A TIME AND A PLACE FOR WISDOM

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Solid Organ Procurement for Transplantation
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I want to thank each of you for taking time out of your busy lives in order to participate in this important workshop. The success of this workshop depends, of course, on the quality of the people involved. But I am convinced that we have brought together the very best representatives from across a broad spectrum of disciplines and interests. I believe we have the quality to assure success.

In many respects, this workshop is possible because you and your many colleagues in this matter of organ procurement and transplantation have already had a measure of public success and recognition. You've worked hard to gain broader public understanding...to solve certain high complex problems of a social, medical, and legal nature...And you have accomplished the ultimate service: you have saved lives. Paradoxically, I believe this is an important workshop because it builds upon the high degree of activity and accomplishment you already display. And, therefore, by all logic, you should be too busy to attend!
THIS EVENING I AM THANKFUL THAT REAL LIFE IS NOT ALWAYS LOGICAL AND YOU ARE HERE AFTER ALL.

SOME OF YOU I KNOW PERSONALLY. MOST I KNOW BY REPUTATION. BUT ALL SHARE SOME THINGS IN COMMON. FOR EXAMPLE, YOU UNDERSTAND, BETTER THAN MOST OTHER AMERICANS DO, THAT WHATEVER SUCCESS HAS BEEN ACHIEVED SO FAR IN ORGAN PROCUREMENT IS ONLY A MODEST BEGINNING...A SMALL TOE-HOLD ON WHAT MAY BE AS DIFFICULT A CLIMB AS THE NORTH FACE OF EVEREST. AND BECAUSE THIS IS SUCH NEW AND STEEP TERRAIN, EACH OF US OUGHT TO MAKE THAT SPECIAL EFFORT TO MAINTAIN A GENEROUS PERSPECTIVE, A BROAD FIELD OF VISION, AND A COLLABORATIVE INSTINCT. WE NEED EACH OTHER -- AND THOUSANDS OF AMERICANS NEED US.

AS IN ANY MAJOR HUMAN UNDERTAKING -- WHETHER INDEED IT IS MOUNTAIN-CLIMBING OR FREE ELECTIONS OR ORGAN TRANSPLANTATION -- WE NEED TO LOOK CLOSELY AT ALL THE ELEMENTS OF THE PROCESS...BIT-BY-BIT AND EXPERIENCE-BY-EXPERIENCE...WE MUST TRY TO UNDERSTAND THEM...AND THEN WE MUST ATTEMPT TO EXERT SOME CONTROL OVER THEM. THE PROCESS IS NOT EASY.

DURING THESE THREE DAYS, WE WANT TO ISOLATE THAT PIECE OF THE PROBLEM THAT DEALS SPECIFICALLY WITH THE "NEED TO UNDERSTAND." IT'S A TOUGH PROBLEM THAT IS GOING TO REQUIRE WELL THOUGHT-OUT SOLUTIONS.
BUT LET ME CLARIFY THAT POINT. THE PROBLEM OF EDUCATING THE PHYSICIAN AND THE GENERAL PUBLIC -- THE SPECIFIC ISSUE WE WANT TO DEAL WITH FOR THE NEXT COUPLE OF DAYS -- PRESUPPOSES THAT WE MAY ALREADY HAVE SOME FEELINGS ABOUT A NUMBER OF OTHER RELATED ISSUES, SUCH AS...

- THE TECHNOLOGY OF ORGAN PROCUREMENT AND TRANSPLANTATION...

- OR THE ETHICAL ISSUES SURROUNDING THE QUESTION, "WHO SHALL BE ELIGIBLE FOR THE NEXT AVAILABLE ORGAN?"...

- OR THE LEGAL QUESTIONS RAISED IN ANY DEFINITION OF DEATH...

- OR THE ISSUES OF COST AND REIMBURSEMENT.

ALL THESE ARE VERY IMPORTANT, VERY DIFFICULT ISSUES. AND I WOULD GUESS THAT EVERYONE IN THIS ROOM HAS SPENT MANY HOURS -- MORE LIKELY, MANY YEARS -- TRYING TO COME TO TERMS WITH THEM.
BUT THOSE ARE NOT THE PARTICULAR ISSUES BEFORE US FOR THE NEXT COUPLE OF DAYS. I BELIEVE THAT IF WE HOLD TO OUR AGENDA AS RIGOROUSLY AS POSSIBLE, WE'LL BE ABLE TO LEAVE ON JUNE 9TH WITH THE FEELING THAT WE HAD, IN FACT, MADE PROGRESS ON AT LEAST ONE MAJOR ISSUE, THE PROCUREMENT OF MORE ORGANS...THAT WE UNDERSTOOD SOME THINGS BETTER THAN WE DID BEFORE WE GOT HERE...AND THAT THERE ARE THINGS WE CAN DO IN THIS AREA THAT WE MIGHT NOT HAVE BEEN SURE ABOUT -- OR EVEN AWARE OF -- BEFORE WE GOT HERE.

THE CHIEF REASON FOR MY OPTIMISM CAN BE FOUND IN THE ATTENDANCE LIST FOR THIS WORKSHOP. I THINK YOU'LL AGREE THAT WE HAVE INVITED RESPONSIBLE REPRESENTATIVES OF AS FULL A RANGE OF MEDICAL, SOCIAL, AND PUBLIC POLICY INTERESTS AS TIME AND SPACE WOULD ALLOW...

° GROUPS SUCH AS THE NATIONAL KIDNEY FOUNDATION AND THE AMERICAN COLLEGE OF SURGEONS...

° INSTITUTIONS SUCH AS THE NATIONAL CHILDREN'S MEDICAL CENTER AND THE UNIVERSITY OF PITTSBURGH SCHOOL OF MEDICINE...

° AND FAMILIES SUCH AS THE FISKES, THE VOSSEKUILS, AND THE KUSHNERS.
OUR STAFF WORKED ESPECIALLY HARD AT MAKING SURE WE HAD THE BEST REPRESENTATION POSSIBLE FROM THOSE GROUPS AND INSTITUTIONS THAT HAVE PIONEERED IN ORGAN PROCUREMENT AND TRANSPLANTATION.

BUT, WITH ALL DUE RESPECT TO EVERYONE HERE, LET ME SAY THAT WE DO NOT PRETEND TO HAVE THE ULTIMATE ATTENDANCE LIST. THE CONSTRAINTS OF SPACE, TIME, AND MONEY HAVE FORCED US TO MAKE VERY DIFFICULT CHOICES -- SOME MIGHT SAY "UNFAIR CHOICES" -- TO INVITE THIS PERSON AND THIS GROUP AND NOT THAT PERSON AND THAT GROUP.

I THINK WE MANAGED TO MAKE OUR CHOICES WITHOUT PREJUDICE AND, IN ALL CANDOR, WITH VERY SLIM CRITERIA. EVERYBODY IN THIS FIELD IS MAKING A CONTRIBUTION. SINCE IT IS SO NEW AND SO EXTREMELY IMPORTANT, HENCE, THE MOST PAINFUL ASPECT OF THIS CONFERENCE WAS THE PROCESS OF DRAWING UP THE INVITATION LIST.

NEVERTHELESS, THAT WOULD SEEM TO BE OUR CONTRIBUTION. I BELIEVE THAT ONE OF THE PRIORITY ACTIVITIES OF GOVERNMENT IS TO BRING TOGETHER AND ENCOURAGE THOSE GROUPS AND INDIVIDUALS WHO HAVE THE CREDENTIALS AS LEADERS. AS THE PRESIDENT HAS SAID ON MANY OCCASIONS, IT IS NOT NECESSARY FOR GOVERNMENT TO BE RESPONSIBLE FOR EVERY IMPORTANT PROBLEM OR TO TAKE CREDIT FOR EVERY IMPORTANT ACHIEVEMENT.
GOVERNMENT OUGHT NOT TO COMPETE WITH THE PEOPLE OF THIS COUNTRY. GOVERNMENT OUGHT TO HELP THEM.

I BELIEVE THAT, TOO, AND, HENCE, I AM SO VERY PLEASED THAT PRESIDENT AND MRS. REAGAN ASKED ME TO ORGANIZE THIS WORKSHOP -- TO BRING TOGETHER THE LEADERS IN ORGAN TRANSPLANTATION FROM AROUND THE COUNTRY...TO RECOGNIZE AND ENCOURAGE THEIR LEADERSHIP -- YOUR LEADERSHIP...AND TO MAKE PROGRESS IN THIS VERY COMPLEX AREA OF INFORMING AND EDUCATING PHYSICIANS AND THE GENERAL PUBLIC.

OVER THE LAST SEVERAL YEARS, THE GOVERNMENT HASCOME GENERALLY TO SUBSCRIBE TO THE NOTION THAT "IF IT AIN'T BROKE, DON'T FIX IT." AND ONE OF THE THINGS THAT "AIN'T BROKE" IS THE PRESENT VOLUNTARY SYSTEM OF ORGAN PROCUREMENT.

IS THIS VOLUNTARY SYSTEM PERFECT? NO, IT ISN'T.

WOULD SWITCHING TO A GOVERNMENT-SPONSORED SYSTEM MAKE IT PERFECT? PROBABLY NOT.
I think it's important for us to accept the current system of organ procurement as voluntary, decentralized, and imperfect...but nevertheless open to improvement. And, having accepted it, relay that information to the public in the most reassuring way possible.

In such an emotionally charged issue, many citizens expect the government to play a stronger role...even the principal role. Certainly there are things the government ought to do and I'm sure we'll hear many good suggestions at this workshop. But taking over the leadership position would not be one of them. To do so would be an attempt to "fix" something that "ain't broke." That would be bad policy and, hence, bad government.

But there are some messages we do need to convey to the public, relative to the roles played by the public and private sectors. For example, I think the public needs to be assured that equity, as well as compassion, is a principle we all treasure. Our educational and informational programs must be firmly grounded in both. And we need to assure the public that, despite the laissez-faire character of organ procurement and transplantation, a genuine effort is made by all parties to work together on this problem.
I feel justified in saying that because, from my own personal experience in private medicine for over three decades and now in federal medicine for the past two years, I believe this is generally true. People want to work together more than they want to work in isolation and apart. In any case, there is no government rule that requires cooperation and coordination. Yet, they are taking place nevertheless, and that is a very good portent for the future.

There is another side to this voluntary, non-governmental aspect of major organ procurement. Thus far, our society has not required persons to donate their organs, either through their own acts or the acts of their guardians or next of kin. It is wholly a matter of personal, individual choice. I think we'd like to keep it that way.

Public education, therefore, is essential. We want more citizens to learn the facts, talk them over with family members, consult their religious leaders, and see if -- or how -- organ donation may coincide with their own ethical and moral values. Experience thus far demonstrates that, once having learned the facts about organ donation and transplantation, most people will choose to do so, given the opportunity.
HOWEVER, IT'S IMPORTANT TO EMPHASIZE THE WORD "MOST" IN "MOST PEOPLE." SEVERAL GROUPS WITHIN AMERICAN SOCIETY HAVE REJECTED THE IDEA OF ORGAN DONATION ON RELIGIOUS, SOCIO-ECONOMIC, OR CULTURAL GROUNDS. THEY HAVE EVERY RIGHT TO DO SO AND WE ARE OBLIGED TO RESPECT THEIR FEELINGS.

BUT, AS SCIENTISTS, WE NEED TO UNDERSTAND THE REASONS BEHIND THEIR REJECTION. THEY MIGHT WELL SHED LIGHT ON OTHER ASPECTS OF THE ENTIRE ORGAN PROCUREMENT PROBLEM. I'M SURE THIS WILL BE ONE OF THE MANY QUESTIONS TO BE RAISED AND DISCUSSED DURING THESE THREE DAYS.

EDUCATION OF THE PUBLIC AND THE MEDICAL PROFESSION SHOULD ALSO INJECT A VITAL NOTE OF REALISM INTO THE WHOLE NATIONAL DIALOGUE REGARDING ORGAN PROCUREMENT. FOR EXAMPLE, PEOPLE NEED A GREATER UNDERSTANDING OF HOW HIGHLY SELECTIVE THE ORGAN PROCUREMENT AND TRANSPLANTATION PROCESSES ARE.

WE KNOW, FOR INSTANCE, THAT AN ELIGIBLE DONOR MUST BE IN A CERTAIN PHYSICAL CONDITION -- PREFERABLY BRAIN DEAD BUT ON A RESPIRATOR -- IN ORDER FOR HIS OR HER ORGANS TO CARRY THE STUFF OF LIFE FROM ONE BODY
TO THE NEXT. THIS KIND OF INFORMATION MAY NOT BE FULLY APPRECIATED BY
THE PUBLIC OR EVEN BY MANY MEDICAL PERSONNEL, YET IT DOES GO A LONG
WAY TOWARD EXPLAINING WHY A PARTICULAR ORGAN MAY BE UNAVAILABLE.

OF COURSE, DURING A TIME OF CRISIS IT'S VERY DIFFICULT TO GET THIS
INFORMATION ACROSS. LOGICAL EXPLANATIONS SOUND LIKE BAD EXCUSES TO
PARENTS WAITING UNDER GREAT TENSION FOR THE RIGHT DONATED ORGAN TO SAVE
THEIR CHILD. NOR IS IT THE BEST TIME FOR MEDICAL PERSONNEL TO WORK
THROUGH THE COMPLEXITIES OF SUCCESSFULLY RAISING THE ISSUE WITH THE
FAMILY OF THE POTENTIAL DONOR. SOMEHOW, WE HAVE TO EDUCATE THE PUBLIC
AND THE MEDICAL PROFESSION TO THE PROBLEM BEFORE THEY MAY EXPERIENCE
IT FIRST HAND.

IN ANY CASE, DESPITE MANY OF THESE PROBLEMS OF PUBLIC UNDERSTAND-
ING, THE VOLUNTARY SYSTEM OF ORGAN DONATION DOES REFLECT AMERICANS'
FEELINGS ABOUT THE WAY THEIR SOCIETY SHOULD CONDUCT ITS AFFAIRS. SO I
BELIEVE WE'LL BE STAYING WITH THE VOLUNTARY SYSTEM, MAKING IT STRONGER
AND MORE EFFECTIVE WHEREVER POSSIBLE, AND THUS BUILDING ON THE GOOD
WORK DONE IN THE PAST.
BUT WE NEED TO DO SO WITH OUR EYES WIDE OPEN. WE NEED TO RECOGNIZE THE IMPORTANT GAPS IN OUR INFORMATION. FOR EXAMPLE...

§ WE KNOW THAT ORGAN DONOR CARDS AND THE NOTATIONS ON DRIVERS' LICENSES HAVE BEEN VALUABLE AS TOOLS FOR PUBLIC EDUCATION, BUT ARE THEY CONTINUING TO EXPAND OUR SUPPLY OF DONATED ORGANS? OR HAVE WE GONE AS FAR AS WE CAN WITH THOSE TECHNIQUES? AND IF WE RETAIN THE DONOR CARD IDEA OR THE LICENSE NOTATION, SHOULD WE REINFORCE THEM WITH OTHER APPROACHES? WE NEED ANSWERS TO THESE QUESTIONS?

§ WE ALSO KNOW THAT OUR KNOWLEDGE BASE IS QUITE LIMITED AT THIS POINT. TO BE PERFECTLY OBJECTIVE AND CANDID, I THINK IT IS NOTHING SHORT OF AMAZING THAT WE'VE COME THIS FAR IN THE FIELD OF ORGAN PROCUREMENT AND TRANSPLANTATION, WITH SUCH SPOTTY, INCOMPLETE DATA AS OUR BASE. THAT JUST HAS TO CHANGE. WE HAVE TO DO BETTER THAN WE'VE DONE SO FAR. AND THE KEY TO AN IMPROVED DATA BASE MIGHT WELL BE THE DEGREE TO WHICH WE RAISE THE LEVEL OF UNDERSTANDING AMONG OUR DATA SOURCES -- AMONG PHYSICIANS, EMERGENCY MEDICAL TECHNICIANS, INTENSIVE CARE NURSES, MEDICAL EXAMINERS, CORONERS, AND MANY OTHERS.
THE DATA PROBLEM IS FUNDAMENTAL, I'M SURE YOU WILL AGREE. WITHOUT GOOD DATA WE CAN'T BE SURE IF WE HAVE A TRUE ORGAN "SHORTAGE" OR IF WE SIMPLY HAVEN'T BEEN ABLE TO SYSTEMATICALLY PROCURE THE ORGANS THAT MAY BE AVAILABLE AFTER ALL.

LET ME GIVE YOU AN EXAMPLE, DRAWN FROM A PROBLEM I'VE BEEN INTERESTED IN FOR ALL MY 35 YEARS AS A PEDIATRIC SURGEON. AS YOU ARE PROBABLY AWARE, WE CAN ONLY GENERATE A ROUGH ESTIMATE OF 160 CHILDREN UNDER THE AGE OF 4 WHO DIE EACH YEAR OF PERINATAL JAUNDICE, BILIARY ATRESIA, AND OTHER CONDITIONS AFFECTING THE BILE DUCTS AND THE LIVER. THE REPORTING IS NOT AS PRECISE AS WE MIGHT LIKE IT TO BE, AND THERE IS EVERY INDICATION THAT HERE, AS ELSEWHERE IN HEALTH STATISTICS, WE MAY BE HANDICAPPED BY A CERTAIN DEGREE OF UNDER-REPORTING.

ON THE OTHER HAND, WE ALSO HAVE ONLY ESTIMATES OF THE NUMBER OF CHILDREN WHO MIGHT BE POTENTIAL LIVER DONORS. IN 1981, CLOSE TO 1,000 CHILDREN, AGE ZERO TO 4, DIED IN HIGHWAY-RELATED ACCIDENTS. OF THAT NUMBER, ABOUT 60 PERCENT WERE KILLED AS A RESULT PRIMARILY OF BRAIN AND SPINAL CORD INJURIES. ONE COULD SAY THAT, THEORETICALLY, THERE WERE 600 OR SO POTENTIAL DONORS OF CHILDREN'S LIVERS IN 1981.
AGAIN, IN THEORY, THEY MIGHT HAVE BEEN THE SOURCE OF MORE THAN ENOUGH HEALTHY LIVERS FOR THE 160 CHILDREN WHO SUFFERED LIVER-RELATED DEATHS DURING THAT SAME CALENDAR YEAR. BUT...

° HOW MANY OF THOSE POTENTIAL DONORS WOULD HAVE ACTUALLY BEEN ABLE TO DONATE A LIVER TO ANOTHER CHILD?

° AND HOW MANY HAD OTHER DISEASE OR INJURY CONDITIONS?

° HOW MANY WERE GEOGRAPHICALLY TOO REMOTE FROM A PROCUREMENT SITE?

° HOW MANY WERE NOT PUT ON A RESPIRATOR OR FED INTRAVENOUSLY UNTIL THE ORGAN DONATION COULD BE MADE? FOR HOW MANY WAS SUCH A PROCEDURE NOT EVEN CONSIDERED?

° AND HOW MANY WERE SHIELDED FROM ORGAN DONATION -- WHETHER INTENTIONALLY OR NOT -- BY PARENTS, GUARDIANS, OR EMERGENCY MEDICAL PERSONNEL?

CLEARLY, THE FEW STATISTICS WE HAVE CANNOT ANSWER ALL OUR QUESTIONS.
I'VE DRAWN A PICTURE PRIMARILY OF THE SITUATION REGARDING LIVERS FOR CHILDREN. BUT THE SAME KINDS OF PROBLEMS EXIST FOR ALL THE MAJOR ORGANS -- KIDNEYS, HEARTS, AND HEART-LUNG COMBINATIONS IN PARTICULAR. IN WHICH CASE, WE NEED TO GATHER MUCH MORE COMPLETE, MORE FINITE STATISTICS, IN ORDER TO SOMEDAY ACHIEVE A SYSTEMATIC RESOLUTION TO THE ISSUES IN ORGAN PROCUREMENT AND TRANSPLANTATION.

I BELIEVE THIS STATISTICAL PROBLEM IS AN INTEGRAL PART OF THE OVER-ALL ISSUE OF EDUCATION OF THE PUBLIC AND OF THE MEDICAL PROFESSION. PHYSICIANS, NURSES, TECHNICIANS, AND THE AVERAGE CITIZEN NEED TO BE SENT A MORE COHERENT EDUCATIONAL MESSAGE, THAT'S TRUE. BUT, AT THE SAME TIME, WE NEED TO GET FROM THEM THE BASIS FOR A MORE COHERENT STATISTICAL PICTURE OF THE PROBLEM.

THERE ARE THE KINDS OF ISSUES TO WHICH WE NEED TO DEVOTE OUR FULL ATTENTION AND ENERGIES DURING THIS THREE-DAY WORKSHOP.

IT'S GETTING LATE AND SO I WILL CLOSE MY REMARKS THIS EVENING WITH A LITTLE QUOTATION FROM ONE OF MY FAVORITE AMERICAN WRITERS, HENRY DAVID THOREAU. IN HIS MARVELOUS BOOK TITLED WALDEN, THOREAU SAID...

"IT IS CHARACTERISTIC OF WISDOM NOT TO DO DESPERATE THINGS."
THIS COULD BE OUR MOTTO, SINCE THE TEMPTATION TO "DO DESPERATE THINGS" IS SO VERY GREAT, WHEN LIVES HANG IN THE BALANCE AND CAN BE SAVED ONLY BY PARTS OF OTHER -- ALBEIT RECENT -- LIVES. BUT WE MUST TAKE UP THOREAU'S CHALLENGE. WE MUST PROCEED WITH WISDOM, NOT DESPERATION.

LET ME EXTEND TO EACH OF YOU THE THANKS OF PRESIDENT AND MRS. REAGAN, WHO WANTED THIS WORKSHOP TO TAKE PLACE. AND PLEASE ACCEPT MY OWN SINCERE THANKS FOR YOUR BEING HERE AND FOR TAKING PART IN THIS WORKSHOP, THEREBY GUARANTEEING US A WISE AND THOUGHTFUL OUTCOME.

THANK YOU.

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