ORIGINAL

3 | PED-AIDS

ADDRESS

BY

C. EVERETT KOOP, M.D., Sc.D.

SURGEON GENERAL

OF THE

U.S. PUBLIC HEALTH SERVICE

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

PRESENTED AT THE FESTSCHRIFT TO HONOR DR. PHILIP L. CALCAGNO

WASHINGTON, D.C.

JUNE 10, 1988

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

IT'S A GREAT PLEASURE FOR ME TO BE HERE, PARTICIPATING IN THIS FESTSCHRIFT FOR DR. CALCAGNO. I WON'T REPEAT ALL THE GOOD THINGS I KNOW WERE SAID ABOUT HIM THIS MORNING, BUT I CERTAINLY WANT TO SECOND THEM.

ANYONE WHO HAS BEEN A DEPARTMENT CHAIRMAN FOR 25 YEARS -- AND CAN STILL FILL A ROOM WITH CLOSE AND ADORING FRIENDS -- HAS GOT TO BE A REMARKABLE PERSON.

AND OF COURSE HE IS. SO I AM DELIGHTED TO COME BY AND JOIN SO MANY OTHER COLLEAGUES IN HONORING A FIRST-RATE PEDIATRICIAN, NEPHROLOGIST, ADMINISTRATOR ... AND HUMAN BEING.

MY ASSIGNMENT AT THIS FESTSCHRIFT IS NOT GOING TO BE VERY FESTIVE, I'M AFRAID. DR. MAGRAB AND DR. COLON ASKED ME TO PROVIDE AN UPDATE OF SORTS ON THE TOPIC OF PEDIATRIC AIDS. IT'S A GRIM BUSINESS ... AND IT'S GETTING WORSE.

SINCE THE EARLY DAYS OF THE EPIDEMIC RIGHT UP TO THIS PAST MONDAY, WE'VE HAD A TOTAL OF 1,013 CASES OF AIDS AMONG CHILDREN UNDER THE AGE OF 13. THAT'S LESS THAN 2 PERCENT OF THE OVERALL TOTAL.

IN A SOCIETY FASCINATED BY HUGE NUMBERS, 2 PERCENT ISN'T VERY MUCH. BUT EACH CHILD WITH AIDS CONFRONTS OUR SOCIETY WITH A SPECIAL MEDICAL AND SOCIAL CHALLENGE, ONE -- I HASTEN TO ADD -- THAT WE ARE STILL GENERALLY UNPREPARED TO MEET.

OF THAT TOTAL NUMBER OF CHILDREN THUS FAR REPORTED AS HAVING AIDS -- 1,013 -- 60 PERCENT HAVE ALREADY DIED.

THAT MORTALITY RATE ITSELF, HOWEVER, IS SUBJECT TO CHANGE AND, I'M SORRY TO SAY, NOT FOR THE BETTER.

IF THE MORTALITY AMONG CHILDREN WITH AIDS PARALLELS THAT OF INFECTED ADULTS, THEN IT WILL RISE TO BETTER THAN 90 PERCENT, WHICH IS THE MORTALITY RATE FOR ADULTS WHO WERE DIAGNOSED AND REPORTED AS HAVING AIDS AS EARLY AS 1981 AND 1982.

WE ESTIMATE THAT BY 1991 THE CUMULATIVE TOTAL OF CHILDREN WITH AIDS SYMPTOMOLOGY WILL RISE TO 3,000. HOWEVER, THE NUMBER OF HIV-POSITIVE CHILDREN MAY BE AS HIGH AS 10,000 BY THEN.

OF THE CURRENT TOTAL, THE LARGEST NUMBER BY FAR -- 779 CHILDREN -- ARE THOSE WHOSE MOTHERS HAVE OR HAVE HAD AIDS OR ARE AT RISK OF HAVING AIDS. THESE CHILDREN ACQUIRED THE VIRUS EITHER IN UTERO OR DURING LABOR OR DELIVERY.

WE CAN'T SAY THAT AN INFECTED MOTHER WILL ALWAYS TRANSMIT THE VIRUS TO HER CHILD. HOWEVER, THE ODDS ARE RUNNING AS HIGH AS 50-50.

BUT THERE ARE STILL A GREAT MANY UNKNOWNS IN THIS AREA. FOR EXAMPLE, WE DON'T REALLY KNOW THE ROLE OF THE PLACENTA AS A VECTOR OR AS AN INHIBITOR.

WE'RE ALSO NOT CLEAR AS TO THE NUMBERS OF CASES IN WHICH TRANSMISSION FROM MOTHER TO CHILD WAS TRANSPLACENTAL, AS OPPOSED TO PERINATAL OR EVEN POSTNATAL TRANSMISSION.

IN ADDITION, WE'RE STARTING OUR RESEARCH INTO PEDIATRIC AIDS FROM A DATA BASE THAT REFLECTS THE ACTIVITY OF THE H.I.V. IN ADULTS. BUT WE'RE FINDING OUT THAT, IN AIDS AS IN SO MANY OTHER AREAS, CHILDREN ARE NOT "LITTLE ADULTS."

THERE ARE A VARIETY OF MEDICAL DIFFERENCES IN THE WAY THE DISEASE IS MANIFESTED IN CHILDREN. FOR EXAMPLE, LYMPHOCYTIC INTERSTITIAL PNEUMONIA -- OR L.I.P. -- IS A CHARACTERISTIC OF CHILDREN WITH H.I.V., ALTHOUGH IT'S RARELY SEEN IN ADULTS.

ON THE OTHER HAND, KAPOSI'S SARCOMA IS COMMON AMONG HOMOSEXUAL MEN WITH AIDS, BUT IS AN INFREQUENT MANIFESTATION AMONG CHILDREN.

ALSO, RECURRENT BACTERIAL INFECTIONS ARE MORE PROMINENT AMONG CHILDREN THAN AMONG ADULTS WITH AIDS. MANY CHILDREN ALSO EXHIBIT A CHARACTERISTIC ENCEPHALOPATHY LEADING TO DEVELOPMENTAL DELAYS OR EVEN THE LOSS OF DEVELOPMENTAL MILESTONES.

WE ARE NOTING THESE AND OTHER DIFFERENCES, BUT WE AS YET HAVE NO EXPLANATION FOR THEM. FOR THESE AND OTHER REASONS, YOU MIGHT SAY WE ARE JUST AT THE "STARTING-GATE," WHEN IT COMES TO RESEARCH FOR THE DIAGNOSIS AND TREATMENT OF CHILDREN WITH AIDS.

BUT SO FAR I'VE JUST TOUCHED UPON SOME AREAS OF BIOMEDICAL INTEREST. HOWEVER, THAT'S A VERY NARROW FRAME OF REFERENCE BECAUSE CHILDREN WITH AIDS PRESENT A RANGE OF SPECIAL PROBLEMS NOT ONLY TO THE BIOMEDICAL COMMUNITY BUT TO THE COMMUNITY AT LARGE.

FOR EXAMPLE ...

* THEY ARE TOTALLY DEPENDENT ON OTHERS FOR HELP.

* THEY TEND TO BE EITHER FROM FAMILIES WHICH ARE THEMSELVES UNDER STRESS OF POVERTY OR DISEASE OR THEY ARE THE CHILDREN OF SINGLE WOMEN WHO CANNOT PROVIDE THEIR CHILDREN WITH ANY HOME OR FAMILY SUPPORT.

* CHILDREN WITH AIDS ARE UNFAIRLY BURDENED BY STIGMA. HENCE, ALTHOUGH THEY MAY BE ASYMPTOMATIC FOR MANY YEARS, THE STIGMA OF SEROPOSITIVITY CLOUDS THEIR SOCIAL DEVELOPMENT AT EVERY STEP OF THE WAY.

LAST YEAR, I CONVENED A "SURGEON GENERAL'S WORKSHOP ON PEDIATRIC AIDS" IN ORDER TO ARRIVE AT SOME BASELINE AGREEMENTS AMONG MEDICAL AND SOCIAL SERVICE PROFESSIONALS AS TO <u>WHERE WE WERE</u> IN OUR UNDERSTANDING OF THE PROBLEM AND <u>WHERE WE OUGHT TO BE</u> IN THE YEARS AHEAD.

IT WAS A VERY FRUITFUL MEETING AND LED TO A NUMBER OF USEFUL DEVELOPMENTS. THE MOST SIGNIFICANT WAS THE ESTABLISHMENT BY THE SECRETARY OF HEALTH AND HUMAN SERVICES, DR. OTIS R. BOWEN, OF A SPECIAL DEPARTMENT-WIDE INITIATIVE ON PEDIATRIC H.I.V. DISEASE.

THE DIRECTOR OF THE WORK-GROUP UNDER THIS INITIATIVE IS DR. ANTONIA NOVELLO. AS MOST OF YOU KNOW, DR. NOVELLO IS ALSO THE DEPUTY DIRECTOR OF THE NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT. MY ROLE IS AS THE SENIOR SCIENTIFIC ADVISOR TO THE WORK-GROUP.

SO FAR, WE'VE LAID OUT A RESEARCH AGENDA IN THE AREA OF PEDIATRIC AIDS. THIS IS, OF COURSE, WITHIN THE CONTEXT OF THE OVERALL RESEARCH EFFORT IN AIDS.

WE HAVEN'T YET ASSIGNED PRIORITIES IN PEDIATRIC AIDS RESEARCH, BUT WE MAY BE ABLE TO DO THAT IN OUR FIRST REPORT TO THE SECRETARY, WHICH IS DUE IN AUGUST.

THIS RESEARCH AGENDA INCLUDES NOT ONLY THE EXPECTED ITEMS, SUCH AS CO-FACTORS, VIROLOGY, AND THERAPEUTICS, BUT IT ALSO INCLUDES RESEARCH THAT MIGHT HELP US MORE EFFECTIVELY INTEGRATE BIOMEDICAL AND BIOBEHAVIORAL RESEARCH WITH A VARIETY OF RESEARCH AND DEMONSTRATION EFFORTS IN FAMILY SERVICES, LEGAL AID, HUMAN SEXUALITY, ETHICS, AND FUNDING.

THE FUNDING QUESTION IS IMPORTANT, BECAUSE -- AS NEAR AS WE CAN FIGURE IT TODAY -- ONLY ABOUT 4 PERCENT OF THE OVERALL H.H.S. BUDGET FOR AIDS IS DEVOTED TO RESEARCH PECULIAR TO PEDIATRIC AIDS. YET, THE COST OF DIAGNOSIS, TREATMENT, AND PLACEMENT OF INFECTED INFANTS AND CHILDREN IS RISING SIGNIFICANTLY.

SHOULD THAT 4-PERCENT FIGURE BE HIGHER? I THINK EVERYONE WOULD AGREE THAT IT SHOULD. HOWEVER, THE AVAILABILITY OF MORE MONEY WILL NOT -- BY ITSELF -- ANSWER THOSE QUESTIONS OF ETHICS, LAW, AND MEDICINE THAT NOW CIRCUMSCRIBE PEDIATRIC RESEARCH <u>IN GENERAL</u>, NOT JUST RELATIVE TO THIS EPIDEMIC.

FOR EXAMPLE, WE WOULD NOT PERMIT EXPEDITIOUS DRUG TESTING IN CHILDREN UNDER THE KIND OF "HUMANE I.N.D." MECHANISM THAT HAS BEEN USED FOR A.Z.T. AND ADULT AIDS PATIENTS. AND THERE ARE GOOD ETHICAL REASONS FOR LIMITING CLINICAL DRUG TRIALS IN INFANTS AND CHILDREN.

I DON'T KNOW HOW TO RESOLVE THAT PARTICULAR PROBLEM, BUT I KNOW WE'LL HAVE TO CONFRONT IT THE MOMENT A RESEARCHER COMES UP WITH A DRUG THAT JUST MIGHT ALLEVIATE -- OR POSSIBLY REVERSE -- AN AIDS-RELATED CONDITION AMONG CHILDREN WITH AIDS.

WE ALSO HAVE TO FACE THE FACT THAT NEARLY ALL THE CHILDREN BORN WITH AIDS THUS FAR ARE IN THOSE MAJOR METROPOLITAN AREAS WITH HIGH CONCENTRATIONS OF BLACK AND HISPANIC MINORITIES: NEW YORK, MIAMI, LOS ANGELES, WASHINGTON, D.C., AND NEWARK, NEW JERSEY, FOR EXAMPLE.

THESE ARE THE SAME AREAS IN WHICH MEDICAL AND PUBLIC HEALTH PERSONNEL HAVE BEEN FIGHTING ENORMOUS ODDS IN THEIR DAY-TO-DAY EFFORT TO DELIVER EFFECTIVE PRIMARY HEALTH CARE ... WELL-BABY CARE, HYPERTENSION SCREENING, MATERNAL AND CHILD NUTRITION, TREATMENT FOR SUBSTANCE ABUSE, AND SO ON.

BUT THE TASK ASSOCIATED WITH AIDS IS A HUNDRED TIMES MORE COMPLEX, NOT ONLY FOR HEALTH PROFESSIONALS BUT ALSO FOR THE COMMUNITY RESIDENTS THEMSELVES.

SUSPICION ... DENIAL ... GUILT ... FRUSTRATION ... ANGER ... ALL THESE FEELINGS WHICH ALREADY CLOUD THE PUBLIC HEALTH PICTURE IN THESE INNER CITY ENVIRONMENTS ARE EVEN MORE EVIDENT WHEN THE SUBJECT IS AIDS.

THESE ARE THE KINDS OF ISSUES AND QUESTIONS THAT ARE <u>ALSO</u> ON OUR PEDIATRIC AIDS AGENDA. AND <u>NONE</u> OF THEM IS EASY.

I CAME TODAY TO PROVIDE YOU WITH A BRIEF UPDATE ON WHERE WE STAND IN THE MATTER OF PEDIATRIC AIDS.

I WISH I COULD HAVE COME PREPARED TO RECITE A NUMBER OF MAJOR ADVANCES ... RESEARCH BREAKTHROUGHS ... OR OTHER EVIDENCE OF DRAMATIC PROGRESS. BUT WE JUST AREN'T THERE YET.

HOWEVER, I BELIEVE THE BREAKTHROUGHS <u>WILL</u> COME, AS A RESULT OF NEW INTEREST AND ATTENTION BY THE PEDIATRIC PROFESSION -- NOT ONLY BY ITS LEADERSHIP, SUCH AS THE STAFF HERE AT THE GEORGETOWN UNIVERSITY CHILDREN'S MEDICAL CENTER, BUT ALSO BY THE YOUNG MEN AND WOMEN JUST ENTERING THE FIELD ... YOUR STUDENTS.

I HAVE SAID THAT OUR BEST HOPE IN THE BATTLE AGAINST AIDS IS EDUCATION ... EDUCATION ... AND MORE EDUCATION, SO THAT PEOPLE WILL AVOID THOSE BEHAVIORS THAT LEAD TO THE TRANSMISSION OF THE AIDS VIRUS.

I STILL BELIEVE THAT'S THE CASE.

BUT IN THE MEANTIME, THE TOLL OF AIDS AMONG CHILDREN CONTINUES TO RISE.

YESTERDAY, THERE WERE A FEW HUNDRED ... TODAY, OVER A THOUSAND ... TOMORROW, POSSIBLY 10 OR EVEN 20 THOUSAND CHILDREN MAY BE INFECTED WITH H.I.V.

THEY WILL NEED OUR HELP. AND WE MUST BE READY TO PROVIDE ALL THE HELP WE CAN.

THANK YOU.

# # # # #