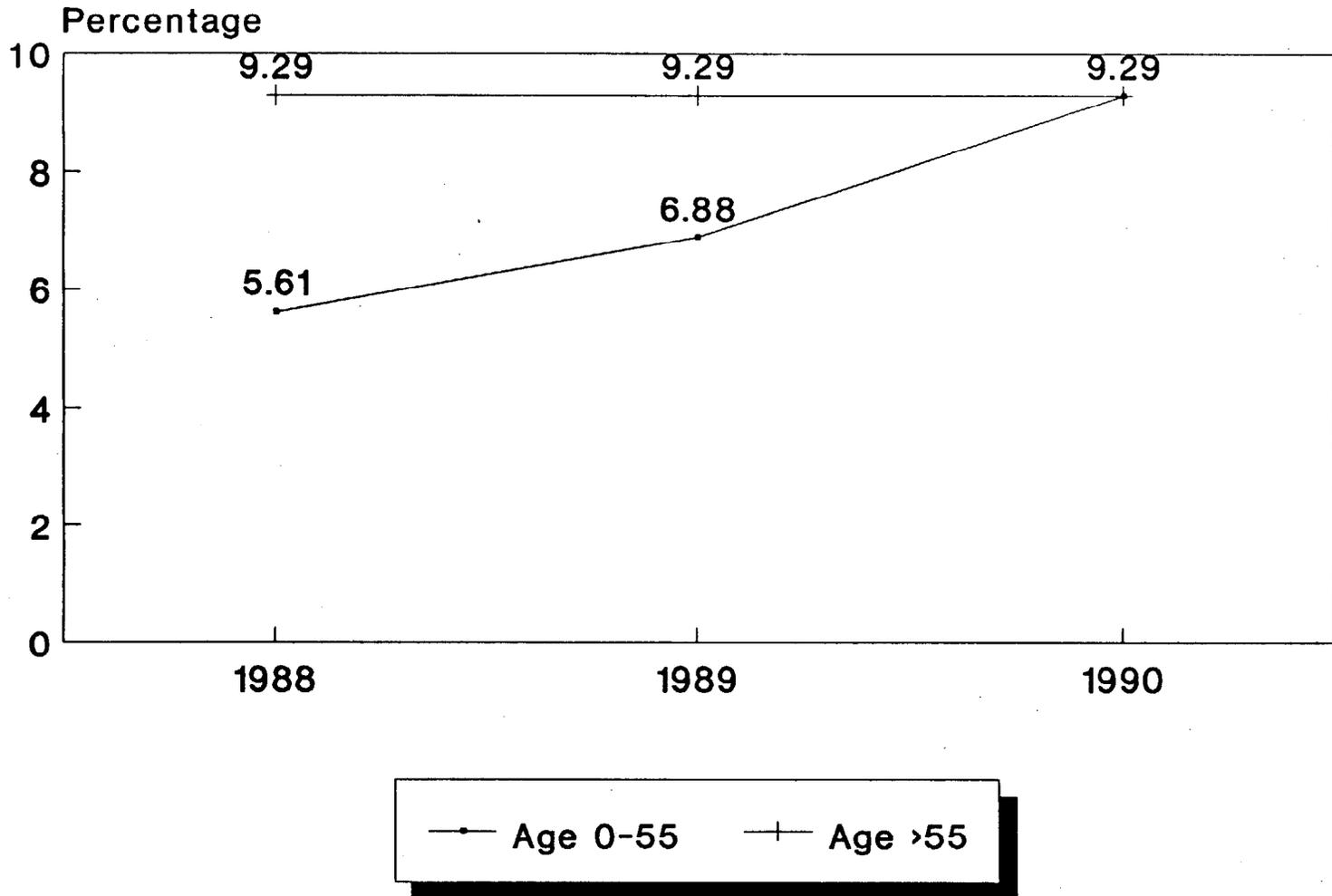


Figure 1.

# CADAVERIC DONORS BY AGE

265

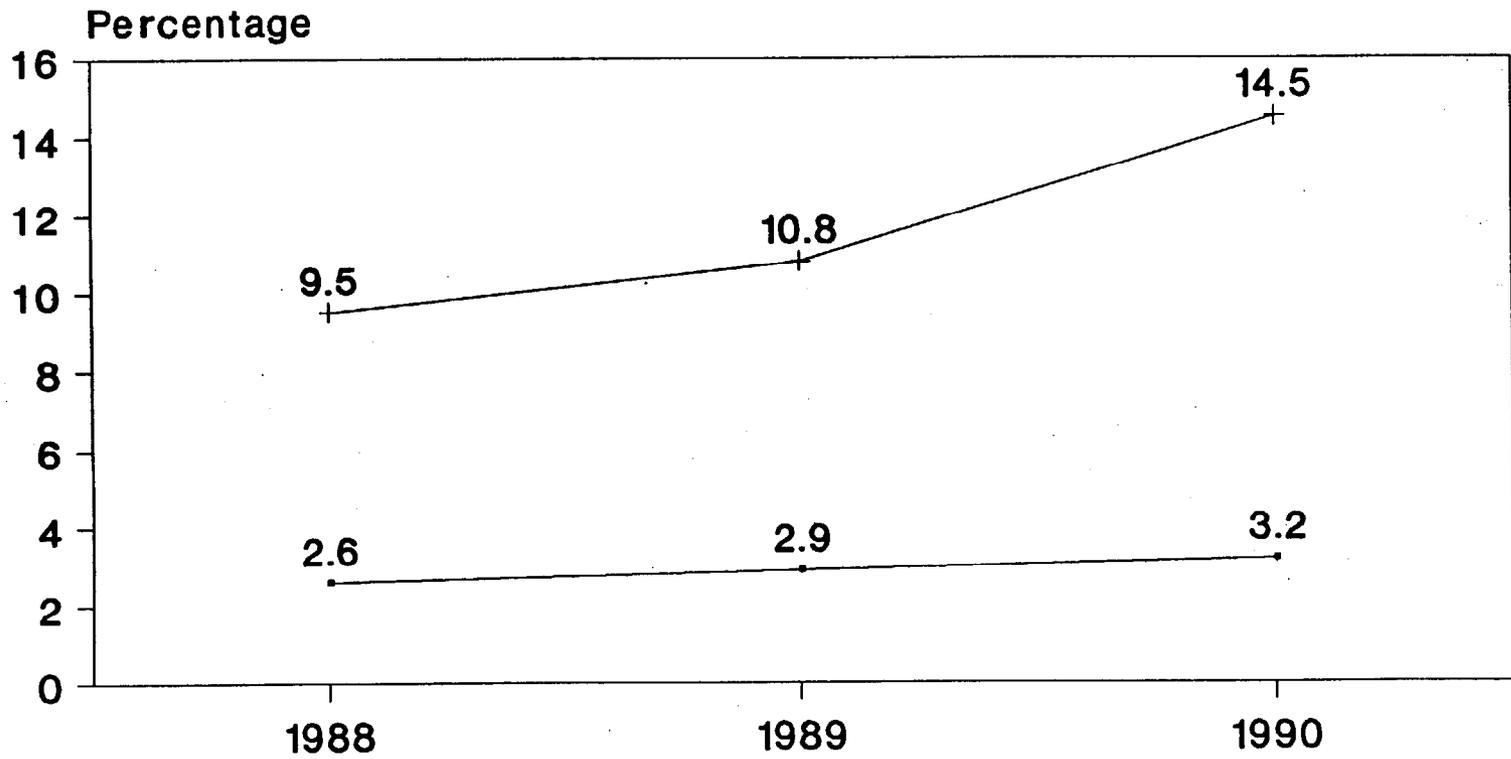


68% increase in donors >55 (1988 - 1990)

Figure 2.

# PERCENTAGE OF CADAVERIC DONORS TAKEN -- BUT ORGANS NOT USED --

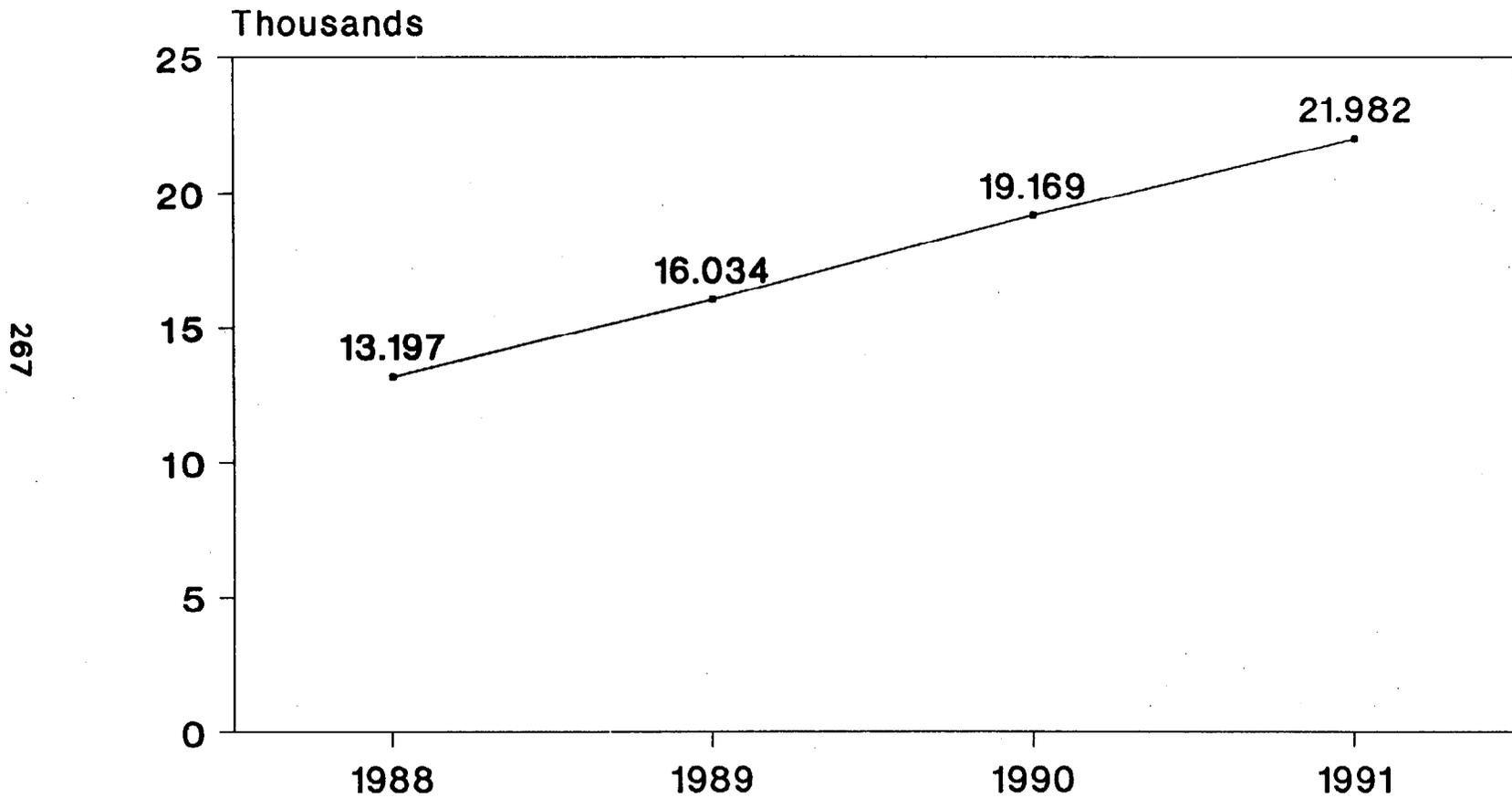
266



—•— Age 0-55    —+— Age > 55

Figure 3.

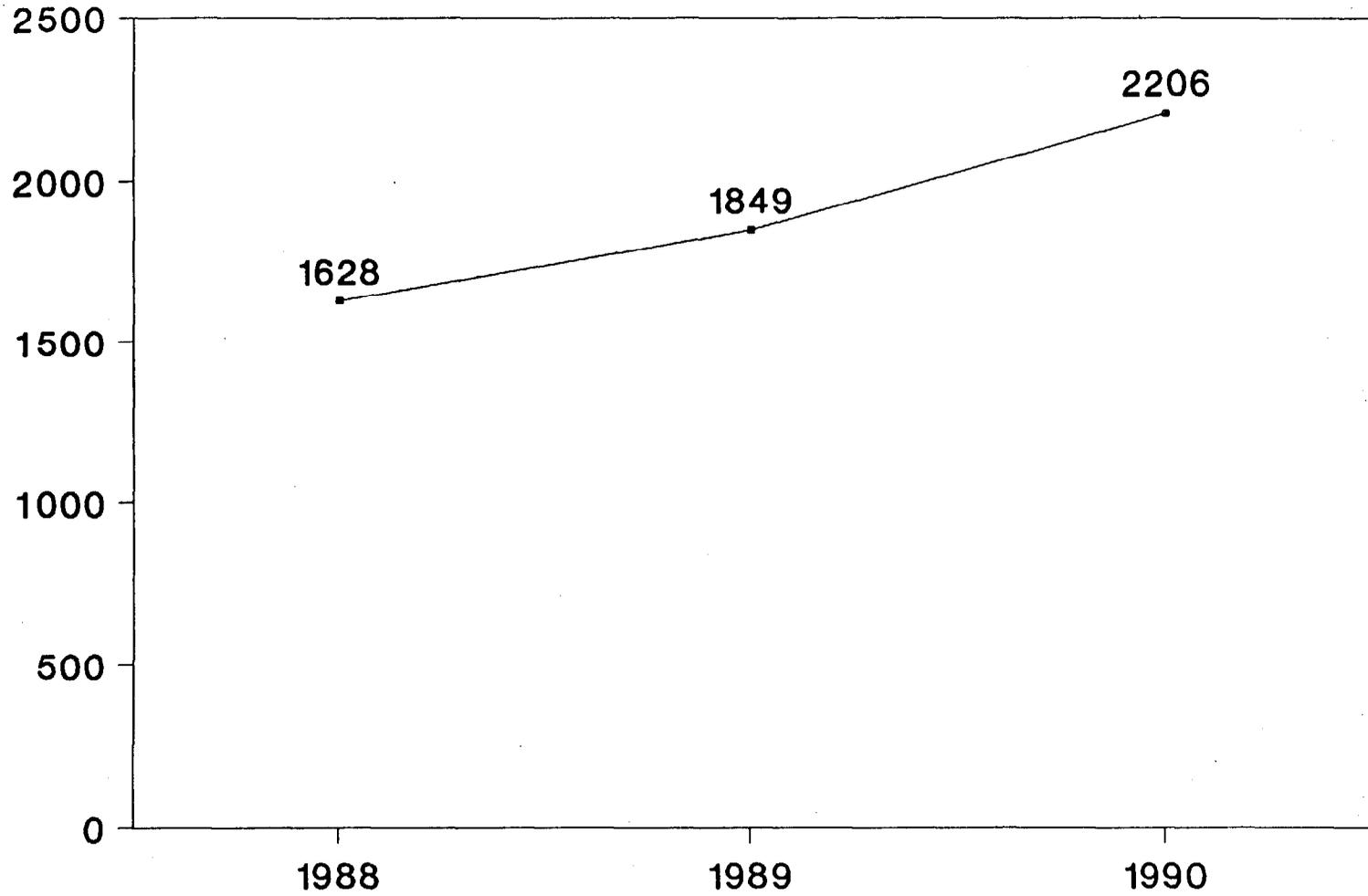
# PATIENTS ON WAITING LIST FOR AN ORGAN -- AT BEGINNING OF YEAR --



Increase of 12.8 % per year (1989-90),  
16.6 % per year (1987-90)

# DEATHS OF PATIENTS ON WAITING LIST

268



Increase of 26.3 % per year

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## RE-EVALUATING DONOR CRITERIA: LIVE DONORS

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The use of living, rather than cadaveric, donors for organ transplantation remains controversial.<sup>1-5</sup> Physicians who consider using living donors face a unique ethical dilemma. They subject a healthy person to a procedure which entails some medical and surgical risk and which does not improve or maintain that person's health. Instead, the risk to the donor is justified by the benefit to the recipient.

This dilemma is often mistakenly perceived as a problem of patient consent. However, Woodruff noted as early as 1964 that consent is not the crucial issue. Many competent adults freely consent to self-sacrificial actions for altruistic reasons. Instead, Woodruff wrote, "The question is not whether the donor is right to offer to give up his kidney, but whether the doctor is right to allow him to do so."<sup>6</sup>

Woodruff proposed that solutions to this dilemma would not be found in moral absolutes but in clinical judgments based on probabilities. He proposed four relevant considerations for physicians who would consider allowing a person to undergo the risk of kidney donation. First, he thought that it must be established that the proposed recipient would die without the kidney (this written in 1964, before dialysis was available and before brain death made the use of cadaver organs feasible). Second, the donor must be in good health. Third, the donation must be entirely voluntary. Woodruff was so concerned about possible coercion that he thought the potential recipient should not be told that transplant was under discussion until the decision was made to proceed. Finally, the donor must be informed of risks, and of the fact that, given the state of the art at that time, there was a considerable chance that his organ donation would turn out to be of little or no benefit to the patient. These arguments, Woodruff thought, justified renal donation in 1964. Many physicians agreed. Live kidney donation became a widely used procedure.

Since 1964, the circumstances under which live donation is offered have changed. With regard to renal transplantation, the development of dialysis and the acceptance of brain death, which allows the timely harvesting of cadaver kidneys for transplant, have led to alternatives to live donation which can extend the lives of patients with end stage renal disease. Use of live donation can no longer be justified as the only alternative to death. Instead, it must be justified as a better

therapy than alternative therapies, either because it offers better quality of life or because it offers better long-term outcome. Similar arguments must be made to justify pancreatic transplants, although they are tougher to make since the alternative therapy is relatively less burdensome. For patients with end stage liver or lung disease, by contrast, no alternative to transplant presently exists, so patients must either wait for a cadaveric organ or consider a transplant from a living donor.

In spite of these modifications, the approach taken by Woodruff, which involves probabilistic balancing of risks and benefits, is still relevant today. Most transplant surgeons do not consider live donor transplants as unacceptable because they involve donor risk, however minimal. Instead, in deciding whether to use living donors, they weigh the relative risks to the donor, which must be low, against the potential benefits to the recipient. Prudent people might be allowed to consent to a small personal risk in order to give another person a great benefit, but not a great risk for a small benefit. Decisions about whether the risks outweigh the benefits allow for individual variations within areas of general consensus among both physicians and potential donors.

This paper will focus on what is now known of the risks and benefits of kidney, pancreas, liver, and lung transplantation using living donors. We will then consider ethical and policy issues surrounding live organ donation.

## **KIDNEY DONATION**

### **History**

The first successful kidney transplant, in the mid 1950s, involved a genetically identical live donor.<sup>7</sup> Attempts at unrelated transplants over the next 5 years were universally unsuccessful.<sup>8</sup> In the early 1960s, immunosuppression with azathioprine and corticosteroids led to improved results and cautious optimism.<sup>9</sup> By the late 1960s, transplantation using both cadaveric and live donors had become a standard therapy.<sup>10</sup> During the 1960s, dialysis also developed to the point where it could be routinely offered. By the 1970s, patients with end stage renal disease and their doctors faced a choice between live donor transplant, cadaveric transplant, or hemodialysis. By the late 1970s, peritoneal dialysis became another widely used alternative. Nevertheless, living donors continued to be used. By 1984, 32 percent of all kidney transplantations done in the United States involved living donors.<sup>11</sup>

## Donor Risks

Live kidney donation requires general anesthesia. Data on the risk of general anesthesia are controversial. A large recent analysis by Lund and Mushin estimated the mortality associated with general anesthesia at 0.1/1000.<sup>12</sup> Mortality estimates from older studies, many of which did not carefully distinguish anesthesia-related deaths from other post-operative deaths, range from 0.6/1000<sup>13,14</sup> to 19.3/1000.<sup>15</sup> The American Society of Anesthesiologists lists the mortality risk for the healthiest (Class I) patients as 1/1250, or 0.8/1000.<sup>16</sup>

In addition to anesthesia risk, nephrectomy may be associated with post-operative mortality. An analysis by Bay and Herbert of 2495 donor nephrectomies reported in the literature, and 5698 donor nephrectomies reported from the 12 largest centers that transplant kidneys from living donors, indicates an approximate incidence of 1 donor death per 1600 nephrectomies.<sup>8</sup> Margreiter estimates that 20 living kidney donors had died by 1987, for a mortality rate of at least 1/1000.<sup>17</sup>

In addition, there is some risk of long-term morbidity as a result of the loss of a kidney. Sobh et al compared 45 living related kidney donors with 20 healthy sex- and age-matched controls. Donors had minor abnormalities in renal function, including lower glomerular filtration rate, higher creatinine, and a greater incidence of albuminuria than controls.<sup>18</sup> However, they had no difference in the incidence of hypertension. Foster, in an uncontrolled study, reports similar findings among 13 patients who had single kidneys and were at least 5 years status post nephrectomies for renal cancer--mild increases in creatinine and albuminuria that appear to be stable over time.<sup>19</sup> Wikstad reports on 36 patients who were born with a single kidney. Patients were followed for 7-40 years. They found microalbuminuria in 47 percent of patients with a single kidney, although none of the patients had renal insufficiency or hypertension.<sup>20</sup> Other studies indicate similar long-term complications of kidney donation.<sup>21,22</sup>

Taken together, these small single-center studies offer some reassurance about the long-term prognosis for kidney donors. However, they offer no guarantees about the long-term safety of living with a single kidney. Each study was small enough to have missed rare but serious complications. In each study, a number of patients were lost to follow up. It is surprising that no long-term multicenter follow-up on a large cohort of renal donors have been reported. Such a study could help quantify donor risks.

## **Recipient Benefits**

Kidneys from living donors are in greater supply than those from cadavers, so one of the primary benefits of using live donors is increased organ availability.<sup>23</sup> However, 86 percent of transplant centers say that they would continue to use living donors even if there were an adequate supply of cadaver kidneys.<sup>24</sup> Thus, in addition to increasing organ supply, live donor transplants are perceived as having other advantages over cadaver transplants. These are primarily related to outcome.

Kidneys from unrelated living donors probably do not confer a better prognosis for the recipient than kidneys from cadavers. In one study comparing 41 patients who received grafts from living unrelated donors with 41 patients who received cadaveric grafts, graft survival rates at 3 years were 81 percent for unrelated living donors and 86 percent from cadaveric transplants.<sup>25</sup> In this study, the grafts from live donors functioned more rapidly than cadaver grafts, with no need for post-transplantation dialysis. Preliminary data on 809 transplants from the International Collaborative Transplant Study also indicates no differences in graft survival between cadaveric and unrelated living grafts. (Newsletter 1, Feb 6, 1991). There are currently no large, multicenter, long-term follow-up studies which address this question. However, that may be remedied soon with the International Collaborative Study and with the UNOS registry.<sup>26</sup>

Kidney grafts from related living donors fare considerably better than grafts from cadavers. The North American Pediatric Renal Transplant Cooperative studied 761 transplants, of which 42 percent were from living related donors. Children who received kidneys from living relatives required less immunosuppressive therapy and had a longer period of time between their transplant and their first rejection (36 v 156 days). One year graft survival was 88 percent in the live donor group and 71 percent in the cadaver group.<sup>27</sup>

A study from the University of Miami compared results from 368 adults who received cadaveric kidneys with those of 263 adults who received living related kidneys. Both patient survival and graft survival were better in the living related group. Ten year actuarial patient survival rates were 72 percent and 58 percent in the two groups. Graft survival rates were 56 percent and 36 percent respectively.<sup>28</sup>

Improvement in survival among recipients of kidneys donated by living relatives appears to be explained by HLA matching. In one study, which had only a small number of living related transplants, survival was no different between those and transplants between HLA A, B, and DR-identical cadaver donors.<sup>29</sup> Nevertheless, the likelihood of finding perfect matches is higher among relatives than among unrelated donors.

Altogether, the sum of risks and benefits have led many renal transplant centers to conclude that continued use of living donors is justified.

## **PANCREAS DONATION**

### **History**

Partial pancreas transplantation from living donors has been performed at the University of Minnesota since 1977. The Minnesota group began exploring the use of live donors with hopes that pancreatic grafts from living donors would be rejected less often than grafts from cadavers.<sup>30</sup> Data showing that partial pancreatic resection would not lead to diabetes was cited to justify the donor risk.

Pancreas transplantation has not been used as extensively as other organ transplants, primarily because insulin therapy for diabetes is believed to be safer than transplantation, even though it may be less effective. A large part of the risk of transplantation comes from the need for long-term immunosuppression. Thus, for patients who are receiving a kidney transplant for renal failure, the additional risks of pancreatic transplant diminish. Such patients have been the primary target population for pancreatic transplants.

### **Donor risks**

Partial pancreas donation is a complicated operation. Some partial pancreas donors have developed pancreatic fistulae and pseudocysts with post-operative pancreatitis. Pancreas donors also face the risks of general anesthesia discussed above.

In addition to operative mortality, partial pancreas donors are at risk of developing pancreatic insufficiency and diabetes. Kendall et al, from the University of Minnesota, found that partial pancreatectomy was associated with deterioration in insulin secretion and glucose tolerance in all of 28 donors when they were evaluated 1 year post-operatively.<sup>31</sup> However, fasting serum glucose levels, fasting serum insulin levels, and daily fluctuation in serum glucose levels during a 24-hour sampling period were all within normal range in the donors. Eight donors were followed for 1 to 6 years, and none showed any further deterioration in pancreatic function. Altogether, 1 of 54 donors in the Minnesota series developed diabetes, and this donor would not have been accepted for donation by the pre-donation screening criteria now in use.<sup>32</sup> Given this small experience, however, there is not enough data to accurately determine the risk of a partial pancreas donor's developing diabetes.

### **Recipient benefits**

Before examining the benefits of live donor pancreatic transplant, we acknowledge that there is serious debate about the indications for any pancreatic transplant.<sup>33</sup> Successful pancreatic transplantation, using either cadaver or living donor pancreas, cures diabetes. Transplant recipients no longer require exogenous insulin for the maintenance of normoglycemia. Pancreatic transplantation also improves some of the complications of diabetes, such as peripheral neuropathy and nephropathy,<sup>34,35</sup> although it is not clear how much improvement transplantation can confer. Retinopathy is not improved by pancreatic transplantation, but early transplantation may prevent the development of retinopathy.<sup>36</sup>

Thus, the potential benefits of pancreatic transplants are for patients who are prone to complications and who do not yet have severe complications.<sup>37</sup> Unfortunately, there is no reliable method for predicting which patients will develop complications, except by selecting those with early complications, such as early renal disease or pre-proliferative retinopathy.<sup>38</sup> Diabetic children whose disease is associated with major neurovascular disease may also be candidates for grafting, although, as of June 1988, only 6 transplants had been done in patients under the age of 20.<sup>39</sup>

Pancreatic transplantation results have been steadily improving. Comparing results from 1966-77 and 1986-89, 1-year recipient survival rates have gone from 39 percent to 87 percent and 1-year graft survival rates have gone from 5 to 56 percent.<sup>40</sup> Results are even better for those United States cases reported to the UNOS Registry. From 1987-89, 1-year patient and graft survival rates were 91 percent and 69 percent respectively.<sup>40</sup>

Grafts from live donors appear to be less prone to rejection than cadaver grafts. In Minnesota, at a time when 1-year functional graft survival rate for technically successful transplants in non-uremic, non-kidney transplanted patients was 32 percent for cadaver donors, the graft survival rate was 73 percent for living related transplants.<sup>41</sup> This probably reflects better HLA matching, as 1-year graft survival in cadaver transplants varies from 67 percent for transplants with 0-2 HLA-AB mismatches to 58 percent for patients with 3 or 4 mismatches ( $p = 0.058$ ).<sup>42</sup>

Thus, to the extent that pancreatic transplantation is indicated, there may be some benefit to the recipient to receive a segmental graft from a live donor rather than from a cadaveric donor. However, the current controversy over the indications for pancreatic transplantation, combined with the relatively high risk to the living pancreas donor, make the use of live donors for pancreatic transplantation difficult to ethically justify.

The number of living pancreas donation procedures has decreased over the past 2 years, suggesting that even the proponents of the procedure may feel that the risk-benefit balance currently does not justify use of this procedure.

## **LIVER TRANSPLANTATION**

### **History**

Liver transplantation was developed throughout the 1960s and 1970s. By 1983, an NIH consensus panel concluded that whole liver transplantation was standard therapy for a number of indications, including biliary atresia, inborn errors of metabolism and nonalcoholic cirrhosis<sup>43</sup>. Technical advances in the 1980s allowed surgeons to transplant reduced-size livers,<sup>44,45</sup> split livers,<sup>46</sup> and eventually to use a portion of a liver from a living donor for transplantation into a child.<sup>47</sup> Liver transplants from live donors have now been performed in at least five centers in four countries.

### **Donor Risks**

The donor requires a general anesthesia for a partial hepatectomy. Anesthesia risks have been discussed above. A partial hepatectomy can be quite risky in the face of underlying cirrhosis, and some surgeons have reported operative mortality rates as high as 11 percent.<sup>48,49</sup> In a number of series involving non-cirrhotic patients, however, the operation has been performed with no or very low mortality.<sup>50-54</sup>

Liver donors have developed operative complications. One patient required splenectomy as a result of an intra-operative laceration of the spleen. Two donors have required non-operative management of bile leaks. As of May 1, 1991, 50 living liver donor procedures had been performed without a death in the donor group (Whittington PF, personal communication). Long-term risks to the donor appear to be low. After partial hepatectomy, the liver regenerates<sup>55</sup> so liver mass is expected to return to normal within 4-6 weeks, although this has not been studied in the living donor situation. Thus, although no long-term data on donors are currently available, there is clinical evidence from comparable patients and some physiologic reason to believe that donors will not have inadequate hepatic function as a result of partial liver donation.<sup>56</sup>

### **Recipient Benefits**

In contrast to kidney and pancreatic transplants, there is no alternative medical therapy for patients dying of end stage liver disease. The primary benefit to the recipient is the availability of an organ suitable for transplant at a time when the recipient is still medically suitable or appropriate for transplant. For a number of

patients, especially children and adults with fulminant hepatic failure, the shortage of suitable cadaveric livers leads to their death or clinical deterioration while waiting for an organ. The use of reduced-size and split livers ameliorates the organ shortage for children, but the shortage remains.

Liver transplantation from living donors, rather than cadavers, may confer other benefits as well. The transplanted organs may be healthier, since there would be decreased ischemic time between organ harvest and transplantation. Cadaver organs may have suffered ischemic injury as a result of the events that led to the donors' death. Furthermore, in other organ transplant situations, organs from family members are less likely to be rejected, most likely as a result of better HLA matching. This may be true for livers as well.

It is hard to evaluate the efficacy of living liver donation since the procedure is so new. Initial results are comparable to results after whole liver transplants from cadaver donors. Preliminary data shows that, for liver transplants from living donors, graft survival rates are 72 percent (36/50). Graft survival rates in the U.S. and Japan, the countries with the most experience, are 80 percent (35/44). The period of follow-up varies from 1-15 months. These are comparable to 6-month graft survival rates of 69 percent for cadaveric liver transplants.<sup>57</sup>

If graft survival is comparable or better, and living liver transplants allow patients who would have died while waiting for an organ to survive, then many people will judge the recipient benefits to outweigh the small known and unquantified unknown risks to the donor.

## **LUNG TRANSPLANTS**

### **History**

Partial lung transplants from living donors have been successfully carried out in animals for a number of years.<sup>58</sup> The first use in humans took place in 1990, with the transplant of a lung lobe from a mother to a daughter.<sup>59</sup> To date, only one such procedure has been performed. As a result, little is known of the feasibility, the risks and benefits, or the likely outcomes of this procedure.

### **Donor Risks**

Because only one such procedure has been done, the donor risks are difficult to assess at this point. However, lobectomies have been done in patients with underlying pulmonary disease, that is, patients who might be expected to be sicker than prospective lung donors, with very low operative mortality.<sup>60,61</sup> The feasibility of this operation makes the use of living lung donation ethically possible.

## **Recipient Benefits**

The shortage of acceptable cadaver lungs for transplant is more severe than for other organs.<sup>62</sup> Patients who become brain dead usually have suffered some lung injury, and the incidence of pulmonary infection, a contraindication to transplant, among ventilated patients is high.<sup>63</sup> Furthermore, lungs may be used either alone or as part of a combined heart lung transplant, which increases the demand for donor lungs. As a result, patients who may benefit from lung transplants are likely to die while awaiting a suitable organ. The use of living donors could improve the chances of such patients receiving a transplant.

## **ETHICS AND PUBLIC POLICY**

Some major differences exist in the four organ transplant situations described above. For kidney and pancreas failure, alternative medical therapies are available, so patients rarely require a transplant to prevent imminent death. Instead, the goal of transplantation is to improve quality of life.<sup>64,65</sup> By contrast, patients with end stage lung or liver failure must either receive a transplant or die. There are differences in operative risks for the donation procedures, although clearly each procedure is associated with some risk -- at least the risk of general anesthesia. In each case, there is some uncertainty about the long-term risks to the donor, especially whether they are at higher risk for disease as a result of donation. These facts and uncertainties must form the basis for judgments about whether the benefits to the recipient outweigh the risks to the donor. These judgments will change as more experience and information is accumulated about each procedure. Nevertheless, in each situation, certain ethical concerns arise that must be addressed.

### **Beneficence and Nonmaleficence**

Physicians set limits on the types of procedures which are offered to patients, and thus, on the procedures to which patients may consent. Generally, physicians are guided in establishing these limits by considerations of beneficence (i.e. the desire to do what is good for the patient) and nonmaleficence (i.e. the desire to avoid harm). Most physicians feel that the donor risks must be minimal, and will not allow patients to donate unless they are in perfect health. Only 10 percent of renal transplant centers will allow patients who are less than optimal donor candidates to donate.<sup>66</sup>

Studies show that many patients would be willing to consent to donation, even if they were in poor health or there was a significant mortality risk to donation, especially if the potential recipient is a relative.<sup>67</sup> This has led some to argue that physicians should loosen the acceptability criteria for donors, allowing patients to

assess risks and benefits for themselves.<sup>68</sup> Regardless of the acceptability criteria used, physicians will still be in the role of deciding whether to consider a particular person for organ donation. In doing so, the physicians' concerns about doing harm to the patient will be weighed against patients desires to act altruistically.

Physicians may consider not only the physical risks of donation but the psychological sequelae as well. For many kidney donors, donation is a difficult, anxiety producing, and painful experience.<sup>69</sup> Kidney donors often have moderately severe depressions for 1 to 2 weeks after the operation.<sup>70</sup> Some donors have even gone on to commit suicide.<sup>71</sup> For most, however, the anxiety and depression resolves after a few weeks and most donors then experience a considerable boost in self-esteem.<sup>72,73</sup> Long-term follow up shows that most donors experience positive psychological sequelae from donation.<sup>74</sup> There are no data on the number of adults who, when asked, refuse to donate, to see whether not donating causes psychological problems. Interestingly, when Gouge et al studied adults who were considered as donors and who went through HLA matching but were not selected as the donor,<sup>75</sup> there were no differences in objective or subjective assessments of quality of life or psychological well-being between this group and the actual donors when assessed a number of years after the transplant occurred.

On the whole, then, it appears that the risks of psychological harm to donors are low, and the potential for long-term psychological benefits quite high. Here again, however, physicians are in the position of having to make clinical judgments about whether, for a particular person, the risk of harm outweighs the likelihood of benefit.

### **Patient Autonomy and Informed Consent**

In most cases, donation is only acceptable if an autonomous patient consents to the procedure. (Possible exceptions include children or incompetent adults.) Valid consent has three elements. First, the patient must have the cognitive capacity to make decisions; second, the patient must be given sufficient information to understand the medical situation; and finally, the decision must be made without undue coercion.

As healthy individuals who are choosing to undergo potentially risky surgery, living organ donors must meet the highest standards of decision making capacity. On rare occasions, such as when the only compatible donor is a minor or an incompetent adult, difficult decisions may arise about the appropriateness of using a donor who lacks decision making capacity.<sup>76,77</sup> The circumstances under which donation by a minor or incompetent adult is acceptable are beyond the scope of this paper, but have been discussed elsewhere.<sup>77</sup>

It is axiomatic that organ donors should have access to all relevant information about the risks of donation. This should include both short-term risks and long-term risks, and must include discussions of current areas of uncertainty, such as the long-term risk of renal failure for kidney donors or the long-term risk of diabetes for pancreas donors. Although standards for disclosure of risks in informed consent for any medical procedure are not well defined, standards for donation should be especially rigorous since the donor does not stand to benefit from the procedure.

Such information may not, however, be a key factor in donor decision making. Empirical studies show that most kidney donors make their decision to donate immediately after the subject of transplant is first mentioned to them, and no additional information has any effect on their decision.<sup>78,79,80</sup> Nevertheless, because some potential donors may change their decisions based on medical data, detailed information about the risks of donation must be provided.<sup>81</sup> Because potential donors appear unwilling or incapable of evaluating information about risks and benefits, physicians may recommend that donors undergo psychological or psychiatric evaluation to determine whether their decision is truly voluntary.<sup>82,83</sup> Unfortunately, since this is an area of psychology that is seldom evaluated in a medical context, it is not clear what evaluative tools psychiatrists should use to assess voluntariness, or whether psychiatrists are truly better than other physicians or social workers in making this assessment.

### **Three forms of coercion: altruism, guilt, and greed**

Given high standards of decision making capacity and adequate disclosure of information about donor risk, the potential for coercion becomes the key element of informed consent. Three possible components of donor coercion should be distinguished. The first is psychological or internal coercion created by the donor's own feelings of guilt because the patient may die without donor participation.<sup>84</sup> This negative or coercive psychological response may, of course, be balanced by positive emotional responses to donation, such as feelings of loyalty, responsibility, love, or duty toward a family member.

Psychological coercion may be unavoidable, but may also be indistinguishable, in many cases, from laudable psychological motivations for donation. In any case, this sort of coercion is not unique to organ transplantation. The need to balance selfishness and altruism is a universal feature of an individual's relationship with his or her family. Because this is a universal element of human interaction, we do not think that it invalidates voluntary consent.

The second element of donor coercion is external. Pressure upon an unwilling donor to consent may come from family members or even from health care workers.<sup>85</sup> If family pressures appear to be unduly coercive and the donor seems

conflicted about the decision to donate, psychiatric evaluation and counseling of both the potential donor and the family may be necessary.<sup>86</sup> Although controversial, physicians might also, with the consent of the patient, inform a family that the decision not to donate was based on medical criteria, such as tissue incompatibility, rather than lack of consent. This would offer the potential donor psychological protection from family pressures.

Pressure from the transplant team may be more difficult to avoid. Surgeons can counter the risk that they will unconsciously coerce donors by highlighting the potential risks of donation, and emphasizing that a decision not to donate would be understandable and acceptable. A "donor advocate," independent of the transplant team, may counsel the potential donor and help work through the tangle of conflicting emotions.<sup>87</sup> However, the use of a mandatory "donor advocate" would subject donors who have no emotional conflicts to a needless and potentially unpleasant psychological evaluation.

A third form of coercion could come from financial incentives to donate. Some people argue that the legalization of organ selling would be coercive, as it would create an irresistible financial incentive. Further, this coercion would be strongest on the poor, who may yield to financial incentives and make decisions that they otherwise would not want to make.<sup>88</sup> Thus, by this argument, remuneration for donation is inherently discriminatory against the poor. Others argue that the coercive elements of a market in organs could be regulated so that the public policy benefits outweigh the ethical risks.<sup>89</sup> We will now examine arguments for and against financial incentives. For the purpose of this paper, we will not discuss the sale of cadaver organs, but will focus on arguments for and against the sale of organs by living persons.

The most compelling argument for financial incentives is that they might increase the supply of organs for transplant. At present, the use of organ transplants is limited by the supply of available organs. Thus, for each of the four procedures discussed above, there is a permanent waiting list of patients for transplant. For liver and lung transplants, in which no alternative therapy is available, a number of patients die because no suitable organ becomes available.

Opponents of policies permitting the purchase or sale of organs argue that other policies might also increase the supply of organs. Such policies include the use of driver's license check-offs to consent to organ donation, required request laws, physician education, and public awareness campaigns. Until such policies are fully implemented and their results evaluated, opponents of markets argue, we can't say that the organ shortage is irremediable, and so should not make a drastic, controversial change in public policy.<sup>90</sup> Opponents further argue that permitting payment for organs will taint organ donation, drive voluntary donors away, and that the organs obtained under a free market system will likely be of inferior or

uncertain quality compared to those obtained today.<sup>91</sup> Thus, they argue, payment for organs may actually decrease the supply or quality of organs.

These opposing positions are based on predictions of how people would respond to particular policies, and on the problems that those predicted responses would create. However, since we don't know whether people would respond that way, the differences between the two positions do not seem solvable hypothetically or rhetorically. The only way to determine the effect of policies which would permit reimbursement for organ donors would be to try them and evaluate them. Policies designed to increase the recovery of cadaver organs have been tried for a number of years and have been only marginally effective.

A second argument supporting policies allowing individuals to sell their nonvital organs is that, if we respect autonomy, we should allow adults to use and dispose of their bodies as they see fit.<sup>92</sup> Opponents also argue that respect for autonomy is not absolute. Society may prohibit certain activities if it deems them too dangerous, as it has done for activities such as bare fist boxing, riding motorcycles without helmets, and working in dangerous work environments. Society may also ban morally reprehensible activities, such as prostitution, baby selling, or selling oneself into slavery.

The question is whether selling organs for transplant is either too dangerous or too demeaning to permit. This question can be further refined. Clearly, it is morally acceptable to many people to allow competent adults to donate organs. People who choose to donate are considered morally praiseworthy for donating. Andrews points out that "It is difficult to justify a prohibition on payment for what would otherwise be a legal and ethical act -- giving up body parts for someone else's valid use."<sup>93</sup> Does the addition of financial incentives tip the balance of moral considerations so steeply that we must reverse our moral judgments? If it does, it is only because we fear that it would turn a voluntary act into an involuntary one.

The arguments on both sides are compelling, and suggest that a compromise position might be appropriate. Some degree of financial reimbursement or remuneration for people willing to give up their organs might increase the supply of organs. Thus, although outright sale of organs might be prohibited, some reimbursement to donors for hospital expenses, or lost wages as a result of donation might be considered acceptable. Harvey suggests that a distinction can be made between payment for organs and commercial exploitation of organs.<sup>94</sup> Policies to allow payment without exploitation might require that people who agree to give up organs for reimbursement wait 30 days to reconsider their decision, to prevent rash or poorly-considered decisions. They might also prohibit individual organ buying transactions, requiring instead that reimbursement be limited to donors who register with an organ bank, as potential bone marrow donors now do, and who agree to be available for donation when an appropriately matched

recipient becomes available. Careful medical screening of such donors, as takes place now, should insure the quality of donated organs.

Under such circumstances, some reimbursement seems justifiable -- at least for pain, suffering, inconvenience, and lost income -- although careful regulation to prevent exploitation would be necessary. With such regulation, it should be possible to increase the incentives for people who might consider giving an organ, without necessarily realizing the worst fears of the opponents of reimbursement for organ donation. Reimbursement would not necessarily turn a morally praiseworthy action into a morally reprehensible one, any more than paying soldiers decreases the altruism and heroism which leads them to risk their lives for their country. The real moral concern is not whether money changes hands but whether exploitation is taking place.

### CONCLUSIONS

The use of living donors for kidney, pancreas, liver, and lung transplantation is likely to increase. In many cases, the use of living donors offers transplant recipients a better outcome than cadaver transplantation. It also increases the supply of available organs. Thus, live donor transplantation saves lives.

In deciding whether the use of live donors is acceptable for any particular clinical situation, it is always necessary to weigh the potential benefits to the recipient against the risks to the donor. Physicians should set guidelines for when donation using living donors is acceptable. Patient autonomy, though important, is not absolute. It is constrained by the traditional professional ethical obligation of physicians to do no harm.

Guidelines for deciding when donation is acceptable and for selecting donors should reflect clinical data on outcomes, the normative values which prohibit donors from undergoing more than minimal risk, and procedural safeguards to prevent coercion. Criteria for determining what constitutes minimal risk may vary between centers. Each center should publish their guidelines so that public scrutiny and peer review might refine them. Published guidelines and prompt reporting of outcomes should allow critical evaluation of the clinical and ethical acceptability of different approaches to live organ transplantation. This will allow transplantation using living donors to continue while safeguarding the rights of patients, donors, and doctors.

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\*U.S. GOVERNMENT PRINTING OFFICE: 1992--619-338/41346