ORIGINAL

#29 | "AIDS"

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Address

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Presented to the Surgeon General's Workshop on

Children with Human Immunodeficiency Virus Infection

and Their Families

Children's Hospital of Philadelphia

Philadelphia, Pennsylvania

April 6-8, 1987

(GREETINGS TO HOSTS, GUESTS, FRIENDS, ETC.)

NEARLY 5 YEARS AGO I CAME BACK TO PHILADELPHIA, MY HOME FOR MANY YEARS, AND STOOD BEFORE A SIMILAR GROUP OF CONCERNED AMERICANS TO SHARE MY CONCERNS ABOUT HANDICAPPED CHILDREN AND THEIR FAMILIES.

MY OPENING REMARKS AT THAT SURGEON GENERAL'S WORKSHOP NOTED THAT OUR TASK WOULD NOT BE EASY. WE WOULD BE CONSIDERING VERY COMPLEX ISSUES, SUCH AS THE EMOTIONAL AND THE MORAL, THE MEDICAL AND THE TECHNOLOGICAL, THE SOCIAL, THE PSYCHOLOGICAL, AND THE FINANCIAL ISSUES ASSOCIATED WITH THE CARE FOR HANDICAPPED CHILDREN.

I ALSO MENTIONED THE AWESOME CHALLENGE OF PUTTING SOME DOLLAR VALUE ON A HUMAN LIFE.

I WISH IT WERE NOT SO, BUT THOSE REMARKS ARE JUST AS APPROPRIATE TODAY -- ALMOST 5 YEARS LATER -- AS WE CONSIDER STRATEGIES TO COPE WITH THE CONSEQUENCES OF ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS) AND HUMAN IMMUNODEFICIENCY VIRUS (HIV) INFECTION IN CHILDREN AND ADOLESCENTS.

WHEN I MADE THOSE REMARKS 5 YEARS AGO, LITTLE WAS KNOWN ABOUT THE NATURE AND EXTENT OF AIDS. AND ALTHOUGH WE SUSPECTED THAT CHILDREN WOULD BECOME INVOLVED, IT WAS THEN FAR FROM REALITY.

A GREAT DEAL HAS CHANGED SINCE THAT TIME, AS YOU ARE WELL AWARE. MANY OF YOU IN THIS AUDIENCE HAVE CONTRIBUTED TO OUR EXPANDING KNOWLEDGE ABOUT AIDS OR ARE IN SOME WAY ASSOCIATED WITH ISSUES RELATED TO THIS DEADLY DISEASE AND, THEREFORE, ARE FAMILIAR WITH ITS HISTORY.

AS OF LAST WEEK, THERE WERE 471 REPORTED CASES AMONG CHILDREN UNDER 13 YEARS OF AGE AND 139 REPORTED CASES AMONG ADOLESCENTS, AGED 13 TO 19, THAT MEET THE C.D.C. CRITERIA FOR PEDIATRIC AIDS.

THE NEARLY 500 CASES AMONG YOUNG CHILDREN IS <u>DOUBLE</u> THE NUMBER OF CASES REPORTED ONLY A YEAR AGO. SIXTY PERCENT OF THOSE CHILDREN HAVE ALREADY DIED.

UNFORTUNATELY, WE EXPECT THE NUMBER OF INFECTED CHILDREN TO CONTINUE TO INCREASE DRAMATICALLY. BY 1991, OUR PUBLIC HEALTH SERVICE STATISTICIANS ESTIMATE THAT 3,000 CHILDREN WILL HAVE SUFFERED FROM THIS DISEASE AND VIRTUALLY ALL WILL DIE.

AS FRIGHTENING AS <u>THIS</u> MAY SOUND, THE NUMBER IS UNDOUBTEDLY UNDERESTIMATED.

WE KNOW THAT HIV INFECTION IN CHILDREN HAS MANIFESTATIONS THAT ARE LEGION AND THAT FULL-BLOWN, C.D.C.-DEFINITION AIDS IS ONLY PART OF THE STORY. AS MANY AS 2,000 CHILDREN ARE REPORTED TO HAVE SYMPTOMS OF THE INFECTION, BUT DO NOT FIT THE SPECIFIC DIAGNOSTIC CRITERIA.

CONGENITALLY ACQUIRED HIV INFECTION, FOR EXAMPLE, MAY AFFECT THE INFANT'S CENTRAL NERVOUS SYSTEM, LEADING TO ALTERATIONS IN GROWTH AND DEVELOPMENT, SIGNS AND SYMPTOMS NOT PREVIOUSLY IDENTIFIED WITH AIDS.

RECOGNIZING THIS, THE C.D.C. HAS DEVELOPED A MORE DETAILED AND EXHAUSTIVE CLASSIFICATION SYSTEM FOR THE ASYMPTOMATIC CHILD versus THE SYMPTOMATIC CHILD, THE IMMUNOLOGICALLY COMPROMISED CHILD, AND THE CHILDREN WITH NEUROLOGICAL DISEASE, LUNG DISEASE, SECONDARY CANCER, CARDIOPATHY, AND NEPHROPATHY.

WE KNOW THIS DISEASE HAS MANY PRESENTATIONS IN CHILDREN AND, AS OUR KNOWLEDGE EXPANDS, SO SHOULD OUR PUBLIC HEALTH SURVEILLANCE OF THIS DISEASE.

THE DEVELOPMENT OF BLOOD SCREENING PROCEDURES AND METHODS OF HEAT-TREATING BLOOD FACTOR PRODUCTS HAS VIRTUALLY ELIMINATED THE RISK OF NEW PEDIATRIC AIDS CASES FROM BLOOD AND BLOOD PRODUCTS.

HOWEVER, SOME CHILDREN DID ACQUIRE AIDS FROM CONTAMINATED BLOOD. THESE CHILDREN AND THEIR FAMILIES NEED OUR ATTENTION. THE BURDEN SUFFERED BY THESE CHILDREN, SOME OF WHOM MAY ALSO HAVE A SEVERE CHRONIC ILLNESS LIKE HEMOPHILIA, IS ENORMOUS.

NEARLY TWO-THIRDS OF PEDIATRIC AIDS CASES ARE THE RESULT OF TRANSMISSION FROM INFECTED MOTHER TO CHILD. WHILE THERE ARE OTHER MODES OF TRANSMISSION OF INFECTION TO CHILDREN AND ADOLESCENTS - SEXUAL ABUSE, DRUG ABUSE, AND SEXUAL INTERCOURSE - OUR MAJOR FOCUS IN PEDIATRIC AIDS MUST BE ON TRANSMISSION FROM THE INFECTED PREGNANT WOMAN.

MOST OF THESE MOTHERS ARE INTRAVENOUS DRUG ABUSERS OR SEX PARTNERS OF DRUG ABUSERS OR BISEXUAL MEN. HOWEVER, AS THE VIRUS CONTINUES ITS SPREAD AMONG THE GENERAL POPULATION, A WOMAN'S LACK OF DIRECT INVOLVEMENT WITH THESE HIGH-RISK BEHAVIORS WILL BE NO GUARANTEE AGAINST HER INFECTION AND TRANSMISSION TO HER FETUS.

CURRENT INFORMATION SUGGESTS THAT UP TO 65 PERCENT OF BABIES BORN TO INFECTED MOTHERS WILL CONTRACT THE DISEASE. THE OUTLOOK FOR THESE CHILDREN IS ALMOST CERTAIN DEATH.

CURRENTLY, THERE ARE ALMOST NO PROGRAMS WHICH PROVIDE COORDINATED, COMMUNITY-BASED CARE FOR PEDIATRIC HIV-INFECTED PATIENTS.

THERE IS A LACK OF FOSTER CARE PLACEMENT FOR HIV-INFECTED INFANTS AND CHILDREN.

PEDIATRIC UNITS ARE OVERWHELMED BY THE SOCIAL AND MEDICAL DEMANDS OF BOTH ILL AND WELL CHILDREN WITH HIV INFECTIONS.

THERE AREN'T ENOUGH HOSPITAL PERSONNEL TO PROVIDE AND COORDINATE MULTI-DISCIPLINARY INPATIENT, OUTPATIENT, COMMUNITY CARE, AND JUST PLAIN HUGGING AND PLAYING WITH THESE CHILDREN.

AND SOME PEDIATRIC HOUSE STAFF ARE CONCERNED THAT THEIR NEONATAL EXPERIENCE THUS FAR DOES NOT HELP THEM CARE FOR NEONATES WITH AIDS OR DEAL WITH THE CONSEQUENCES OF THEIR MOTHERS' DRUG ADDICTION.

MANY OF THESE CHILDREN ARE NOT ONLY VICTIMS OF MALADAPTIVE BEHAVIOR BUT ALSO SUFFER ABANDONMENT BY THE MOTHER AND SOCIETY.

I SHOULD ADD THAT BECAUSE OF THE STIGMA OF AIDS, THERE ARE FEWER FOSTER HOMES OPEN TO THESE CHILDREN. IN FACT, THE STIGMA HAS BEEN AN INVISIBLE BUT VIRTUALLY INPENETRABLE BARRIER BETWEEN THEM AND A WHOLE VARIETY OF SOCIAL AND PUBLIC HEALTH SERVICES.

YOUNG VICTIMS OF THIS DREAD DISEASE MUST BE AFFORDED AS NORMAL AND DIGNIFIED LIFE AS POSSIBLE. THEY MUST BE NURTURED, HELPED TO GROW AND DEVELOP, ALLOWED TO INTERACT WITH PEERS, ATTEND SCHOOL, AND ENCOURAGED TO ENJOY AND PARTICIPATE IN ALL ACTIVITIES OF CHILDHOOD DESPITE SHORTENED LIVES.

THE AIDS EPIDEMIC IS IMPOSING SEVERE SOCIAL AND ECONOMIC BURDENS IN MANY COMMUNITIES. IT WILL TAKE THE COMBINED RESOURCES OF ALL LEVELS OF GOVERNMENT AND THE PRIVATE SECTOR TO MEET THE COST CHALLENGES PRESENTED BY THIS DISEASE...CHALLENGES SUCH AS...

THE INCREASING COSTS OF IN-PATIENT CARE FOR AN EXPANDING PATIENT POPULATION...

THE NATURE AND COST OF EDUCATIONAL EFFORTS TO REDUCE HIGH-RISK BEHAVIOR...

THE COST OF MAINTAINING AN EFFECTIVE RESEARCH EFFORT FOR IMPROVED PREVENTION, TREATMENT AND CURE...

AND THE COSTS OF THE SOCIAL SUPPORT TO PROVIDE THE JUVENILE AIDS VICTIMS AND THEIR FAMILIES WITH THE MOST NORMAL AND DIGNIFIED EXISTENCE POSSIBLE.

SO FAR I HAVE BEEN FOCUSING ON THE ISSUES RELATED TO CHILDREN WITH AIDS AND THE HEART-FELT CONCERN WE HAVE FOR THESE CHILDREN.

ALTHOUGH WE HAVE LEARNED A GREAT DEAL ABOUT AIDS IN A SHORT TIME, OUR KNOWLEDGE IS NEVERTHELESS EXTREMELY LIMITED. PRUDENT JUDGMENT MUST CONTINUE TO GUIDE US.

UNDER ALL CIRCUMSTANCES WE MUST REMAIN COMMITTED TO PROVIDING HUMANE AND DIGNIFIED CARE. AND WE MUST BE WILLING TO BEAR THE RESPONSIBILITIES AND THE COSTS DURING THE SHORT, TROUBLED LIVES OF THESE CHILDREN.

LET US LOOK AT THIS PROFOUND TRAGEDY FROM YET ANOTHER PERSPECTIVE.

WHILE AIDS CAN AFFLICT CHILDREN AT ALL LEVELS OF SOCIETY, IT IS OCCURRING DISPROPORTIONATELY AMONG THOSE FAMILIES WITH THE LEAST CAPACITY AND RESOURCES TO COPE.

OVER HALF OF ALL BABIES BORN WITH AIDS ARE BLACK WITH ONE OR BOTH PARENTS CARRYING AIDS. ANOTHER 25 PERCENT OF ALL BABIES BORN WITH AIDS ARE HISPANIC.

WHAT WE'RE SEEING IN REFERENCE TO AIDS, THEREFORE, IS MORE TRAGIC EVIDENCE OF THE DEMOGRAPHY OF HIGH-RISK PREGNANCIES AND BIRTH.

IN OUR SOCIETY, SUCH HIGH-RISK PREGNANCIES ARE MOST LIKELY TO OCCUR AMONG BLACK WOMEN UNDER THE AGE OF 19...WHO ARE POOR...WHO ARE NOT READY FOR THE WORLD OF WORK...WHO MAY NOT EVEN HAVE A HIGH SCHOOL DIPLOMA...AND WHO DO NOT HAVE READY ACCESS -- FOR WHATEVER REASONS -- TO GOOD PRENATAL AND PERINATAL HEALTH CARE.

THIS IS THE POPULATION OF YOUNG WOMEN WHO PRODUCE A DISPROPORTIONATELY LARGE NUMBER OF LOW-BIRTH-WEIGHT BABIES...BABIES BORN WITH A DRUG HABIT...AND BABIES WITH FETAL ALCOHOL SYNDROME.

LIFE FOR THESE BABIES IS A STRUGGLE FROM "DAY ONE"...AND MANY OF THEM NEVER MAKE IT TO "DAY TWO."

THIS IS ADDITIONAL CATASTROPHIC NEWS FOR THE BLACK COMMUNITY, WHICH ALREADY IS UNDER GREAT ECONOMIC AND SOCIAL STRESS. AND IT'S ALSO MORE EVIDENCE OF THE APPARENT INABILITY OF AMERICAN SOCIETY IN GENERAL TO MAKE MUCH HEADWAY IN HELPING YOUNG BLACK WOMEN CONTROL THEIR OWN SEXUALITY AND THEIR OWN DESTINIES.

THE NUMBERS ARE NOT LARGE. BUT IF WE LOOK ONLY AT THE NUMBERS, WE'LL MISS THE TRUE MEANING OF WHAT'S GOING ON. AND I'M SPEAKING OF THE PROFOUND DYSFUNCTION OF FAMILY LIFE THAT IS TAKING PLACE AMONG A SIGNIFICANT NUMBER OF OUR FELLOW AMERICANS.

FROM THIS PERSPECTIVE, PEDIATRIC AIDS IS NOT -- BY ITSELF -- THE ISSUE. RATHER, IT IS MORE -- AND DEADLIER -- EVIDENCE OF LARGER ISSUES FACING SOCIETY AS A WHOLE...

ISSUES OF ACCESS TO CARE...
OF EQUALITY OF OPPORTUNITY...
OF RACIAL, ETHNIC, AND CULTURAL SEPARATION AND ISOLATION...
AND OF THE CLASH BETWEEN PERSONAL AND COMMUNITY VALUES.

CHILDREN WITH AIDS ARE INNOCENT VICTIMS OF A DISEASE, YES. BUT THEY ARE ALSO AN INDEX OF OTHER TROUBLES WITHIN OUR SOCIETY, TROUBLES WHICH UNFORTUNATELY CAN LIMIT OUR ABILITY TO IMPROVE THE MATERNAL AND CHILD HEALTH CARE DELIVERED IN THIS COUNTRY.

ASSEMBLED HERE TODAY IS A GROUP OF NATIONAL EXPERTS FROM THE SCIENCES, THE PROFESSIONAL COMMUNITY, GOVERNMENT, AND THE COMMUNITY AT-LARGE TO ADDRESS A PUBLIC HEALTH PROBLEM OF GREAT IMPORTANCE TO OUR NATION AND TO ALL PEOPLE OF THE WORLD.

PRESIDENT REAGAN HAS CALLED AIDS, "PUBLIC HEALTH ENEMY NO. 1."

AS THE SURGEON GENERAL OF THE UNITED STATES PUBLIC HEALTH SERVICE AND THE PRINCIPLE PUBLIC HEALTH AUTHORITY FOR THE UNITED STATES, I AM ASKING YOU TO JOIN WITH THE PRESIDENT TO BRING TO BEAR ALL OUR SKILL, EXPERTISE, AND RESOLVE, OVER THE NEXT SEVERAL DAYS, TO FOCUS ATTENTION ON THE BROAD RANGE OF HEALTH CONCERNS RELATED TO CHILDREN SUFFERING FROM AIDS.

YOUR TASK IS TO DEVELOP RECOMMENDATIONS FOR A NATIONAL STRATEGY FOR REDUCING THE TREMENDOUS BURDEN OF THIS DEVASTATING CONDITION, ESPECIALLY AMONG OUR CHILDREN.

I ASK THAT YOUR RECOMMENDATIONS GIVE SPECIFIC ATTENTION TO THESE ISSUES:

- THE DEVELOPMENT OF AN EXPANDED KNOWLEDGE BASE...

- THE IDENTIFICATION OF THE HEALTH RESOURCES AND SERVICES NECESSARY TO ADDRESS THE AIDS PROBLEM, AND...

- A SENSE OF THE SOCIAL STRATEGIES NECESSARY TO ASSURE THAT OUR KNOWLEDGE AND RESOURCES ARE BEST APPLIED IN THE SERVICE OF BETTER HEALTH FOR OUR CHILDREN.

THE RECOMMENDATIONS THAT WILL EMERGE FROM THIS SURGEON GENERAL'S WORKSHOP CAN CHANGE ATTITUDES IF THEY REPRESENT WORK DONE WITH CALMNESS, CONFIDENCE, AND CLARITY. LET US NOT, BY INADVERTENCE, AGGRAVATE WHAT IS ALREADY A VERY, VERY DIFFICULT SITUATION REGARDING THESE CHILDREN. RATHER, LET US PROVIDE THE MODEL OUR COMMUNITIES COULD FOLLOW, IN BRINGING TOGETHER GOVERNMENT OFFICIALS, HEALTH PROFESSIONALS, EDUCATORS, RELIGIOUS LEADERS, AND PARENTS FOR AN INTERDISCIPLINARY, MORAL, AND JUST APPROACH TO THE BATTLE AGAINST AIDS.

AND NOW, LET ME TAKE JUST A MOMENT FOR A FEW ANNOUNCEMENTS.

WE ONCE THOUGHT OF HAVING ONE WORKSHOP JUST FOR CLERGYMEN, BUT THEN WE DECIDED IT WOULD BE BETTER TO ASSIGN A CLERGYMAN TO EACH WORKSHOP.

ALSO, I AM VERY PLEASED AT THE COOPERATIVE EFFORTS INVOLVING THE DEPARTMENT OF DEFENSE AND THE UNITED STATES PUBLIC HEALTH SERVICE REGARIDNG PEDIATRIC AIDS.

DR. VIRGINIA ANDERSON IS WITH US TODAY. SHE IS DETAILED FROM THE PUBLIC HEALTH SERVICE TO THE ARMED FORCES INSTITUTE FOR PATHOLOGY, WHERE SHE HAS JUST ESTABLISHED AN INTERNATIONAL NETWORK ON PEDIATRIC AIDS. DR. ANDERSON WILL BE RECEIVING SURGICAL AND AUTOPSY MATERIAL FROM ALL OVER THE WORLD FOR COMPUTER CATALOGING AND ANALYSIS. THROUGH THIS NETWORK WE WILL ALSO BE COORDINATING CLINICAL STUDIES ON PEDIATRIC AIDS AND PEDIATRIC IMMUNOLOGY.

YOU MAY WANT TO SEEK HER OUT AND SEE HOW YOU MIGHT HELP IN THIS EFFORT.

I WISH YOU WELL AND LOOK FORWARD TO WEDNESDAY AND THE RESULTS OF YOUR DELIBERATIONS AT THIS WORKSHOP.

THANK YOU.

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