REPORT OF THE SURGEON GENERAL'S WORKSHOP ON ORGAN PROCUREMENT

Βy

C. EVERETT KOOP, M.D. SURGEON GENERAL

AND

DEPUTY ASSISTANT SECRETARY FOR HEALTH

LIVER TRANSPLANTATION -NIH CONSENSUS DEVELOPMENT CONFERENCE NATIONAL INSTITUTES OF HEALTH BETHESDA, MARYLAND

JUNE 21, 1983

Almost from the very moment I arrived in Washington more than two years ago I have been involved in some way in the transplantation of organs and early meetings with some of you out there actually had something to do with the organization of this particular consensus conference. As time went on, increased success with transplantation made it absolutely obvious that we were going to need more organs than were available. We witnessed the pathetic appeals of parents to the media and the public looking for donated livers for children who would otherwise die without them. The President became involved in several of these, as you know, and asked me to help. Then, one could not but look back on the history of renal transplantation with some concern. Kidneys have always been in short supply since the beginning of the transplant era and people, even today, must often remain on dialysis when they could be independent if a kidney were available for transplantation. Unfortunately, there is no dialysis procedure available when we are considering liver transplantations.

So with these increasing pressures, and at the President's request, I convened a group of experts two weeks ago to discuss methods for increasing the supply of solid organs - kidneys, hearts, (heart and lung preparation) and livers. And we hope that any lessons learned in that process might eventually help in the supply of other body parts as well.

WE HAD REPRESENTATIVES OF IMPORTANT GROUPS WITH US. THESE INCLUDED THE SOUTHEASTERN ORGAN PROCUREMENT FOUNDATION WITH ITS ASSOCIATED ORGANIZATION, THE UNITED NETWORK FOR ORGAN SHARING. THIS LATTER ORGANIZATION KNOWN BY THE ACRONYN, UNOS, PLAYS A ROLE IN SHARING ORGANS AMONG TRANSPLANT CENTERS. ALSO FRESENT WERE REPRESENTATIVES OF THE NORTH AMERICAN TRANSPLANT COORDINATOR'S ASSOCIATION AND THESE ARE PEOPLE WHO SEEK OUT POSSIBLE DONORS AND ASK RELATIVES FOR PERMISSION TO REMOVE ORGANS. OTHER REPRESENTATIVES INCLUDED THOSE FROM THE AMERICAN ASSOCIATION OF CRITICAL CARE NURSES, THE AMERICAN COLLEGE OF SURGEONS, THE AMERICAN MEDICAL ASSOCIATION, THE AMERICAN LIVER FOUNDATION, THE AMERICAN SOCIETY FOR TRANSPLANT SURGEONS, THE CHILDREN'S LIVER FOUNDATION, THE LIVING BANK AND STILL OTHERS.

IN MY OPENING REMARKS TO THE GROUP THAT MET DOWN IN VIRGINIA I SAID THAT "I BELIEVED THAT ONE OF THE PRIORITY ACTIVITIES OF THE GOVERNMENT IS TO BRING TOGETHER AND ENCOURAGE THOSE GROUPS AND INDIVIDUALS WHO HAVE THE CREDENTIALS AS LEADERS. AS PRESIDENT REAGAN HAS FREQUENTLY SAID, IT IS NOT NECESSARY FOR THE GOVERNMENT TO BE RESPONSIBLE FOR EVERY IMPORTANT PROBLEM OR TO TAKE CREDIT FOR EVERY IMPORTANT ACHIEVEMENT."

"I ASKED THE GROUP WHETHER THE VOLUNTARY SYSTEM WAS PERFECT? OF COURSE, MY ANSWER WAS "NO, IT IS NOT." I ALSO ASKED, WOULD SWITCHING TO A GOVERNMENT-SPONSORED SYSTEM MAKE IT PERFECT? THE ANSWER TO THAT WAS, "PROBABLY NOT."

WITH SUCH AN EMOTIONALLY CHARGED ISSUE I THINK MANY CITIZENS EXPECT THE GOVERMENT TO PLAY A STRONGER ROLE - PERHAPS EVEN THE PRINCIPAL ROLE. CERTAINLY THERE ARE THINGS THE GOVERNMENT SHOULD DO BUT TAKING OVER THE LEADERSHIP POSITION, IN A SITUATION SUCH AS THIS, I DON'T THINK IS ONE OF THEM. THAT WOULD BE BAD POLICY AND, HENCE, BAD GOVERNMENT.

-2-

I CLOSED MY REMARKS ON THE OPENING DAY WITH A QUOTATION FROM THOREAU - "IT IS CHARACTERISTIC OF WISDOM NOT TO DO DESPERATE THINGS," AND SAID THIS COULD BE THE MOTTO OF OUR CONFERENCE SINCE THE TEMPTATION TO DO DESPERATE THINGS IS SO VERY GREAT WHEN LIVES HANG IN THE BALANCE AND CAN BE SAVED ONLY BY THE PARTS OF ANOTHER ALBEIT RECENT LIFE. BUT WE MUST TAKE UP THOREAU'S CHALLENGE AND PROCEED WITH WISDOM AND NOT DESPERATION. I BELIEVE THAT THE WORKSHOP DID JUST THAT.

WE ACCEPTED, AS A STARTING POINT, THE PRESENT VOLUNTARY SYSTEM OF ORGAN DONATION AS A FRAMEWORK AND AVOIDED ANY DISCUSSION OF THE SO CALLED "PRESUMED CONSENT" LAWS. WITH PRESUMED CONSENT, IT IS ASSUMED THAT UNLESS YOU SAID NO IN ADVANCE THAT WHEN YOU DIE THAT YOUR ORGAN WOULD BE AVAILABLE FOR SOMEONE ELSE. TO CHANGE FROM OUR PRESENT SYSTEM IN THIS COUNTRY, WHICH IS TOTALLY VOLUNTARY, TO THAT PRESUMED CONSENT SYSTEM WOULD REQUIRE A VERY NECESSARY AND LABORIOUS CHANGE IN THE RATIONALE UNDERLYING THE UNIFORM ANATOMICAL GIFT ACT THAT STATE LEGISLATURES PASSED IN THE EARLY 1970S. ALSO, AT THE CONFERENCE WE AVOIDED ANY DISCUSSSION OF PROCUREMENT OF ORGANS FROM LIVING DONORS.

WE HAD LEARNED A LOT AS WE PREPARED FOR THIS CONFERENCE. AMONG THINGS THAT I THINK WE WERE UNCERTAIN OF BEFORE IS THE FACT THAT AMERICANS DO FAVOR TRANSPLANTATION. PERHAPS THEY ARE NOT AS EXCITED ABOUT IT AS THEY WERE IN 1958 WHEN THE FIRST TRANSPLANT TOOK PLACE, YET FAVORABLE ATTITUDES TOWARD TRANSPLANTATION STILL REMAIN HIGH. YOU MAY KNOW THAT AS RECENTLY AS JANUARY OF THIS YEAR THE GALLUP ORGANIZATION DID A SURVEY FOR THE NATIONAL KIDNEY FOUNDATION AND WHEN THE QUESTION WAS ASKED WHETHER RESPONDENTS WOULD DONATE

-3-

KIDNEYS OF A LOVED ONE AFTER THAT PERSON'S DEATH ALMOST THREE FOURTHS OF THOSE ASKED RESPONDED THAT THEY WOULD BE VERY WILLING TO DO SO.

WE KNOW THAT MORE ORGANS ARE AVAILABLE THAN ARE BEING HARVESTED AND THAT IS VERY APPARENT FROM A STUDY DONE BY THE PUBLIC HEALTH SERVICE'S CENTERS FOR DISEASE CONTROL AND FROM A REVIEW CONDUCTED BY DR. ROGER EVANS WHO IS WITH US HERE FROM THE BATTELLE HUMAN AFFAIRS RESEARCH CENTERS.

But how do you translate the availability of cadaver organs and the Willingness of relatives to give permission into the actual donation of organs? Many people have assumed, I believe, and probably incorrectly that if you signed a Uniform Donor Card that somehow or other something very magical would take place. Granted, Uniform Donor Cards do serve a very important educational purpose and they may well cause a relative to give permission to remove organs from someone who has died. Yet, it is fact that only a very small percentage of the people who do become organ donors ever carry a donor card. Transplantation teams rightfully refuse to accept the donor cards as legal authority for removing organs.

FURTHERMORE, THE UNIFORM DONOR CARD DOES NOTHING ON ITS OWN. AT A PERSON'S DEATH, FORTHRIGHT ACTION IS NECESSARY BY SOMEONE -- A RELATIVE PERHAPS MIGHT START THE PROCESS OR A MEMBER OF THE MEDICAL TEAM OR A TRANSPLANT COORDINATOR -- IF ORGAN DONATION IS TO BECOME A REALITY. WE ARE LEARNING, THEREFORE, THAT TO FOCUS ONLY ON PERSUADING PEOPLE TO SIGN UNIFORM DONOR CARDS IS TO NEGLECT SOME VERY OTHER IMPORTANT FEATURES IN THE WHOLE PROCESS OR ORGAN PROCUREMENT.

-4-

AT OUT WORKSHOP, WE DIVIDED THE PARTICIPANTS INTO EIGHT GROUPS AND WE ASKED EACH GROUP ONE OR MORE QUESTIONS. THEY WERE QUESTIONS SUCH AS THESE: HOW CAN RELATIVES BE ENCOURAGED TO THINK OF THE USEFULNESS OF ORGAN DONATION AT THE TIME WHEN THE PATIENT IS EITHER ON A RESPIRATOR AND IS DEAD OR NEAR DEATH? OR, HOW CAN MEDICAL PERSONNEL BE ENCOURAGED AT THAT PARTICULAR TIME? HOW CAN WE AVOID WASTAGE OF THE ORGANS THAT ARE AVAILABLE. HOW CAN WE OVERCOME ANY BARRIERS THAT MAY EXIST IN PROCURING MULTIPLE ORGANS FROM ONE BODY?

TIME DOES NOT PERMIT ME TO DO ANYTHING BUT JUST GIVE YOU A SAMPLING OF SOME OF THE INTERESTING CONCLUSIONS. THE GROUP OF EXPERTS THAT DISCUSSED THE PROCUREMENT OF MULTIPLE ORGANS FROM ONE DONOR CONCLUDED THAT TECHNICAL AND SURGICAL ASPECTS PRESENTED HARDLY ANY BARRIER AT ALL. ON THE OTHER HAND, THEY CONCLUDED THAT AWARENESS AND COMMUNICATION ON THE PART OF PROFESSIONAL PEOPLE IS A SIGNIFICANT PROBLEM. FOR EXAMPLE, THOSE WHO MIGHT SEE THE PROCUREMENT OF ONE TYPE OF ORGAN <u>ONLY</u> AS BEING EXCLUSIVELY IMPORTANT WOULD BE WELL BE ADVISED TO LIFT THEIR EYES TO VIEW THE ENTIRE MODERN SCENE.

THE PUBLIC'S AWARENESS OF THE USEFULNESS OF MULTIPLE ORGAN PROCUREMENT ALSO NEEDS TO BE HEIGHTENED AS DOES THE WILLINGNESS OF RELATIVES TO PERMIT THE DONATION OF, SAY, KIDNEYS BUT HAVE RELUCTANCE TO PERMIT THE DONATION OF A HEART. THIS HAS TO BE EXPLORED. THE EXPERTS STATED THAT ANOTHER IMPORTANT PRIORITY WAS TO FIND WAYS TO IMPROVE THE MAINTENANCE OF A DONOR'S BODY IN THE EVENT OF MULTIPLE DONATIONS.

-5-

IT WAS ALL TO EVIDENT, TOO, THAT WE LACKED MANY IMPORTANT DATA. FOR EXAMPLE, WHEN WE ASKED ONE GROUP AT THE WORKSHOP TO EXPLORE THE BARRIERS TO FINDING ORGANS FOR SMALL CHILDREN ITS MEMBERS CAME BACK WITH WHAT THEY CALLED THE "NUMBER ONE PRIORITY." THERE IS A CRITICAL NEED TO COLLECT, COLLATE, ANALYZE AND INTERPRET EXISTING DATA WHICH WILL CLEARLY QUANTIFY AND CHARACTERIZE PEDIATRIC DONORS, THEIR FAMILIES AND PEDIATRIC RECIPIENTS. MEMBERS OF ANOTHER GROUP RECOGNIZED THAT SOME PHYSICIANS FAIL TO PARTICIPATE IN THE ENTIRE ORGAN PROCUREMENT PROCESS AND THEY CALLED FOR THE COLLECTION OF BASIC DATA THAT WOULD FOCUS ON THE ATTITUDES AND BELIEF SYSTEMS OF THESE NON-PARTICIPATING PHYSICIANS.

At the conclusion of the Workshop I responded, I made some suggestions of my own and I made certain promises. Although not quite two weeks have passed, let me tell you what has already taken place. Dr. Kenneth Sell, of the National Institute of Allergy and Infectious Diseases, has accepted the chairmanship of a group from several institutes here at the National Institutes of Health, as well as experts from the private sector to address the problem of the maintenance of the multi-organ donor and to provide necessary guidelines according to the best science of the day. Dr. Sell is already at work and I know that he will shepherd this task to prompt completion.

I MET LAST WEEK WITH THE PRESIDENT OF THE AMERICAN ACADEMY OF PEDIATRICS, DR. JIM STRAIN, FOR A DISCUSSION OF THE SEVERAL ISSUES SURROUNDING THE TRANSPLANTATION OF ORGANS INTO CHILDREN AND THE PROCUREMENT OF ORGANS FROM CHILDREN. THIS MONTH A COMMITTEE OF THE ACADEMY OF PEDIATRICS WILL MEET WITH

-6-

When we met at the Workshop the vigor with which the private groups conduct organ procurement was very evident to all concerned. If I had not already assumed that organ procurement would be ill served by the Government's trying to take control, I would have been convinced by the dedication of the people that met at the Workshop. Yet, I had to agree with the conclusions of experts of one of our groups — the one that discussed the follow-up to the Conference — and this is what they said: "Individuals and organizations should continue their specialized efforts but need now to identify common interests and unite in the pursuit of goals that are beyond the ability of any one person or group to accomplish."

IN RESPONSE TO THAT I WILL CONVENE A WORKING GROUP IN WASHINGTON WITHIN THREE MONTHS OF THE WORKSHOP TO ADDRESS THE FORMATION OF A FEDERATION OF THOSE ORGANIZATIONS AND OTHER GROUPS CONCERNED WITH THE SUBSTANCE OF THE SURGEON GENERAL'S WORKSHOP, AND I WOULD HOPE THAT BY DOING THAT WITHIN THREE MONTHS WE WOULD BE ABLE TO GUARANTEE THAT WITHIN SIX MONTHS THE FIRST MEETING OF SUCH A FEDERATION WOULD TAKE PLACE WITH AN APPROPRIATE AGENDA ON HAND.

LET ME CLOSE THESE REMARKS BY RETURNING TO THE THOUGHT I TRIED TO EXPRESS AT THE BEGINNING AND THAT IS THAT WITH EVERY IMPROVEMENT THAT YOU AND I WILL WITNESS IN SURGICAL TECHNIQUE, EVERY ADVANCE THAT COMES ALONG IN IMMUNOSUPPRESSION WILL INFLUENCE SOME OTHER ASPECT OF THE WHOLE TRANSPLANTATION SCENE. ONE ASPECT -- THE ONE THAT WE ADDRESSED TWO WEEKS AGO -- THE PROBLEM OF PROCURING ORGANS -- TRANSPLANTATION MUST TAKE ITS PLACE WITH OTHERS THAT SEEM TO BE DIFFICULT OF SOLUTION. I AM ABSOLUTELY CONVINCED THAT

-8-

The private sector will continue to apply their intelligence and their hard work to this task and all that I can do for you here today is to promise that you have my own commitment to this task and that I will do everything I can to make the moral subside of the Office of the Surgeon General available to that effort.

.