"I am the Surgeon General of the heterosexuals and the homosexuals, of the young and the old, of the moral or the immoral, the married and the unmarried. I don't have the luxury of deciding which side I want to be on."

—C. Everett Koop
The Washington Post Health Magazine
24 March 1987
Report of the Surgeon General's Workshop on Children With HIV Infection And Their Families

Presented by the
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Division of Maternal and Child Health

In conjunction with
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This book is dedicated to the memory of Samuel Jared Kushnick in testimony of how much “his life has counted” and how well “his voice is heard.”

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The photograph of the AIDS virus used in the logo was taken by Mr. Robert J. Mann, Department of Pathology, School of Medicine, University of California, Davis, CA 95616
PREFACE

This Surgeon General's Workshop on Children with HIV Infection and Their Families provides an opportunity to summarize the current knowledge about AIDS (Acquired Immunodeficiency Syndrome) in children and to make recommendations about future directions in research, prevention, and amelioration of the effects of pediatric AIDS. Surgeon General's Workshops, of which this is the fifth, have been useful vehicles for assembling experts to improve the health of mothers and children. Representatives of major professional and voluntary organizations and from various components of the Department of Health and Human Services insure not only a comprehensive coverage of the subject but also a network to disseminate and implement the recommendations.

In the early eighties we realized that children could develop AIDS when it became apparent that this then very mysterious disease could be transmitted by blood transfusions and the administration of blood products to treat hemophilia. Initially it was difficult to distinguish this entity from the rare and puzzling congenital immunodeficiency diseases in children.

By 1984 the numbers of children with AIDS had begun to escalate, especially in New York City, Newark, and Miami. The Division of Maternal and Child Health first held an ad hoc meeting to try to delineate the nature of the problem in NYC where infants were occupying acute care hospital beds unnecessarily because no alternative living arrangements were available. DMCH joined other departmental groups in cosponsoring the first National Meeting on Pediatric AIDS in November, 1984. Attendees at this meeting agreed that AIDS did occur in children, that the number of children involved was undercounted in the CDC surveillance system, and that infected infants and children and their families were subject to discrimination and sometimes barred from basic services. Participants expressed concern about seemingly insoluble problems, although some told of initial efforts to solve them.

DMCH, the New York State Health Department, and the Albert Einstein College of Medicine cosponsored a second National Pediatric AIDS Meeting held in March, 1986. A larger group—predominantly of physicians but also of other health workers, child welfare workers, and educators—exchanged information about the clinical spectrum and treatment efforts. A new confidence resulted from the increasing knowledge about the etiology and transmission of AIDS. We recognized that many generic solutions were applicable to HIV infection. Many could remember when most infections could be managed even without vaccines and antibiotics. It has been especially heartening to hear how the State Health Department, the Hemophilia Treatment Center, and the local school had worked together in Swansea, Massachusetts, to retain a boy with AIDS in school in a manner that evoked the best instincts of his classmates and their families.

This, then, is actually the third national meeting on pediatric AIDS, and is conducted as a Surgeon General's Workshop to bring our best efforts to bear against this new disease.

C. Everett Koop, M.D., Sc.D.
Surgeon General
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Department of Emergency Medicine
WORKSHOP PROGRAM

Monday, April 6, 1987

Plenary Session
The Children's Hospital of Philadelphia

Greetings
John Hutchings, M.D.
Assistant Director
Division of Maternal and Child Health
Department of Health and Human Services
Rockville, MD

Presiding
Stanley A. Plotkin, M.D.
Director, Division of Infectious Diseases
The Children's Hospital of Philadelphia

Welcome
Edmond F. Notebaert, President and Chief Executive Officer
The Children's Hospital Foundation
The Children's Hospital of Philadelphia

Robert Zimmerman, M.P.H.
Acting Deputy Secretary for Public Health Programs
Pennsylvania State Department of Health

Harriett Williams
Deputy Commissioner for Community Health Services
City of Philadelphia

Keynote and Charge
C. Everett Koop. M.D., Sc.D.
Surgeon General
Public Health Service
Department of Health and Human Services

Global Epidemiology
Thomas C. Quinn, M.D., M.S.
National Institute of Allergy and Infectious Diseases
Associate Professor of Medicine
Johns Hopkins University, Baltimore, MD

The Human Immunodeficiency Virus
Wade P. Parks, M.D., Ph.D.
Director of Pediatrics
Division of Immunology and Infectious Disease
University of Miami School of Medicine
Miami, FL

Immunology of HIV Infection
Arthur J. Ammann, M.D.
Director, Collaborative Research
Genentech, Inc.
South San Francisco, CA

Epidemiology and Transmission of Pediatric Infection
Martha F. Rogers, M.D.
AIDS Program/Center for Infectious Diseases
Centers for Disease Control
Atlanta, GA

Approaches to Prevention of HIV Infection
Walter R. Dowdle, Ph.D.
Acting Deputy Director (AIDS)
Centers for Disease Control
Atlanta, GA

Natural History of HIV Infection I
Gwendolyn B. Scott, M.D.
Associate Professor of Pediatrics
Head, Division of Infectious Disease and Immunology
University of Miami School of Medicine
Miami, FL

Natural History of HIV Infection II
James Olasky, M.D.
Associate Professor
Department of Pediatrics
College of Medicine and Dentistry of New Jersey
Newark, NJ
Tuesday, April 7, 1987

HIV Transmitted by Blood Products
Margaret W. Hulgartner, M.D.
Professor of Pediatrics
Director, Division of Pediatric Hematology/Oncology
New York Hospital-Cornell Medical Center
New York, NY

Supportive Treatment of Pediatric HIV Infection
Arye Rubenstein, M.D.
Professor of Pediatrics, Microbiology and Immunology
Albert Einstein College of Medicine of Yeshiva University
Bronx, NY

Drug Abuse and Women's Medical Issues
Constance B. Wofsy, M.D.
Co-Director, AIDS Activities
Principal Investigator, Project AWARE
San Francisco General Hospital
San Francisco, CA

Education to Prevent HIV Infection
Karolynn Siegel, Ph.D.
Director of Research
Department of Social Work
Memorial Sloan Kettering Cancer Center
New York, NY

Legal Issues
Harold M. Ginzburg, M.D., J.D., M.P.H.
Chief, Epidemiology Branch
AIDS Program
National Institute of Allergy and Infectious Diseases
Bethesda, MD

Management of Children with HIV Infection
Mary Boland, R.N, M.S.N., C.P.N.P.
Director, AIDS Program
Children's Hospital of New Jersey
Newark, NJ

Vaccine Strategies
Gerald V. Quinnan, Jr., M.D.
Division of Virology
Office of Biologics Research and Review
Center for Drugs and Biologics
Food and Drug Administration
Bethesda, MD

A Mother's Viewpoint
Helen G. Kushnick
General Management Corporation
Los Angeles, CA

Wednesday, April 8, 1987

Individual Work Group Recommendations
Plenary Session: Work Groups' Summation and Presentation

Surgeon General's Response
C. Everett Koop, M.D., Sc.D.
Close
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GREETINGS:

As Governor of the Commonwealth of Pennsylvania, it gives me great pleasure to extend greetings to all those gathered for the AIDS workshop being held by United States Surgeon General, Dr. C. Everett Koop, M.D. at The Children's Hospital of Philadelphia.

I applaud all of you for the dedicated and professional efforts you have taken to improve and strengthen pediatric health care.

Best wishes for a productive and meaningful workshop.

Robert P. Casey
Governor