The Surgeon General's
Workshop on

INCREASING ORGAN DONATION

PROCEEDINGS

Washington, D.C.
July 8-10, 1991

U.S. DEPARTMENT OF
HEALTH & HUMAN SERVICES
Public Health Service

ACKNOWLEDGEMENTS

The Surgeon General's Workshop on Organ Donation was supported by the Division of Organ Transplantation, Bureau of Health Resources Development, Health Resources and Services Administration.

Veretta W. Blake was a much valued consultant to the Division of Organ Transplantation, bringing courage and inspiration to the many lives she touched. Her contribution to the planning and conduct of this workshop was invaluable. Ms. Blake died on January 5, 1992. She will remain an inspiration to her colleagues and friends and she will be dearly missed.

FOREWORD

The Surgeon General's Workshop on Increasing Organ Donation held in July 1991 was a response to the critical need to raise donation levels. The workshop brought together approximately 125 individuals from very diverse backgrounds including medicine, nursing, law, bioethics, hospital administration, public relations, and funeral homes. Other participants included transplant recipients, lawmakers, social workers, members of donor families, and representatives of national health associations. Minority groups were also represented.

After two days of careful thought and discussions, the participants submitted a list of recommendations on how to increase donation levels. Those recommendations are presented in this document. A companion publication contains the background papers written specifically for this workshop.

It is my sincere hope that these publications, representing the collective thoughts of some of the best minds in the transplant field, will motivate more people to promote organ donation and confirm the efforts of those already fighting for this important cause. Most important, I hope that the results of this workshop and the ensuing implementation of the recommendations will translate into a second chance at life for all who await donor organs.

Antonia C. Novello, M.D., M.P.H.
Surgeon General

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ABBREVIATIONS

AATB	American Association of Tissue Banks
ABTC	American Board of Transplant Coordinators
ACT	American Council on Transplantation
AHA	American Hospital Association
AOPO	Association for Organ Procurement Organizations
ASHI	American Society for Histocompatibility and Immunogenetics
ASTP	American Society for Transplant Physicians
ASTS	American Society for Transplant Surgeons
CDC	Center for Disease Control
DHHS	Department of Health and Human Services
DOT	Division of Organ Transplantation
EBAA	Eye Bank Association of America
ESRD	End Stage Renal Disease
HCFA	Health Care Financing Administration
HHS	Health and Human Services (Department of)
HIV	Human Immunodeficiency Virus
HRSA	Health Resources and Services Administration
IHS	Indian Health Service
MOTTEP	Minority Organ/Tissue Transplant Education Center

MHC	Major Histocompatibility Complex
NATCO	North American Transplant Coordinators Organization
NIH	National Institutes of Health
NKF	National Kidney Foundation
OPO	Organ Procurement Organization
OPTN	Organ Procurement and Transplantation Network
PHS	Public Health Service
RFC	Request for Contract
RFP	Request for Proposal
SEOPF	South-Eastern Organ Procurement Foundation
TRIO	Transplant Recipients International Organization
UNOS	United Network for Organ Sharing
USRDS	United States Renal Data System

CONTENTS

Page

Remarks and Presentations

Recommendations

Monday, July 8, 1991

OPENING REMARKS

Judith B. Braslow
Director
Division of Organ Transplantation
Bureau of Health Resources Development
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U.S. Department of Health and Human Services

Good afternoon. I'm Judy Braslow, Director of the Division of Organ Transplantation. We are delighted you are here. We've spent the last 15 months preparing for this Surgeon General's workshop. It's required a great deal of time, planning, and assistance from many people, from staff in the Division of Organ Transplantation, staff in the Office of the Surgeon General, and commitment from the HRSA Administrator, Dr. Robert Harmon. Dr. Harmon has been the HRSA Administrator since February 1990. Previous to coming here, he was the Director of the Missouri Health Department, and prior to that, he was the county health officer in Maricopa County. While at HRSA, he's spent a great deal of his time and energy improving relationships between State and county health departments and the Federal Government. He has been of enormous support to the Division of Organ Transplantation. Without his support we wouldn't be doing this workshop today, and so it is my pleasure to introduce to you Dr. Robert Harmon.

Robert Harmon, M.D., M.P.H.
Administrator
Health Resources and Services Administration
U.S. Department of Health and Human Services

Thank you, Judy, and welcome. I bring you greetings from the Health Resources and Services Administration. We are very honored to have this opportunity to be part of the Surgeon General's Workshop on Increasing Organ Donation.

HRSA was created in 1982, and is one of eight agencies that comprise the U.S. Public Health Service. We've been given the leadership responsibility in promoting access to health care services for medically underserved populations, and for special populations, such as the homeless, persons with HIV infection, and persons who need organ transplantation. HRSA is composed of four bureaus, all of which focus on developing community-based health resources which will improve access for those populations in need.

The Division of Organ Transplantation is located in our Bureau of Health Resources Development. It has worked long and hard to bring to the attention of the public and health care professionals the need for more organ and tissue donors. In conjunction with the Office of the Surgeon General, the Division has brought together leaders in the field to tackle the issue of increasing donation. HRSA is working closely with Secretary Sullivan, Assistant Secretary for Health Dr. James Mason, the Surgeon General, and the PHS agencies, in this important task.

I would like to introduce to you the Surgeon General. Dr. Antonia Novello is the fourteenth Surgeon General of the U.S. Public Health Service. She was sworn in on May 9, 1990. She entered the PHS in 1978 after practicing pediatrics and nephrology in the private sector. Prior to her appointment as the Surgeon General, her PHS career was spent at the National Institutes of Health, where she served in various capacities, eventually becoming the Deputy Director of the National Institute of Child Health and Human Development. In that position, she directed extramural programs and coordinated pediatric AIDS research. Also while at NIH, Dr. Novello was detailed to the Senate Committee on Labor and Human Resources, where, as a legislative fellow, she worked with Sen. Orrin Hatch and was directly involved in drafting the National Organ Transplant Act of 1984. I'm sure most of you are aware of the significant impact of this legislation. From the Transplant Act, we have the Organ Procurement and Transplantation Network and the Scientific Registry. These two programs provide the basis for most of the transplant activities in this country.

Dr. Novello is acutely aware of the need for more organ donors and has seen first hand the impact of renal disease in children. Among the major public health issues that are brought to her attention, she has singled out the need for more organ donors as a major priority. In Dr. Novello, the transplant community has a dedicated, outspoken advocate. I know she is committed to seeing that your recommendations receive maximum attention, both in the Public Health Service and by the general public. Please welcome the Surgeon General of the U.S. Public Health Service, Dr. Antonia Novello.

Antonia C. Novello, M.D., M.P.H.
Surgeon General of the U.S. Public Health Service
U.S. Department of Health and Human Services

Good afternoon, dear colleagues and friends. Welcome. Thank you for committing yourself to working on this important issue.

This is the second Surgeon General's Workshop on Organ Donation. The first was held in June 1983. There has been considerable change in these 8 years. We can acknowledge that and still know that we need to accelerate progress. There is no question in my mind of the urgent need to address organ donation.

Today we need to reach all Americans, but especially members of minority groups, and convince them of the value of organ donation. We need to allocate the donated organs in the most effective and efficient way, and with due respect for these gifts of life.

We need to get to the American public and convince them that organ donation saves lives, in some cases lives of their friends and families. We need to honor the needs of both: the donor and the recipient of these gifts of life.

Organ donation is a complex medical issue that cannot be considered in isolation from social issues. Organ donation must be considered with a sophisticated awareness of the racial, ethnic, religious, and educational diversity of this country.

Those of you present today represent a broad cross-section of professionals and individuals committed to increasing the supply of organs and tissues for transplantation in this country. I urge you to bring your insights and your cultural sensitivities into play, so that as we listen to one another we can come up with sound recommendations.

Whether you are a transplant recipient, a surgeon, a nephrologist, a nurse, an organ procurement specialist, a health policy analyst, a teacher, a student, or a lawyer, I urge you to bring and share your own personal knowledge and perceptions regarding organ donation. You know a great deal about other people of similar backgrounds. Bring all that awareness, all that knowledge, and all that sensitivity to the discussions, so that we can all benefit from it.

I cannot talk about the issue of organ donation as Surgeon General without being aware of my minority heritage and my professional life as a pediatric nephrologist. We may not agree on every point, and depending on our background, we might have to take practical realities into account. But there is no question that we all agree on the importance of organ donation. Few issues reach so far into the human heart.

Although many of the issues related to organ donation might be called technical, we must not disregard the issues of the heart and soul. I want you to draw on your own experiences, I want you to look into your heart. This is an issue where we need to try and understand the most serious human realities: life and death.

Since we will be concentrating on problem issues -- and I intend to drive you hard in this meeting -- I think we can take just a moment to celebrate progress.

I know many of you here today contributed to magnificent improvements in the field of transplantation. I want to acknowledge that.

For example, in the past 8 years we have seen the number of patients receiving kidney transplants almost double from 5,358 in 1982 to 9,560 in 1990, and the number of patients receiving dialysis for end-stage renal disease increasing from 65,000 in 1982 to 125,000 in 1991.

Eight years ago about 100 patients had heart transplants, while last year about 2,085 procedures were performed at 150 hospitals across the country.

At a pioneering transplant center at the University of Pittsburgh, 62 liver transplants were performed in 1982, and last year 2,656 transplants were performed.

We've also seen major changes in legislation. We have landmark legislation combining all organ procurement and transplant activities into a single national network. There is Federal assistance for organ procurement organizations, increased coverage and reimbursement for heart and liver transplants, and extensive legislation requiring hospitals to incorporate the option of organ donation into routine practice. Breakthroughs in immunosuppressive therapies, donor screening, organ preservation, and techniques to diagnose rejection have also brought improved graft survival rates for over 15,000 patients who had transplants in 1990.

Now having said all this, I must turn all of us to reality.

There are over 23,000 patients on lists today, waiting to receive an organ. Before this workshop is over, at least another 50 transplant candidates will be added to the list. Some will receive a transplant and go on to live a near normal and productive life. Others will not be so fortunate.

Each of you here today has a responsibility. Each of you has been assigned to one of seven workgroups depending upon your area of expertise and/or interest. You will be asked to discuss some very specific issues, develop recommendations, and come up with sound strategies for implementation.

We're not going to avoid the hard issues. We're not here for that. We're going to confront head-on some serious controversies and address complex technical problems, such as the importance of matching, of living donors, of informed consent -- and I mean truly informed consent.

We're going to talk about money -- about the policy of stopping payment for immunosuppressants after 1 year or continuing to finance immunosuppressive drugs for longer than that. We're going to face the truth about high rejection rates, about dialysis versus transplantation survival, and even about the risks/benefits of either dialysis or transplantation. We're going to talk about educating health care workers, particularly those in emergency rooms, so that they can be both committed and comfortable in talking to grieving relatives about organ donation. We'll be thinking about <u>how</u> and <u>when</u> is the right time to talk to families of donors and indeed when and how to talk to prospective donors themselves.

We have a priceless opportunity in this workshop to make major changes for the good.

I want all of us to give our best while we are here. You have very hard work ahead of you.

Thank you.

Tuesday, July 9, 1991

CURRENT ISSUES IN DONATION AND TRANSPLANTATION

Dr. Novello: Good morning. I am pleased to see that you are ready for action. We have 2 days to address the issues and draft recommendations. We have a terrific sense of urgency to accomplish all of this.

Transplants started in 1954. We have almost 40 years of experience, and with it we have a climate of acceptance. For the most part, people are willing to donate. But they need to be reminded that only people can donate for people.

It is clear that the field of organ transplantation continues to develop. The goal of this workshop is to increase organ donation, particularly donation from minority groups. This workshop also gives us the opportunity to look back and to anticipate the future of organ transplantation.

Today we have better ways to prepare and preserve organs, better matching procedures, and better immunosuppressive treatments. Cyclosporine was approved by FDA in 1983, and today FK506 appears very promising. Through research, the future will bring tolerance induction, genetic engineering, and xenotransplantation.

We have learned to transplant portions of organs, such as split livers and portions of lungs. A new procedure permits the recovery of kidneys from non-heart beating donors. Today, tissues and organs can be obtained from virtually every person who dies. We are close to an artificial pancreas, and as genetically engineered tissues become a reality, to other artificial organs as well.

We have the possibility of using animal organs in some future cases. We may ✓ have new gene therapies for diabetes and lung diseases. We have made progress, but we have also created some serious problems.

Current

In 1986, Congress required that hospitals receiving Medicare and Medicaid funds establish a written protocol to identify potential organ donors. By April 1989, 43 States and the District of Columbia had enacted legislation for this required request.

Nevertheless, written donor agreements account for a very small fraction of today's donor pool, perhaps only 3 percent of all organ and tissue donations. Although they may be valuable as a notice to families of the individual's preference and commitment to donate, surgeons still routinely require family approval. Reasons for this include the fear of legal liability and respect for grieving relatives.

Taking all of this into account, the fact remains that we might not only have an absence of donors, we might have an absence of askers as well. Too many people are not receiving the organs they need and too many people go unasked for organs they can donate. It is estimated that based on age, cause of death, and other criteria, that as many as 14,000 of the 2.2 million Americans who die every year could donate life-saving organs to those on waiting lists. A recent report noted that in 1990, 2,206 people died while waiting for organs. As I stated earlier, while we are here today, about 50 more people will be added to the transplant list. The process is never ending.

Let me briefly review the history of organ transplantation so we can put the issue in its true perspective.

In 1984, Congress passed the National Organ Transplantation Act. This required the Secretary of Health and Human Services to contract for an Organ Procurement and Transplantation Network with a private, non-profit entity. In 1986, the Secretary awarded the contract to the United Network for Organ Sharing (UNOS) with the understanding that all transplanting hospitals, when participating in Medicare and Medicaid, must become members of UNOS. UNOS, in turn, maintains the Nation's computerized list of individuals waiting for organ donations. For the first time in this country, the Transplant Act and the contract with UNOS created an equitable and efficient national system of tracking organ donations and transplantation.

As of mid-June, there were almost 19,000 patients waiting for kidney transplants; 2,000 waiting for a heart transplant; almost 1,500 waiting for a liver; 171 waiting for a heart/lung transplant; almost 600 waiting for a pancreas; and nearly 500 waiting for a lung transplant. About 12 percent of these will need a repeated transplant.

We also know that approximately half of those on waiting lists are between the ages of 19 and 45, and over 90 percent are between the ages of 19 and 64. About 40 percent are women and 60 percent are men.

Each year about 15,000 whole organs from 4,500 donors are transplanted at 261 transplant centers, with the help of 69 organ procurement organizations. We have come a long way, but something is interfering with the momentum.

Approximately 2,000 new patients are added to the list of those already waiting for organs each month. Sadly, between a third to a half of all Americans on transplant waiting lists will die before a transplantable organ is found.

The recommendations generated by the National Kidney Foundation in February gave us points for discussion and innovative strategies to consider solutions. The participants emphasized obtaining organs from living donors and examined the issue of presumed consent, concluding that it is not yet ready for acceptance in this country. In addition, Medicare payments for the life of a transplanted organ was discussed for those patients who have no other insurance.

When we look at the issues from the Kidney Foundation meeting, and remember the article in the June 1st New York Times, which reported the successful transplantation of the small intestine in three children and two adults, a medical first, we realize once and for all that we do have important issues to consider in this workshop.

The issues, no matter what they are, intertwine: the relative importance of matching and the need for minority donors; and the appeal for scarce organs to be used in the community of origin and the imperative of finding the best possible match.

There are difficult decisions to be made. Which patient should receive a given organ -- the patient with the most urgency or the patient with the best match? Should live organ donations be given only to those with economic means? If there were more organ donations, and organ availability for all, some of these issues would vanish.

In the absence of that, we have issues of money and social status which we must review. The United States has come a long way in assuring that lack of money is not a barrier to organ transplantation -- but have we come far enough, and should it be reevaluated in today's world? Although nearly all kidney transplant candidates are reimbursed by Medicare, those who are not may find costs prohibitive. The estimated cost of a kidney transplant is $51,000. Furthermore, the Medicare program only covers the cost for immunosuppressive drugs for the first year after transplantation, and those drugs may cost as much as $3,000 a year. Many patients, especially minorities, might find this cost too high. Worries about lifelong cost of immunosuppressive drugs can cloud their relief at having an organ transplant. We must work at removing this disincentive.

There are also co-insurance and deductible requirements which can substantially limit access to kidney transplants. Can you imagine what happens with other organ transplants?

Are transplant patients really able to go back to work? Can they start paying for their immunosuppressive drugs when Federal funding stops after one year? Is one year enough to rehabilitate, and if not, do we need to readdress this issue in detail?

We must look at socioeconomic status and disease -- poverty breeds disease and often limits care. How does this affect the need for organ transplantation? Let me illustrate. I don't think we have to document the link between minority status and low socioeconomic status at this meeting. The risk of end-stage renal disease among blacks is four times higher than for whites. The prevalence is also higher. Blacks make up approximately 12 percent of the U.S. population, yet in 1987 they accounted for 27 percent of the patients with end-stage renal disease. Although blacks have an increased prevalence of hypertension and diabetes, the increased incidence of end-stage renal disease among blacks versus other minorities cannot be attributed to any one cause. The 1989 Report of the Department of Health and Human Service's Office of the Inspector General stated that there were problems in equitable distribution of organs. For instance, the report found that blacks on kidney waiting lists waited almost twice as long as whites for a first transplant: 14 months compared to 8. Patients at some centers waited as long as 18 months while at others they waited less than 6 months. Thirty percent of those waiting were black, yet only 23 percent of cadaver kidneys went to blacks. The report also said that in 1988, only about 8 percent of all cadaver kidney transplants were from black donors. Since most donors are white, whites were more likely to have a better chance at matching.

These problems can be found in other minority groups as well. For adult Native Americans living in the U.S., the overall risk of end-stage renal disease is approximately three times higher than for whites. We don't know much more about renal disease and Hispanics. One study of Hispanics in California showed a risk about the same as whites, but a study in Texas reported a three times higher risk of end-stage renal disease in this population. To make things more complicated, what we refer to as "Hispanic" is really a number of different genetic groups and, therefore, the antigens among Latino subgroups may vary, making matching more difficult.

In 1985, HCFA indicated that for blacks the percentage of end-stage renal cases was larger than the percentage of transplants. A smaller percentage, however, had transplants from living donors. Even in the presence of this bleak picture, some black families are not willing to give permission for the donation of even one cadaveric organ. Is this small percentage of donations due to cultural or religious patterns, educational levels, or basically the way these families are approached? We need to address this.

You will be hearing from experts pertaining to this issue. Some of the reasons cited for this have been religious objections, fear that organs will be taken before the person is dead, a desire to spare the departed more suffering, fear of mutilation of the body or a desire to bury the body intact, or even distrust of the medical system as a whole. Is it part of the consequence of minority status to be more fearful of exploitation? Is it that the one who asks for the donation is not cognizant of the minority individual's cultural sensitivities, or is not perceived as understanding such sensitivities? Would it help if the person raising the issue of donation was black or Hispanic? Probably so, and all these issues must be discussed.

We know that a higher socioeconomic status and a higher level of educational attainment allows individuals to be willing to talk about organ donation. What we do not know is whether other groups, including minority groups, would be more willing if they were approached in a more culturally sensitive and compassionate manner. We must address this as well.

Throughout medicine and biomedical research, we have made assumptions that are increasingly being questioned. For instance, there is an assumption that minorities are less likely to comply with medical regimens or less likely to donate organs. Truth or prejudice? We all must look at this.

Look dispassionately at the issues that affect minority donations and minority transplants. Differences in ABO blood groups, the major histocompatibility-complex antigens, inadequate financial coverage, the knowledge that transplant outcomes in blacks might be worse than in whites, the presence of cultural barriers and countless other factors -- these affect the rate of transplantation but might not be the whole problem. These issues have to be factored into the discussion but are not to be used as scapegoats to avoid looking further into other issues.

We know that there are racial differences in the distribution of major histocompatibility-complex antigens. The racial differences in ABO blood groups and phenotypes also make it more likely that a candidate for transplantation will receive a well-matched kidney from a member of the same race; however, we must not be limited by this. We have overcome less than perfect matches with the advent of better immunosuppressant drugs, but research must continue in this field.

These are undoubtedly issues we have to interpret for potential donors and their families, and these are some of the barriers we need to overcome in order to increase donations from minority groups -- issues I expect to be thoroughly discussed and skillfully addressed in this meeting.

Consider for example, the standards for brain death and the need to communicate these standards to a desperately grieving relative. Should we remove this definition altogether, as it confuses the public, or explain it more sensitively to the ones in need?

I want this group to consider everything that will increase donation, not only donations from biologically related family members but also those "related" through marriage, friendships, and strong emotional ties.

Discuss the well recognized use of living donors for kidney transplantation, and explore the practice as it relates to liver, pancreas, and lung transplantation.

Also, don't be afraid to discuss and list the hidden costs associated with being a living donor -- not just surgery, but the added cost of health insurance and time lost from work. Consider as well the need to think about presumed consent and the potential legal issues attached to this.

As Surgeon General, I cannot talk about this issue without being aware of my Hispanic heritage and my professional life as a pediatric nephrologist. We may not always agree on every point, and we have to take practical realities into account, but there is no question that we agree on the importance of organ donations and the fact that there was never a better time, or a better team, to help implement your recommendations and move the field forward.

Although many of the issues related to organ donation are technical, many are issues of the heart and soul, no matter how we disguise them. In the next 2 days, I want you to draw on your own experience and look into your own heart. Organ donation is an issue where we need to try and understand the most sophisticated medical knowledge and the most serious human issues, and translate them into action.

We need to continue to look at education of the public to encourage organ donation. In doing so, we must face hard issues, such as how many tissues and organs should be obtained from one donor and then be transplanted? How do we assure the public that their specific donation request will be honored?

What about AIDS, hepatitis, and other infectious diseases? The FDA, under the auspices of Dr. Mason, is setting a process in motion to address this problem.

What limits are there on donors -- how old and how sick can they be? Should children and babies donate organs? How do we address these ethical issues?

We must also address the issue of what constitutes informed consent. How should people be protected against pressure to be a living donor? Can they be protected, or is the natural stress in a family when a member is dying beyond control? Should we hesitate to ask? Should we routinely ask? We know that some countries such as Norway have 50 percent of their organs donated by living donors, and nearly 100 percent in Japan.

We need to look at the large picture. Can the transplant networks be improved? How do we educate health professionals, particularly those who work in emergency rooms or intensive care units, to regularly and compassionately talk with surviving relatives about organ donation? When is the right time? Who is the right person?

I urge you to focus on increasing organ donation in this country, particularly minority organ donation. I urge you to develop strategies suggesting how these recommendations might be implemented for all those in need.

Today your primary assignment is to develop recommendations. Tomorrow morning your chief assignment will be to develop strategies. In both of these tasks, please be as specific as possible and indicate which agencies, both public and private, need to be involved in the implementation.

Keep in mind that your recommendations will be shared with the individuals and organizations in charge of implementing them, such as health care professionals, private institutions, and non-profit organizations, as well as many levels of Government. Do not let that repress you. Speak candidly about the issues.

Once you present me with the recommendations, I will review them with the Advisory Committee over the next few months and work with the Division of Organ Transplantation to develop the report from the workshop.

We will publish the valuable background papers prepared for this meeting, as well as the relevant recommendations and implementation strategies proposed at this workshop. After this, the Advisory Committee that helped plan this workshop will continue to provide guidance in implementing the recommendations and strategies, and will monitor the field progress in carrying out such tasks.

I've been using a motto: "Good Science, Good Sense," since I've been Surgeon General. Rarely has my motto been so appropriate as at this workshop. Before me, I see the best people in the field of transplantation. Before us is the challenge of drafting the agenda for organ donors and recipients for the next millennium. The possibility of saving future lives makes it all worthwhile.

Thank you.

OVERVIEW OF WORKSHOP AND CHARGE TO PARTICIPANTS

Ms. Braslow: Thank you, Dr. Novello. This morning I want to show you where the Department is on some of the key issues related to transplantation and how your work at this meeting will fit into that context.

An important project is the release of center-specific data. In the transplant amendments of 1990, Congress asked us to provide to the public, information related to center-specific survival rates. We've received a lot of comment about this. Institutions are concerned that if the Government releases the information, it won't be interpreted correctly. It is not, however, a judgment call on our part. The Congress has told us that this is what we are going to do. We have to find the most acceptable and meaningful way to release this information. We've worked very closely with the Scientific Advisory Committee of UNOS. We've brought in a group of consultants and people from the Health Care Financing Administration, which had lead responsibility for the Mortality Data Report. If you recall, the first time HCFA released those data several years ago, it caused a major storm, so we thought we could learn from their experiences. We've discussed it with the UNOS Board, and we are now moving ahead.

We are trying to have a few variables that will distinguish one center from another and one kind of transplant from another. The variables were determined by the organ-specific subcommittees of the UNOS Scientific Advisory Committee. In 1991, we will look for kidneys. We will model the data so that we look at "first" vs. "subsequent" transplant, race, and cadaveric vs. living-related donors. There will be two time points: 3 month survival and 12 month survival.

For liver, the criteria will be age, the medical status at the time of transplant, and 3 and 12 month points in time. For heart, it will be first vs. subsequent transplant, the medical status of the individual at the time of transplant, congenital vs. all other disease categories, and 1 and 12 month points in time. For pancreas, we're looking at first vs. subsequent transplant, and also at the recipient category. We will want to know whether it was a simultaneous kidney/pancreas transplant, just pancreas, or pancreas transplant following a kidney transplant. For pancreas, it will be a 3 and 12 month data point as well. That data will be delivered to HRSA by UNOS near January 1, 1992. Then the Department will decide how that data will be released.

Another important concern, as Dr. Novello has indicated, is the recent case of HIV transmission through transplanted organs. The UNOS Board appointed a committee to study recommendations of a DHHS workgroup established to examine issues of HIV and other communicable disease transmission in relation to organ and tissue transplants.

As a result of our deliberations, we are suggesting that there be a pre-transplant HIV serology. We are not suggesting that the transplant be held up while awaiting results, but should the patient develop HIV, we want to know if that patient was seropositive. The workup 2 or 3 months prior to transplant routinely has an HIV serology; however, we want one immediately prior to transplant.

Secondly, we want post-transplant serologies at 6 and 12 months, which will cover the window period for almost 99 percent of patients. When HIV is identified in the post-transplant follow-up, we want it immediately reported to the UNOS Scientific Registry Data System. That allows us to identify other individuals who received organs from the same donor. Obviously, all donors are screened and we are very confident that the organ procurement agencies and transplant centers are doing a good job of donor screening. Their job is limited, however, by the sophistication of the tests available. Because that window period exists, it's important that we know when somebody is HIV positive post-transplant so that we can identify individuals who received organs from the same donor. And it's important that we receive immediate reports of AIDS and HIV-related death of a transplant recipient. We have asked UNOS to develop a system for how they're going to identify those individuals and what actions they will take when a red flag is raised. These are the HIV testing guidelines that we have begun to put in place, and I'm pleased with the response we've received from the transplant community.

There is a national effort that I think is very exciting, and we're interested in receiving your reaction to it. The Association of Organ Procurement Agencies decided about a year ago to begin a national campaign and contracted with an advertising agency to develop the campaign. At the Association's annual meeting a few weeks ago, the results of that effort were released. For the first time we had an effort that has been bought by virtually all the organ procurement agencies in this country which have agreed to adopt this slogan, "Be an organ donor, it's the chance of a lifetime." They will be using this on billboards and brochures throughout the country in their donor education and awareness efforts. You have copies of these materials. Please look at them. We're very interested in your reaction.

Now, let's get to the major task for these 2 days: developing recommendations on how to increase organ donation in the United States and developing strategies suggesting how these recommendations might be implemented. Each of you is assigned to one of seven workgroups, focusing on a specific topic related to donation. Each workgroup is to develop a set of recommendations on how to increase organ donation from the perspective of its specific focus. Today your primary assignment is to develop recommendations. Tomorrow morning your chief assignment will be to develop specific strategies and to indicate which agencies, both public and private, need to be involved in their implementation.

The seven issues fall into three categories: public education, including the general public, minority groups, and children; the health care environment, including regulatory practices and professional education; and revaluating donor criteria, including those used for cadaveric donors as well as live donors.

The groups addressing public education will zero in on the issues related to conducting a national campaign. Group I will make recommendations with the general public in mind. How should such a campaign be structured? Group I–B will also help answer that question by recommending ways to increase donation among individuals from various cultural backgrounds. What unique barriers need to be overcome before minorities will feel equally as interested in donation? Group I–C will focus on children, youth, and young adults, an important component of a public education campaign because they are often the most receptive to the idea of donation. Establishing their beliefs at a very young age will help insure that donation is acceptable to them now and in their adult life. Most important, children are often catalysts for educating parents about important public health issues.

Groups II–A and II–B will focus on the health care environment in which donation is likely to occur. The first group has one of the hardest tasks: examining the regulations, laws, and policies that shape the practices of health care professionals involved with donation, and making recommendations for improvement. This group will need to decide if new laws and regulations are needed or whether we should make better use of the instruments that are already available.

Group II–B will hone in on the measures necessary to educate the various health care professionals directly or indirectly involved with the donor process, assessing current educational efforts, and recommending future programs.

The last two groups will focus on the actual criteria for donation. One will discuss criteria for cadaveric donors, both adult and pediatric. It seems we must expand the limits of traditional donor criteria in order to obtain more organs for transplant. Much discussion and some research has focused on expanding the upper and lower age limits for cadaveric donors. Besides expanding the age criteria, what traditional medical contraindications can be reexamined in hopes of increasing the number of donors? Is there an acceptable gray zone for diabetics or donors with histories of hypertension, drug abuse, or less than perfect organ function? What research needs to be done in order to assist the transplant community in reaching a consensus on these criteria? By transplanting these marginal donors, are we jeopardizing the recipient's chance for a healthy recovery?

The final workgroup will focus on issues surrounding the use of live donors for transplantation, not just clinical issues of donor suitability, but also ethical and legal concerns. We want you to consider not only donations from biologically related family members, but those related through marriage, friendship, and other emotional ties. We want you to discuss the well recognized use of live donors for kidney transplant along with the practices that relate to liver, pancreas, and lung transplantation.

You have all received background papers which are to serve as catalysts for your discussion. However, do not feel limited in your discussion by the points that have been made in the background papers. Please make your recommendations as specific and realistic as possible. Those recommendations must be implemented by health care professionals, private institutions, non-profit organizations, and many levels of Government.

Our final charge is that you speak candidly about the issues before you.

Again, our sincere thanks to all of you.

INTRODUCTION OF DR. M. ROY FIRST

Dr. Novello: Our speaker is Dr. Roy First, who is Professor of Internal Medicine and Director of the Section of Transplantation in the Division of Nephrology and Hypertension at the University of Cincinnati Medical Center. He graduated from medical school at the University of Witwatersrand in Johannesburg in 1966. After completion of his military service, he did his internship and residency at the Johannesburg General Hospital. This was followed by a fellowship in nephrology which was done at Michael Reese Hospital in Chicago, Illinois. He was appointed to the staff of the University of Cincinnati Medical Center in 1974. He has been active in the field of transplantation over the past 15 to 20 years, and has become a national and international authority in the field. He is the immediate past President of the American Society of Transplant Physicians. He has over 120 manuscripts and 13 book chapters published in the transplant literature. In addition, over 140 of his abstracts have been presented at the national and international transplant meetings.

The topic of today's address by Dr. First is "Transplantation in the Year 2010." Obviously, this is a highly speculative topic, but I can think of no one more suitable than Dr. First to give this address.

DONATION AND TRANSPLANTATION: WHERE WILL WE BE IN 2010?

M. Roy First, M.D.
Professor of Medicine
Division of Nephrology and Hypertension
University of Cincinnati Medical Center

Dr. Novello, ladies and gentlemen, it is indeed a pleasure and a privilege to be here today. The talk I've been asked to give this morning, transplantation in the year 2010, is obviously very speculative. I thought we should look at where transplantation has come to the present time, and then speculate some about the future. If we look at the current 1-year survival rates for first transplants (Table 1 - this data was recently published by UNOS for all 1988 transplants for which

12 month follow-up is available), we can see that the results have reached an all-time high: patient and graft survival for living-related donor kidneys are 97 and 91 percent, respectively; for cadaver kidneys, 92 and 81 percent; for pancreas, 89 and 71 percent; for liver, 76 and 69 percent; for heart, 83 and 82 percent; for heart/lung, 57 percent; and for lung transplantation, 48 percent. The last two are in their infancy relative to the other organ transplants, and I'm sure that over the next decade we'll see substantial improvements in heart/lung and lung transplant results.

Over the past 8 years, transplantation has grown, and as you're all aware, last year over 15,000 solid organ transplants were done in the United States, a record number (Table 2). Of these, 9,560 were kidney transplants. There were over 2,600 liver transplants, 2,085 heart transplants, and a large growth in pancreas transplantation, which reached 549 last year, largely due to the pioneering efforts of Dr. Sutherland in Minneapolis.

With these excellent results, and the increased number of transplants, what is the problem? The problem is why so many experts are here today. The problem is one of organ donation. The UNOS organ transplantation waiting list released last week has over 23,000 people on it. Of major concern are the deaths of those on this waiting list. In 1989, almost one in three potential heart transplant recipients died while waiting. Almost a quarter of those awaiting a liver transplant died. The figures out for 1990 reveal that there were 2,206 deaths of patients on the waiting list. This translates to over six a day: every 4 hours, one patient on the waiting list for solid organ transplantations is dying.

TABLE 1.
ONE YEAR SURVIVAL RATES FOR FIRST TRANSPLANTS IN 1988 *

ORGAN	PATIENT SURVIVAL	GRAFT SURVIVAL
KIDNEY (RELATED DONOR)	97%	91%
KIDNEY (CADAVER DONOR)	92%	81%
PANCREAS	89%	71%
LIVER	76%	69%
HEART	83%	82%
HEART-LUNG	57%	57%
LUNG	48%	48%

* Data from UNOS report

TABLE 2.
SOLID ORGAN TRANSPLANTATION IN THE UNITED STATES
1982-1990

	1982	1983	1984	1985	1986	1987	1988	1989	1989
KIDNEY	5,358	6,112	6,968	7,695	8,975	8,967	9,123	8,706	9,560
LIVER	62	164	308	602	924	1,199	1,682	2,164	2,656
HEART	103	172	346	719	1,368	1,438	1,644	1,700	2,085
PANCREAS	35	61	87	130	140	142	242	419	549
HEART-LUNG	0	20	22	30	45	41	71	68	50
LUNG							32	119	262

I have some numbers, supplied by Dr. Alan Hull, on kidney acquisition per million population per year from a number of different countries (Table 3). If we look at roughly the middle of the decade of the '80s – '84 and '85 – we can see that the figures for the U.S. reveal that organ acquisition in this country was on a par with many European countries (Table 4). Nevertheless, organ acquisition in the U.S. still lags far behind the leaders of Western Europe: Belgium has 41 kidneys per million population per year; and Austria, where laws of presumed consent are actively applied, has over 52 kidneys per million population per year.

What are some of the possible solutions to the dilemma of organ donation and distribution? (Table 5) There's no question in my mind that the major issue remains improved professional and public education. This meeting is going to go a long way towards improving the public knowledge about what is needed in this country with regard to organ donation. The recently published report of the Office of the Inspector General notes that there is a paucity of minority donors in this country. This is another area that needs to be actively pursued, especially considering that approximately 30 percent of the patients on the waiting list for kidneys are black. Relaxed donor criteria need to be looked into further. The recent increase in organ donation last year is largely a result of the use of donors who may not have been accepted in the past, largely older donors, and I think this is an area that's going to be addressed at this meeting and has been addressed in the past by my colleague from Cincinnati, Dr. Wesley Alexander.

The question of the use of non-heart beating donors prior to obtaining consent also has been raised recently. Increasing the number of donors by using living, unrelated donors; the whole question of improved application of the routine request; and the possibility of going to routine referral of potential organ donors -- all need to be considered. Presumed consent, while effective in many European countries, probably would not be acceptable in this country to the general public. One area that has been discussed extensively over the past year has been the question of financial incentives to donor families, and I personally think that this is an area that deserves further study. And finally, research into xenotransplantation so that animal organs may be used to overcome the shortage is something that one might look at in transplantation 20 years from now.

So where are the future directions that I see transplantation going? (Table 6) First, a number of new immunosuppressive agents are on the horizon. Some have been used in laboratory animals with excellent results; others have been used in clinical studies with very impressive and exciting results. Over the next 5 years, we will hear a lot more about many of these drugs. To complement this, a number of new monoclonal antibodies are on the horizon and should be released in the next few years. Beneficial effects also have been shown by drugs that affect the prostaglandin-thromboxane system.

TABLE 3.
KIDNEY TRANSPLANTATION WORLDWIDE 1989 *

COUNTRY[1]	CADAVER KIDNEYS[2]	KIDNEYS TRANSPLANTED CAD	KIDNEYS TRANSPLANTED LRD (% TOTAL)
EUROTRANSPLANT			
BELGIUM (9.9)	41.3	409	
AUSTRIA (7.5)	52.1	391	
W. GERMANY (60.5)	30.5	1,847	
LUXEMBOURG (0.37)	16.2	6	
NETHERLANDS(14.8)	24.4	361	
SCANDINAVIA TRANSPLANT			
SWEDEN (8.4)	34.5	290	81 (22)
NORWAY (4.2)	20.0	84	76 (48)
DENMARK (5.1)	25.3	129	18 (12)
FINLAND (5.0)	29.2	146	39 (17)
INDEPENDENTS			
FRANCE (56.2)	33.8	1,900	57 (3)
ITALY (57.4)		604	10.5
U.K. (60.9)	28.4	1,732	122 (7)
USA (248.8)	27.5	6,844	1,862 (21)

* Data from Hull, A.

[1] Country and population (in millions)
[2] Cadaveric kidney retrieval rate in number of kidneys per million population per year

TABLE 4.
KIDNEY ACQUISITION IN THE DECADE OF THE EIGHTIES*
(MILLION POPULATION/YEAR)

COUNTRY	AUSTRIA	BELGIUM	FRG	NETHERLANDS	FRANCE	USA
YEAR						
80	12.5	16.7	12.0	16.7	12.3	
81	15.2	15.7	13.7	22.0	13.0	
82	18.7	14.0	15.0	22.1	15.8	16.0
83	14.4	19.5	16.2	23.6	16.7	18.6
84	29.9	20.8	20.0	25.9	17.5	22.4
85	27.6	21.3	20.4	18.8	21.0	24.6
86	30.9	26.8	25.8	25.7	24.0	29.5
87	42.5	37.4	26.0	28.6	29.0	29.0
88	39.0	38.0	26.9	25.5	32.5	29.1
89	52.1	41.3	30.5	24.4	33.8	27.5

* Data from Hull, A.

TABLE 5.
POSSIBLE SOLUTIONS TO THE DILEMMA OF ORGAN DONATION AND DISTRIBUTION

1. Improve professional and public education
2. Train minority requestors
3. Relax donor criteria
4. Use of non-heart-beating donors
5. Use of living unrelated donors
6. Routine request and routine referral
7. Presumed consent
8. Financial incentives to donor families
9. Xenotransplantation

Other future directions involve the question of: 1) cellular transplantation, 2) small bowel transplantation, 3) tolerance induction, 4) xenotransplantation, and 5) genetic engineering. These are the areas that are going to receive attention in the next 10-20 years. For the remainder of my talk, I want to focus on each of these 5 areas.

First, cellular transplants. Islet cell transplantation has been successful in animals. In humans, amelioration of diabetes has been incomplete or transient, and there's a need for multiple islet donors for a single recipient. Some of these problems are related to the fact that the islets are exquisitely sensitive to biophysical or immunological injury when they are separated from the pancreas. An interesting attempt to overcome this problem has been the recent report and development of the biohybrid perfused artificial pancreas, which is designed to incorporate islet tissue and a selectively permeable membrane that isolates this tissue from the immune system of the recipient. This device is reseedable through silicone rubber ports in the event the islets must be replaced periodically. Work on this perfused artificial pancreas by the group in Boston, led by Tony Monaco, was reported recently in Science. A vascular graft, made of PTFE, is incorporated into the circulation in the experiments in dogs in much the same way as an arteriovenous shunt. This vascular graft is surrounded by a housing device and then a hollow fiber membrane. The pancreatic islets are inserted through the seeding port and are separated from the circulation by this hollow fiber membrane. This hollow fiber is of a size that allows glucose to pass through to stimulate the islets; it allows insulin to pass through in the other direction, and also allows nutrients to reach the islets. However, it prevents lymphocytes and antibodies from getting through to the transplanted, or the seeded, pancreatic islets. Using this device, they were able to keep dogs euglycemic without any need for insulin and no immunosuppression for up to 6 months. This is certainly something that's going to warrant future consideration, and might well play a role in the treatment of the many diabetics with and without end-stage renal disease.

There are a number of areas where cellular transplants have been used, for example, in Parkinson's disease. In Parkinson's disease, there is selective destruction of the dopaminergic neurons of the substantia nigra of the brain. The cells of the adrenal medulla release dopamine, and clinical trials have been done utilizing either adrenal medullary autografts (taking the person's own adrenal medulla), and fetal neural tissue grafts into the caudate nucleus. Reports on this research come from Mexico and Scandinavia, and are somewhat conflicting; some showing significant improvement in the neurological symptoms of Parkinson's disease; others have not been that impressive. But certainly this is a fertile area for future research on the use of cellular transplants.

Next, small bowel transplantation, which is in its infancy, and has had only a few cases described. In small bowel transplantation, predominant problems are: acute and chronic rejection, graft vs. host disease, diagnosis of rejection, and the digestive and non-digestive functions of the small bowel graft. In experimental animals, the use of FK506 has been shown to prevent acute rejection and the fatal graft vs. host disease. A few isolated clinical papers show excellent results, and of these, the most prominent come from Toronto. There, patients have survived almost 2 years with normal bowel functions. Excellent results also come from Pittsburgh and other centers. The successful clinical results have occurred with vigorous pre-treatment of the donor with monoclonal and polyclonal antibodies to the donor of the small bowel, and in very vigorous immunosuppression of the recipient. In this way, it has been possible to control both the acute and chronic rejection phases, and the transfer of donor lymphocytic tissue in the graft that causes the graft vs. host disease. The application of new surgical techniques, the diagnosis and treatment of rejection, and the availability of new immunosuppressive agents, will undoubtedly result in successful transplantation of the small intestine by the year 2010.

The next area is the induction of tolerance, which is the induction of a state of antigen-specific unresponsiveness, so that an individual would be unresponsive to the particular tissues of the donor but would maintain other immune functions. Experimentally, this is possible to do in animals using donor bone marrow, anti-lymphocyte serum, and cyclosporine. In other animal experiments, conducted largely by David Sachs at the N.I.H., the use of monoclonal antibodies, whole body irradiation, thymic irradiation, and allogeneic bone marrow transplantation, have resulted in the induction of chimerism. Tolerance has also been achieved in concordant animals against the xenogeneic barrier. In human beings, partial tolerance has been achieved in humans with post-transplantation bone marrow transfusion, as has been described by the University of Alabama in Birmingham, and with total body irradiation. In the Birmingham studies, the patients who received the donor bone marrow had far less rejection and very good outcomes when compared with the matched controls. However, this is difficult to achieve. In our institution, led by Wes Alexander, we've been studying the role of donor-specific blood transfusions in living-related and cadaveric donor transplantation. This involves taking blood from the donor, giving it to the recipient, and delaying the transplant for 12-18 hours. The early results have been encouraging, although there has been a fair amount of rejection: one graft out of about 20 has been lost.

Next is the issue of xenotransplantation, or cross-species transplantation. If this could be achieved, the successful use of animal organs for transplantation into humans could solve the organ shortage that exists. If this can be achieved through advancements in immunobiology and immunopharmacology, 20 years from now we won't have to worry about people dying due to a lack of organs. However, this will be difficult to achieve because humans have natural, or preformed, antibodies against all animal species.

Clinical xenotransplantation has been performed approximately 30 times. In some instances, the organs function for a very short while and then fail. The most recent case that comes to mind is the one in Loma Linda in which a chimpanzee or baboon heart was transplanted in a young girl for whom no donor could be found. The girl lived only a few days. Cross-species transplantation has been successful in concordant animal species, such as rodents, mice, and rats, because those are the types of animals that lack preformed antibodies against the donor. There's been renewed interest in xenotransplantation with the introduction of FK506, 15-deoxyspergualin, new monoclonal antibodies, and with tolerance induction. Xenografting has been classified into two functional groups: the concordant, or species combinations, in which the graft survives several days and rejection tends to be along classical pathways, with cellular and humoral immune mechanisms; and the discordant, where there's immediate or hyperacute destruction of the graft. This is mediated by preformed natural antibodies, the complement cascade, activation of endothelial cells lining the vessels of the donor organ, and platelet aggregation. Attempts have been made to achieve accommodation of the xenograft so that the natural antibodies can be removed by plasmapheresis or immunoadsorption. This has been successful in the laboratory. Production of a transgenic pig, which expresses a human DAF (a molecule that inhibits activation of C3 and C5) also has been performed, preventing activation of the complement cascade. In the third level, involving internal damage and platelet aggregation, models have used the platelet activating factor antagonists to prevent the platelet aggregation. There's a lot of experimental work going on in this field. It is conceivable that early in the 21st century, we might see clinical xenotransplantation evolving successfully.

Another very interesting model of xenotransplantation was recently described by the group in Boston. This involved prevention of the xenograft rejection by masking the donor HLA class I antigens. Rejection of human pancreatic islets and liver cells were circumvented by masking the donor antigens with W6-32, an antibody to HLA class I. This is done before transplantation of these cells under the kidney capsule of mice. In this model, the islets have functioned without immunosuppression beyond 200 days, as demonstrated by normal histology and C-peptides secretion in response to a glucose load. This might be another way to fool the immune system and prevent rejection, and to get animals and humans to accept tissues from other species.

Finally, we come to the issue of genetic engineering. Using molecular biological techniques, entire genes or groups of genes can be produced and inserted into the genome of specific cells; that is, into the genetic material of the cells. Gene alteration therapy could be used to correct metabolic diseases, leading to end-stage organ failure, or to alter the host immune response. It's very likely that 20 years from now, we'll see genetic engineering therapy aimed at changing the genes for insulin-dependent diabetes, or polycystic kidney disease, or to alter the immune response of an organ recipient to prevent rejection.

Transplantation has also been used in the treatment of genetic disease. Bone marrow and liver transplantations provide the necessary feasibility tests of gene transfer therapy for many genetic diseases. Transplantation allows for assessment of a single organ correction of a specific enzyme deficiency by the introduction of normal genes. There are a number of conditions where the basic abnormality is in a single organ due to a genetic or inherited metabolic disease (such as alpha-one antitrypsin disease, Wilson's disease, and primary hyperoxaluria), and where replacement of that organ has resulted in correction of the genetic disease. Another example of gene transfer therapy is the use of pigs as potential blood donors to humans. Copies of the human DNA that make hemoglobin are inserted into a one-cell fertilized egg from a pig. In about 0.5 percent of these cases, the DNA successfully copies itself and is inserted into the DNA of the pig. The pig then gives birth to transgenic piglets, meaning they carry the genes of both the maternal pig and the human DNA inserted into it. The offspring of these pigs permanently carry the human DNA, make hemoglobin, and pass it on to their offspring. Such pigs have a mixture of human and pig hemoglobin. The human hemoglobin can be separated and theoretically used for transfusion into humans. In much the same way, one can imagine other modifications of genes to overcome diabetes and diseases that cause liver damage, or to alter the immune system. Therefore, genetic engineering, by adding or deleting genes involved in the immune responses or by induction of tolerance, can be done at the embryonic level, leading to a transgenic strain, or at a later level by inserting a vector for DNA transfer. There are a number of different levels at which one can alter the DNA of an animal, and this may one day be true of human beings as well.

It is very likely that over the next 20 years, many of these areas will come to fruition. However, for the foreseeable future, there will be a shortage of organs, and that is going to be the focus of the next couple of days.

Once again, thank you very much for inviting me here today.

LUNCHEON ADDRESS

LOUIS W. SULLIVAN, M.D.
SECRETARY OF HEALTH AND HUMAN SERVICES

Good afternoon. I appreciate the invitation to participate in this important meeting.

Let me begin by saying to you, Dr. Novello, that I have been very impressed with your work. You have been at the forefront of the efforts to make organ transplants a reality for more Americans, particularly minority citizens. I thank you for your leadership and dedication on this vital area of national health.

I'd like to spend a few minutes discussing organ donation specifically within minority populations, and then talk about current Federal efforts to improve rates of donation and the recent successes we've seen across the country through heightened public awareness.

The sessions today paint a picture of transplantation in this country -- a picture often not as encouraging as we would like it to be. Today, almost 24,000 Americans are waiting for an organ transplant -- and little more than half are likely to receive one.

Major advances in science, medicine, and biotechnology have given us the capability and the know-how to perform successful transplants. Last October Dr. Vaughn Starnes of Stanford University, a participant in this workshop, performed the world's first single-lung transplant using a lung segment from a living related donor. In January, he successfully repeated the procedure in a one-month-old baby girl. Dr. Starnes, your work is clear testimony to the tremendous potential for transplantation. This is truly one of the wonders of medicine to replace a deteriorated vital organ with a healthy one.

But, as the Washington Post noted last week, "the biggest constraint on organ transplantation is neither technology nor cost but the shortage of available donor organs." Indeed, the number of available organs has leveled off after doubling during the 1980s, while waiting lists have continued to lengthen. Fortunately we have seen an encouraging break in this plateau -- during 1990, donation increased by approximately 11 percent, but this still falls short of the need.

Rates of organ donation are especially low among members of minority communities, and require particular attention. We have well-documented evidence of the substantially lower rates among Hispanic and black populations than among white communities. I am pleased to note that an entire session of this workshop has been devoted to improving rates of donation among minority communities.

Overcoming the myths and misunderstandings that surround organ transplantation to increase rates of donation will require the efforts of everyone -- from Federal, State, and local governments to community leaders, from health professionals to church organizations.

The Federal Government has a number of initiatives underway to address these problems, including efforts to help educate the public about the need for donations and to improve the medical aspects of transplantation.

One of the barriers to donation is the perception of inequality in transplantation. The report published by the Office of the Inspector General this spring raised the key issue of disparities among populations. The report indicates that citizens of the black community wait almost twice as long as do people of the white communities for a kidney transplant -- nearly 14 months compared to only seven-and-a-half months, even when controlling for blood type, age, and locational factors.

While the Report presents a disturbing picture, I'm pleased that we are moving quickly to put in place its recommendations and to further evaluate the results of the study. Projects to increase donation among minorities have been given high priority in my Department.

For example, the Office of the Assistant Secretary for Planning and Evaluation is overseeing research to evaluate and identify the causes of the disparity in kidney transplantation among population groups.

Additionally, the National Institutes of Health have numerous clinical trials underway that will be important in increasing the success of organ transplantation. For example, the National Institute of Allergy and Infectious Disease is conducting studies of the immune system, with the goal of helping to control transplant rejection and increasing the quality of tissue typing.

But we need to do more than study the factors behind the dilemma. Increasing the rate of organ donation and access to transplantation for members of minority communities demands our urgent attention.

The Division of Organ Transplantation is devoted to managing the Organ Procurement and Transplantation Network and Scientific Registry contracts and providing special grants, contracts and educational programs for projects designed to improve rates of donation among minority groups.

Public education is clearly the critical element. We need to reach people about the increasing need for organs, but other issues must also be addressed.

As the transplantation field expands with new successes and more people come to depend on transplants, it is important that organizations for organ donation maintain high standards of safety. Commissioner David Kessler will spear-head a group of representatives of PHS agencies to determine the most effective strategies to prevent the transmission of lifethreatening infections through organ transplantation. While we cannot guarantee that it is completely risk-free, the risks involved in receiving a life-saving organ far, far outweigh the very remote chance of contracting any infection -- including the AIDS-virus.

Additionally, since 1988, the Health Care Financing Administration has been certifying organ procurement organizations to assure that they meet certain qualifying criteria for designation and meet minimum standards of performance. Such regulation helps to ensure that unnecessary risks are eliminated from donation procedures.

I am encouraged by evidence that in some areas of the country, donation rates among minority groups are on the rise. In St. Louis for example, the Mid-American Transplant Association (a grantee of the Division of Organ Transplantation) reports that donations among blacks rose from 8 percent in 1989 to 16 percent in 1990. The success of the program has been attributed to minority public education campaigns and to including more minorities in programs requesting donations from minority families.

In fact, I am encouraged by the increase in overall organ donation last year -- a significant move up from previous levels. A great deal of dedication and hard work have gone into crafting sound legislation and implementing programs geared towards increasing donations nationwide.

I am especially pleased that Dr. Novello has agreed to lend her support and direction in the drive to increase organ donation. The recommendations from this workshop will provide us with a progressive and sound approach for increasing organ and tissue donation in this country.

Today thousands of Americans are waiting for an organ transplant. Hundreds of thousands of others could be helped with a tissue or corneal transplant. If this waiting list grows as projected, the decisions we face will only get harder, and the choices before us will become more difficult.

We must work together to increase public awareness and to help those who need an organ to receive a transplant, and we must strive to make sure that this process is equitable and just. I want to thank each of you for your interest and input. I am confident that our work together will help more people receive the gift of life.

Thank you, and Godspeed you in your work.

Wednesday, July 10, 1991

Ms. Braslow: This has been very exciting for all of us who have spent the last 15 months preparing for this workshop. The discussions in the workgroups over the last 2 days have been extraordinarily exciting and interesting, and I hope we can collectively capitalize on this enthusiasm and take it back to our respective places of work.

I want to make a few general comments about the recommendations and strategies we have received. The first thing I noticed was that there are common themes. Even though the charges to the groups were often different, some of the recommendations that came back were very similar.

Several of the recommendations called for creating a task force. If we were to create all these task forces, we would have no money left to do anything else. So we will rely on our Advisory Committee to help us address some of the issues you recommended be addressed by task forces.

Some of the recommended projects can be done through our grant program. Some can be done through evaluation funds which support research studies. Some can be done by other Public Health Service offices that may not be represented here. And some of the projects can be done by you. For example, if a transplant center or an OPO is interested in taking the lead on a particular project or recommendation, we would be very interested in hearing about that. The Public Health Service cannot do everything. We do not have the resources, and we need your help. This is a community effort, and we want to hear your ideas on how to accomplish many of these recommendations.

Dr. Novello: We have come to the moment of truth. We have met for 2 days to come up with recommendations for the future. I would love to work on each recommendation myself, but the Surgeon General must work on other programs as well. However, organ donation has personal meaning for me and I will definitely keep abreast of the progress made on these recommendations.

As we proceed with the presentation of recommendations if anyone has a minority opinion, please present it – despite our time constraints. It would be nice to have a consensus, but we are all human beings with different opinions.

However, the more we agree on these recommendations, the better our chances of successfully implementing them.

Before we begin with the presentations there are two issues I would like to mention. First, in talking to the public, if I tell them that we have 23,000 people waiting today for organs, I am sure that will have an impact. But I also need to inform the public that even greater numbers of Americans are at risk of needing a transplant in the future. Therefore, I plan to share with them the following data:

- more than 13 million Americans have kidney and urologic disease today.

- 190,862 Americans were listed in 1989 as having end-stage renal disease.

- 58 million Americans have high blood pressure -- 30 percent of all adults ages 18-74 have high blood pressure; 38 percent of Blacks compared with 28 percent of Whites suffer from high blood pressure.

- 122,257 end-stage renal disease patients were on dialysis on 12/31/89 out of a total of 163,069 end-stage renal disease patients at that same point in time. More than 100,000 end-stage renal disease patients have high blood pressure; 43,000 have diabetes. Additionally,

- 16,500 Americas have chronic heart disease;

- 14,000 Americans have chronic liver disease;

- 4,500 have chronic heart and lung disease;

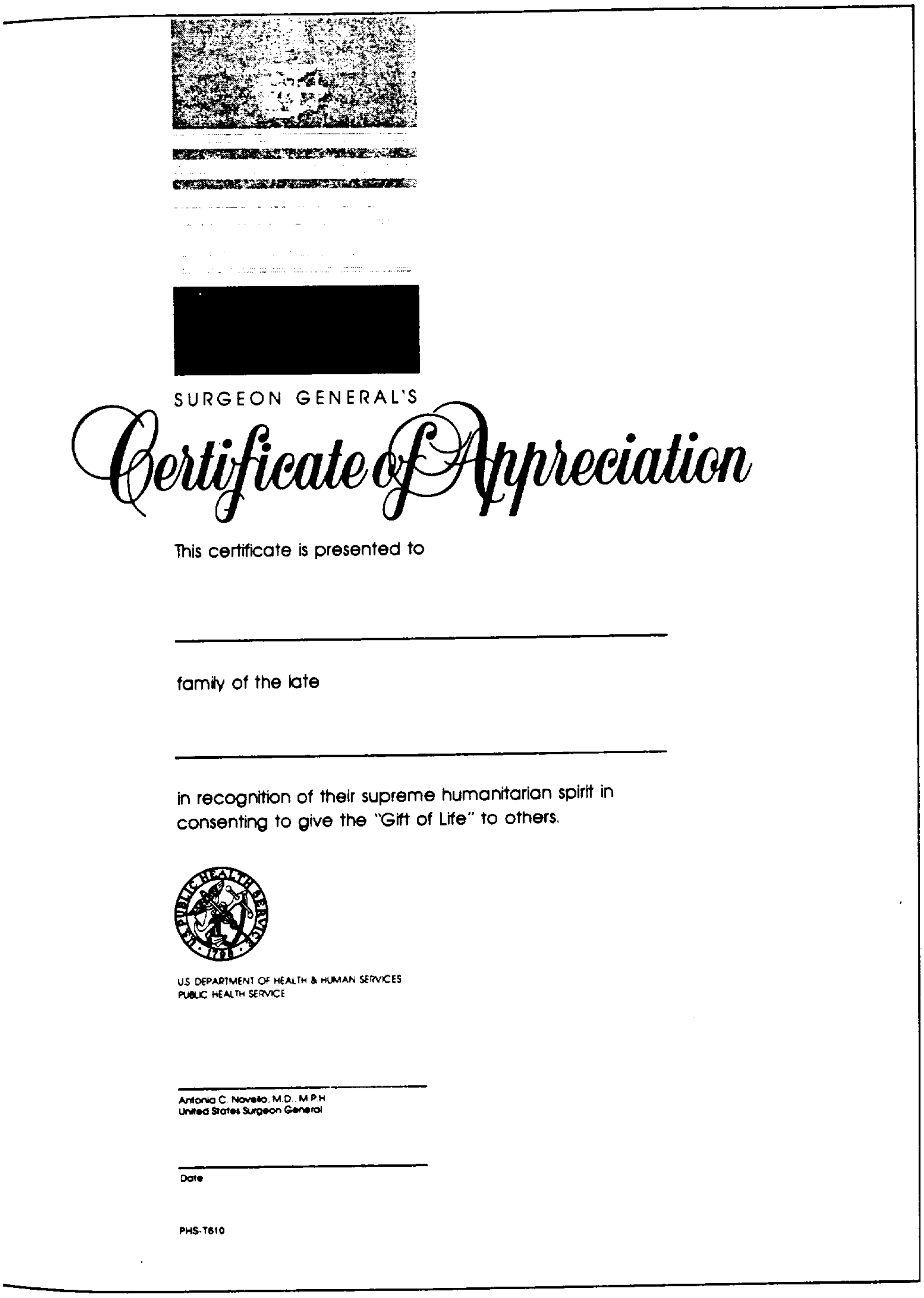
- 4,100 patients have non-functional pancreas; and

- 3,300 have chronic lung disease.

If I talk about these numbers, the public will realize that while I am worried about 23,000 today, we must plan for all of these patients who, until we find better preventive methods, might be added to the transplant waiting list. We must take responsibility for making the public aware of this situation.

I wish to share one other thing with you. We have been told that sometimes donor families receive little attention or appreciation for their most altruistic gift. It was suggested to us that there be a medal or certificate for donor families in recognition of their gift of life. The Office of the Surgeon General, together with the Division of Organ Transplantation, designed a certificate of appreciation for donor families which we would like to distribute through the OPOs. I wanted to tell you about the certificate and show you this slide so you can see what it might look like. It is a certificate of appreciation from the Surgeon General with the name of the donor on it, and will include a little note of appreciation. We would hope to send it in recognition of every donor in the United States recognizing them for having given the most precious gift -- the gift of life.

Now we will turn to the presentation of the recommendations.



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SURGEON GENERAL'S

Certificate of Appreciation

This certificate is presented to

____

family of the late

____

in recognition of their supreme humanitarian spirit in consenting to give the "Gift of Life" to others.

US DEPARTMENT OF HEALTH & HUMAN SERVICES
PUBLIC HEALTH SERVICE

____
Antonia C. Novello, M.D., M.P.H.
United States Surgeon General

____
Date

PHS-T610

WORK GROUP I-A: A NATIONAL CAMPAIGN: FOCUSING ON THE GENERAL PUBLIC

Chairperson:	Jeffrey Prottas, PhD
Co-Chairperson:	Wanda W. Bond
Background Papers:	Elaine Bratic Arkin
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	Charles F. Shield, III, MD
	Sylvester Sterioff, MD
	Moraima Trujillo, MD

INTRODUCTION

The appropriate goal of public education in organ donation is to increase the number of organ donors. This occurs primarily by increasing the number of families who say yes when asked to donate.

To achieve this, the goals of public education should be to create a more favorable predisposition by:

1. Increasing family discussions of the issues.
2. Increasing the signing of organ donor cards.
3. Decreasing misconceptions and fears of the public regarding organ donation.

RECOMMENDATIONS TO INCREASE ORGAN DONATION THROUGH PUBLIC EDUCATION

I-A.1. The Surgeon General should become the national spokesperson for organ and tissue donation and transplantation. (short-term)

I-A.2. There should be a consistent, uniform, national theme, nomenclature, and symbols for the promotion of organ and tissue donation. (short-term)

I-A.3. The Surgeon General should support an independent evaluation and testing of the AOPO public education campaign. If successful, the campaign should be endorsed as a national public education campaign. (short-term)

I-A.4. Form a task force of experts including communications specialists to review existing public education campaigns and establish criteria for future donation campaign design and evaluation. (short-term)

> I-A.4.Str.1: This task force should develop methods to gather information about minorities and other target audiences, message content, persuasive appeals, and communications channels.

I-A.5. Collect and analyze existing and new data regarding why families do or do not donate and develop strategies to increase donation. (short-term)

I-A.6. Conduct research to identify opportunities for increasing family discussion. In designing campaigns, attention should be given to the importance of stimulating family discussion. (short-term)

I-A.7. Develop a national effort to encourage signing and carrying organ donor cards. (intermediate)

> I-A.7.Str.1: Develop a comprehensive long-term plan in cooperation with organizations not currently involved in the organ and tissue business such as the National Highway Traffic Safety Administration.
>
> I-A.7.Str.2: Obtain support of the Advertising Council for this campaign.

I-A.8. Obtain and publicize donor card signatures of U.S. Congresspersons, governors and mayors at annual meetings of appropriate organizations including the National Governors Association and U.S. Conference of Mayors. Encourage similar support from local political leaders. (short-term)

I-A.9. Develop methodologies and implement a project to establish standardized donor information on drivers licenses throughout the United States. (long-term)

I-A.10. Create a task force to explore ways of recruiting voluntary health organizations to disseminate messages to increase organ and tissue donation. (intermediate)

I-A.11. The Surgeon General should seek support from the business community to promote organ and tissue donation and transplantation. Equivalent activities should be encouraged at the State and local levels. (intermediate)

I-A.12. The Surgeon General should seek support from the Business Round Table to promote organ and tissue donation and transplantation in the work place. (short-term)

I-A.13. The Surgeon General should approach individual national labor and union organizations (e.g., AFL-CIO) and ask them to promote organ and tissue donation among their members. (short-term)

I-A.14. The Surgeon General should seek support from the religious community through the National Council of Churches and other major religious groups in order to dispel misconceptions about organ and tissue donation. Equivalent activities should be encouraged at the State and local levels. (short-term)

> I-A.14.Str.1: Encourage leaders of U.S. churches and synagogues to communicate to their members the churches' support for organ and tissue donation.

I-A.15. The Surgeon General should seek support from national fraternities and sororities throughout the United States. Equivalent activities should be encouraged at the State and local levels. (intermediate)

I-A.16. The Surgeon General should approach the national PTA regarding education strategies for regional/local implementation. (intermediate)

I-A.17. Develop and maintain relationships with health educators and develop strategies to encourage them to educate individuals about organ and tissue donation. (intermediate)

I-A.18. Develop and maintain relationships with mass media executives, journalists, producers, and TV and movie script writers to encourage accurate programming and articles about organ and tissue donation, including family discussions of organ and tissue donation. (intermediate)

> I-A.18.Str.1: Develop relationships with organizations such as the American Society of Newspaper Editors and the National Association of Science Writers and Writers Guild of America. Also encourage science writers' seminars through the National Institutes of Health and other organizations.

I-A.19. Promote the UNOS 1-800-24-DONOR Line as a 24-hour-a-day hot line with access to bilingual callers. (short-term)

WORK GROUP I-B: A NATIONAL CAMPAIGN: FOCUSING ON DIVERSE SOCIO-ECONOMIC AND CULTURAL GROUPS

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Ernesto Rive-Mora, MD
Maritza R. Sanchez
Eduardo A. Santiago-Delpin, MD
Mark E. Whitlock, MS

INTRODUCTION

The Surgeon General should be highly commended for facilitating the first forum to allow minorities to present their problems regarding organ donation and to suggest solutions to their problems in a unified way.

The charge to the group for "A National Campaign Focusing on Minorities" has been to make recommendations to increase donations amongst diverse socio-economic and/or cultural groups within the U.S. population. Two groups were to serve as models: African-Americans and Hispanics. Discussion of Native Americans was also included in this group's deliberations. Asians and Pacific Islanders are another important minority which should be involved in future forums.

The entire work group met to discuss issues that cut across different minority populations. The members then divided into two sections, one focusing on Hispanics and the other on African Americans, in order to address issues that are specific to these two populations. The group members representing Native Americans participated in the Hispanic section. The following preamble and recommendations focus on minorities as a whole. This is followed by recommendations and strategies for African Americans and Hispanics with a few comments focused specifically on Native Americans.

OVERALL PREAMBLE AND RECOMMENDATIONS

There are some well recognized considerations that cut across the three minority groups discussed at this forum (African Americans, Hispanics, and Native Americans). These commonalities are: 1) each minority group represents a different and distinct culture; 2) the amount of poverty in each group is greater than that for the general U.S. population; 3) the education level in each group is less than that of the general U.S. population; 4) the overall health status of each group is lower than that of the general population; 5) the mean age in each group is significantly less than the White population. The fifth issue has particular importance as we embark on campaigns to increase organ donation in minority groups.

RECOMMENDATIONS

I-B.1. Current Federal funding for organ/tissue donation education for minorities is inadequate and should be allocated at an amount not less than $10 million a year for 5 years.

I-B.2. The funds identified in I-B.1. should be used to improve organ donation and to study all aspects of ESRD in all minorities.

I-B.3. The funds identified in I-B.1. should be used for African Americans/Blacks, Latinos/Hispanics and Native Americans as outlined in the subsequent recommendations and for other minority groups which were not addressed specifically during this workshop, such as Asians/Pacific Islanders.

I-B.4. The development of a minority coalition is absolutely necessary to allow minorities to address their concerns related to organ/tissue donation and transplantation. There should be adequate funding to enable this dialogue to continue on an on-going basis and to allow minorities to frame and implement solutions to their own problems, emphasizing interventions at the community and "grass roots" levels.

I-B.5. A national minority organ/tissue transplant educational program (MOTTEP) should be supported and funded at a level commensurate with the successful pursuit of its goal of increasing organ/tissue donation and transplantation among all minorities.

AFRICAN AMERICANS

Preamble

It should be the right of every American citizen to have equal access to the benefits of modern science and medicine. In the field of organ transplantation, discrepancies have been cited in the procurement and dispensation of donated organs. Specifically, African-Americans are less likely than whites to have undergone kidney transplantation and are over-represented on transplant waiting lists. Potential explanations for such disparities include: 1) limited fund of knowledge of the benefits of organ transplantation, due mostly to reduced access to medical care; 2) decreased rate of organ donation, and 3) institutional bias. These and other barriers to organ transplantation in African-Americans can be overcome by implementing a broad-based educational program utilizing mass media as well as community grass roots organizations.

Comprehensive educational efforts should proceed with the firm support of policy-makers and appropriations committees at the Federal, State, and local levels. Programs should have a precise target population, well-defined goals and tracking measures, and should be under the scrutiny of a central coordinating group. The overall, long-term goal of the educational campaign is to positively influence the attitudes and behavior of the target group towards acceptance of organ donation as an unselfish, "right" thing to do. The hallmark of the campaign in the African-American community, or with any ethnic minority, is the use of culturally sensitive instructional tools and emphasis on volunteerism. Based on these premises, the following recommendations are offered.

RECOMMENDATIONS

I. PROBLEM IDENTIFICATION

I-B.6. Allocate funds, no less than $5 million per year, for an in-depth analysis of medical and socio-economic factors that contribute to a low rate of organ donation and transplantation among African Americans.

> I-B.6.Str.1: Develop and convene a minority coalition encompassing the previously identified ethnic groups (African Americans/Blacks, Latinos-Hispanics, American Indians, and Pacific Island/Asian) to guide public education efforts targeted at these populations.

I–B.6.Str.2: Using extensive surveys and questionnaires, conduct large multi–center comparative studies of attitudes of all cultures toward organ and tissue donation.

I–B.7. Allocate funds for the development of a national campaign geared at increasing the rate of African American organ and tissue donors. This funding should be commensurate with the disproportionate degree of ESRD in African Americans.

I–B.7.Str.1: Examine replication of MOTTEP at regional and local levels.

I–B.7.Str.2: Conduct a mass media communication campaign aimed at minorities.

I–B.8. Funding should be made available for scientific projects that help determine the role of MHC tissue antigens and ABO blood types in graft survival and how immunogenetics impact upon graft allocations.

I–B.8.Str.1: Clarify indeterminate antigens in African Americans and examine their impact on allocation of organs.

I–B.8.Str.2: Identify specific HLA–A, B and DR antigens and subtypes and their correlation with graft survival.

I–B.9. Funding should be made available for exhaustive studies on why African Americans are disproportionately afflicted with kidney disease and other end–stage organ disease.

II. PUBLIC AND PROFESSIONAL EDUCATION

I–B.10. Public and professional education initiatives should incorporate the organized use of culturally sensitive instructional tools to increase the awareness of organ donation in the targeted populations.

I–B.10.Str.1: Mass media campaigns should be conducted which use clearly identifiable, positive, ethnic role models, including children. Information should be targeted to and appropriate for use at the community "grass roots" level.

I–B.10.Str.2: Convene a consensus conference of minority and majority participants to discuss utilization of minority requestors.

I–B.10.Str.3: Expand and replicate existing effective minority–focused donation education programs, such as those developed by the St. Louis OPO, the Howard University Program, and the Houston OPO.

I-B.10.Str.4: Develop proposed curricula for institutions of higher education which encompass donation and transplantation information. Disseminate curricula to all institutions of higher education, with a special emphasis on historically Black colleges and universities.

I-B.10.Str.5: Use Black History Month to emphasize donation/transplantation and the contributions of the African American community to the field of organ transplantation.

I-B.10.Str.6: Use culturally sensitive and ethnically similar speakers (donor families, recipients, clergy, etc.) to address religious concerns of minority populations.

I-B.11. Encourage medical and nursing schools to provide transcultural curriculum that sensitizes students to issues in organ donation specific to African Americans.

I-B.12. Private sector sponsorship of donor and transplant awareness programs should be aggressively pursued at Federal, State, and local levels.

I-B.13. African American organ donors (cadaveric/living) and recipients should participate in public education efforts and provide personal accounts of their transplant experiences to overcome major obstacles of apathy and fears that inhibit donation.

III. LEGISLATIVE INITIATIVES

I-B.14. This work group firmly opposes the use of any financial incentives for organ donation. However, medical expenses for living related donors should be subsidized.

I-B.14.Str.1: Funding should be made available for a recuperation period and hidden costs associated with live donation. Such costs might accrue from:

a. child care
b. surgery-related medical expenses
c. expanded period of disability and loss of work

I-B.15. Burial expenses for all cadaver organ donors should be made available.

I-B.15.Str.1: OPOs should contribute a set amount of monies to a general fund managed by a non-profit independent organization to which any donor family can apply.

I–B.16. States should incorporate questions on organ donation in their respective drivers manuals and examinations.

IV. ADDRESSING INSTITUTIONAL BARRIERS WITHIN ORGANIZATIONS SUCH AS HOSPITALS, OPOs, AND TRANSPLANT CENTERS

I–B.17. Transplant centers and OPOs must recruit culturally sensitive and ethnically similar staff.

> I–B.17.Str.1: National transplant organizations (ASTS, ASTP, NATCO, AOPO) should encourage the education and training of minority professionals.
>
> I–B.17.Str.2: Transplant centers, OPOs and hospitals should hire culturally sensitive and ethnically similar transplant coordinators and other personnel to enhance transplantation and donation among minorities.

I–B.18. Culturally sensitive and ethnically similar personnel must be recruited at all levels of transplant policy–making and implementation.

I–B.19. The Surgeon General must continue to address the presence of institutional barriers to organ transplantation for African Americans and should be commended for her current efforts.

HISPANICS

Preamble

Hispanics are one of the largest and fastest growing minority groups in the U.S. They comprise 9 percent of the Nation's total population and grew by 53 percent between 1980 and 1990. Hispanics are an aggregation of different national origin subgroups (primarily Mexicans, Puerto Ricans, and Cubans) with different geographic distributions. A few States and several cities contain the majority of the U.S. Hispanic population. Although Hispanics share a common language, they are acutely aware of the country of origin and of historic and ethnic differences among these subgroups.

The Hispanic population is concentrated primarily in five States: California, Texas, Florida, New York, and Illinois. In California, Hispanics make up one–fourth of the State's 30 million population, and are projected to exceed Whites in numbers by the year 2030.

The major health problem facing Hispanics is that they have much less access to health care providers and institutions than any other group in the United

States. Factors which limit access include lower rates of insurance coverage (private or public), lower income levels, language differences, and scarcity of Hispanic health providers. Uninsured rates are:

37 percent of Mexican Americans
20 percent of Cuban Americans
15 percent of Puerto Ricans compared to 10 percent of the non-Hispanic White population

Another major problem is that there are less national data available about the health status of Hispanics than for any other ethnic group. For example, the incidence of ESRD in the general Hispanic population or any Hispanic subgroup is essentially unknown.

Although studies exist on the demography and epidemiology of renal disease in the country or area of origin of the sub-groups (which can serve as comparative databases) only a few local U.S. studies address these issues in Hispanic populations. At best, therefore, one can only estimate the incidence of disease in the U.S. Hispanic population. The best study appears to be the San Antonio study where Mexican Americans were found to have an incidence of ESRD three times that of non-Hispanic Whites.

Other San Antonio data are also important for transplantation: 52 percent of the population are Hispanic, 80 percent of organ recipients are Hispanic, but Hispanics account for only 14 percent of organ donors. In general, cadaveric donation in Latin America follows a similar pattern with 64 percent of transplants being performed from live related donors as an overall average.

In the U.S., a number of additional factors have been identified as affecting organ donation. Sometimes decisions are made by a group, sometimes by the elders, sometimes by prominent members who are respected by the family, and frequently these do not coincide with the next-of-kin. Also, discussions are very lengthy, and family members frequently wait for calls or visits from members living far away. This "extended family" affects the request and donation process, especially with its time constraints.

Secondly, the emotional reaction of the family upon the news of death is often overtly expressed, frequently as uncontrolled anguish, many times to the point of a contagious form of hysterics. During this time, communication with the family is almost impossible.

Other factors affecting the donation rate of Hispanics relate to the small number of Hispanic coordinators/requestors with the necessary cultural awareness and sensitivity to communicate effectively with this population. Language is an important barrier as well. Ignorance of the donation process, of Hispanic disease statistics, and of the need for donation may result in a climate of distrust of the health care system, creating an additional barrier to donation. Most studies do not signal religion as a major disincentive or barrier to donation or transplantation for Hispanics, but a significant minority do regard organ donation as against their religion.

RECOMMENDATIONS

Immediate Action

I-B.20. Identify principal decision-makers and next-of-kin upon the potential donor's admission to the hospital.

> I-B.20.Str.1: Develop education document for transplant community: "What Works for Hispanic Organ Donation." (Identify barriers and suggest how to overcome them).
>
> I-B.20.Str.2: Establish culturally sensitive hospital-based resource teams with a focus on minority needs and issues.
>
> I-B.20.Str.3: AHA and State hospital associations shall establish guidelines for identifying decisionmakers and next-of-kin.

I-B.21. Establish awareness and understanding by requestors of the role of the extended family in Hispanic populations, their emotional reaction to death, and the grieving process.

> I-B.21.Str.1: Establish culturally sensitive hospital-based resource teams with a focus on minority needs and issues.

I-B.22. Make educators, counselors, and requestors aware of the importance of cultural and sub-group differences.

> I-B.22.Str.1: Develop education document for transplant community: "What Works for Hispanic Organ Donation." (Focus on barriers and how to overcome them).
>
> I-B.22.Str.2: Establish culturally sensitive hospital-based resource teams with a focus on minority needs and issues.
>
> I-B.22.Str.3: Provide education and scholarship funds for Hispanics to work in the organ donation field.

I-B.23. Increase the number of trained Hispanic requestors.

I-B.23.Str.1: Develop education document for transplant community: "What Works for Hispanic Organ Donation." (Focus on barriers and how to overcome them).

I-B.23.Str.2: Establish culturally sensitive hospital-based resource teams with a focus on minority needs and issues.

I-B.23.Str.3: OPOs serving large Hispanic populations shall hire and train Hispanic requesters.

I-B.24. Increase the participation of Hispanic donor families, live donors, and recipients and their families in the public education and donation process.

I-B.24.Str.1: Establish culturally sensitive hospital-based resource teams with a focus on minority needs and issues.

I-B.24.Str.2: The Surgeon General shall plan, direct, and fund a national campaign on organ donation using national Spanish speaking media.

I-B.25. Use bilingual consent forms and donor cards.

I-B.25.Str.1: Establish culturally sensitive hospital-based resource teams with a focus on minority needs and issues.

I-B.25.Str.2: OPOs with large Hispanic populations shall assure that bilingual consent forms and donor cards are used.

I-B.25.Str.3: Federal documents on organ donation shall be bilingual.

I-B.26. Train and encourage Hispanic physicians to participate in public and professional education related to organ donation and transplantation.

I-B.26.Str.1: Establish culturally sensitive hospital-based resource teams with a focus on minority needs and issues.

I-B.26.Str.2: Use teleconferencing to target large populations for education and discussion.

I-B.27. Increase the participation of Hispanic clergy in donation education activities.

I-B.27.Str.1: Establish culturally sensitive hospital-based resource teams with a focus on minority needs and issues.

I-B.27.Str.2: Establish in schools of medicine, allied health, and theology curriculum on organ donation and transplantation with an emphasis on minority communities.

I-B.27.Str.3: Use teleconferencing to target populations for education and discussion.

I-B.28. Encourage intra-family discussion of the donation process.

I-B.28.Str.1: Send information to households of card signatories (e.g., Motrain).

I-B.28.Str.2: Develop education document for transplant community: "What Works for Hispanic Organ Donation." (Focus on barriers and suggest how to overcome them).

I-B.28.Str.3: Establish culturally sensitive hospital-based resource teams with a focus on minority needs and issues.

I-B.29. Eliminate use of the term "brain death." Use "death" only.

I-B.29.Str.1: Establish culturally sensitive hospital-based resource teams with a focus on minority needs and issues.

I-B.29.Str.2: The Surgeon General shall communicate to neurological specialists and other appropriate physicians the need for timely declaration of death.

I-B.30. Present a simple, direct message of the need for and benefits to Hispanics to consent to organ donation.

I-B.30.Str.1: Conduct ongoing basic evaluation research on all education materials for the Hispanic community.

I-B.30.Str.2: Translate and disseminate the Pope's message on organ donation and encourage similar messages from other religious leaders.

Intermediate Action

I-B.31. Identify effective mechanisms and methods of communicating the subject of organ donation to the Hispanic population.

I-B.31.Str.1: OPOs shall actively recruit and encourage participation of Hispanic clergy, organ donors, recipients and their families in education about donation.

I-B.31.Str.2: Federal documents on organ donation shall be bilingual.

I-B.31.Str.3: Develop slide or video presentation in Spanish for use in public education initiatives targeted at Hispanics.

I-B.31.Str.4: Include bilingual information on organ donation in States' departments of motor vehicles, IRS, and Social Security documents.

I-B.31.Str.5: OPOs shall develop and distribute during Hispanic Heritage Week an information packet in Spanish on organ donation and transplantation.

I-B.32. Educate the public and professionals about the different roles of health care professionals in the donation process.

I-B.32.Str.1: Establish in schools of medicine, allied health, and theology curriculum on organ donation and transplantation with an emphasis on minority communities.

I-B.33. Reduce delays in declaration of death.

I-B.33.Str.1: Establish hospital-based resource teams.

Legislative Action

I-B.34. Determine demographic and epidemiological characteristics of Hispanic populations and sub-groups including genetic studies. Target studies to ESRD networks and OPOs serving large Hispanic populations in the United States.

I-B.34.Str.1: DHHS shall develop an RFC to establish a database on epidemiological parameters of the U.S. Hispanic population.

I-B.35. Improve access of Hispanics to the health care system, especially the medically and socially indigent.

I-B.35.Str.1: The minority coalition should develop a strategy to address this issue.

I-B.36 Provide financial assistance for health care and child care during rehabilitation of living organ donors.

I-B.36.Str.1: The minority coalition should develop a strategy to address this issue.

I-B.37. Investigate minimizing or eliminating burial costs to donor families.

I-B.37.Str.1: The Surgeon General shall encourage the identification of groups or panels of funeral homes who donate burial or provide burial at lower costs.

AMERICAN INDIAN/ALASKAN NATIVE (AI/AN)

In discussing means to increase organ donation in various socio-economic and/or cultural groups, there are two key issues which are important for American Indian/Alaska Native (AI/AN) populations in the U.S.: diversity and data.

1. **Diversity:**

   - In the 1990 census approximately 2 million persons identified themselves as American Indian/Alaska Native. These people comprise a very diverse group. There are more than 400 Federally recognized tribes and nations in the U.S., each tribe/nation representing a distinct cultural entity. While many people think of American Indian/Alaska Natives as living in rural reservations, more than half now live in urban (or near-urban) areas.

2. **Need for more accurate data:**

   - Too little is known about the characteristics of AI/AN with regard to awareness and attitudes related to organ donation, organ donor rates, reasons why AI/AN people do not donate organs, and accurate measures of need for organ transplantation. Similarly, too little is known about health care providers' attitudes and understanding of AI/AN individuals with whom they work.

RECOMMENDATIONS

I-B.38. The following organizations and groups should collaborate immediately to determine key organ donation and transplantation characteristics of AI/AN tribes and nations from all regions of the U.S.: AI/AN tribal leaders, the Indian Health Service, USRDS, OPOs, UNOS, HCFA, and HRSA.

I-B.38.Str.1: Develop an information base on American Indians/Alaskan Natives.

A. Describe awareness and attitudes related to organ donation issues for AI/AN groups in at least six regions of the U.S.

B. Describe and publish accurate information related to AI/AN populations on the following issues:

1. prevalence of diseases that result in end-stage organ failure
2. transplantation rates for these diseases
3. organ donation rates

I-B.38.Str.2: Conduct a workshop on the need for, current status of, and ways to increase organ donation in AI/AN. This workshop shall be organized by the DOT/HRSA and IHS. Participants at the workshop shall include at least the following: leaders of AI/AN tribes and nations; leaders of AI/AN urban clinics; health care workers who serve AI/AN people; and selected experts from the field of organ procurement, transplantation, education, and public relations.

OBSERVATION

Virtually all of the recommendations and action steps developed in this work group for Hispanics are pertinent to understanding organ donation in AI/AN. While it is likely that many AI/AN leaders would concur with these recommendations it is not possible to speak on behalf of all AI/AN. Recognizing the diverse cultural backgrounds and sensitivities of AI/AN is of paramount importance to improving the health of these people.

WORK GROUP I-C: A NATIONAL CAMPAIGN: FOCUSING ON CHILDREN, YOUTH, AND YOUNG ADULTS

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PREAMBLE

Any improvement in organ donation depends in large part on the education of children, youth, and young adults. This can only be achieved though the development of a wide variety of educational vehicles and opportunities in the public and private sector. Coordination of these educational activities and programs requires the leadership of the DOT. Educational efforts will also require the involvement of professional educators, transplant care givers, minority group representatives, and advocates for children, youth and young adults in a unique partnership which the DOT must foster. This task must begin now. We are pleased to be part of the Surgeon General's Workshop and hope that our efforts contribute to this important goal.

RECOMMENDATIONS

I-C.1. The DOT grant program should be substantially increased to encourage experimental programs to increase awareness among children, youth, and young adults, overcome barriers to donation, and promote family discussion of the issue.

Immediate Action:

I-C.1.Str.1: Approach minority groups to encourage organ donation education among children, youth, and young adults and to fund pilot projects.

I-C.1.Str.2: Require local OPOs and tissue banks to offer educational awards to schools for student essays and dramatizations which promote organ and tissue donation awareness.

I-C.1.Str.3: Support through grants the experimental programs Teens for Transplant, MOTRAIN, Kids On The Block, and the D.C. Organ Donor Committee's curriculum.

I-C.1.Str.4: The anticipated decrease in grant funds available for FY 92 is inconsistent with the growing donor gap and the educational needs identified by this work group and should be reversed through increased Congressional funding.

I-C.1.Str.5: Offer specific grant support for developing educational materials for students that have as a goal encouraging family discussion.

I-C.2: The DOT should expand its role in making basic research and other resource materials available to OPO officials and other advocates of organ and tissue donation.

Immediate Action:

I-C.2.Str.l: Develop a Current Health Information Database (CHID) subfile on organ and tissue donation for the purpose of identifying and making available unpublished reports, educational materials, and other "fugitive" literature.

Intermediate Action:

I-C.2.Str.2: Collaborate with other DHHS research agencies to sponsor new research (see I-C.2.Str.1.) on children, youth, and young adults.

I-C.2.Str.3: Compile existing survey and focus group research and conduct new research as necessary to:

1. Identify distinct target audiences among children, youth, and young adults.

2. Survey current knowledge, attitudes, and psychological barriers to donation; and,

3. Develop strategies for motivating increased donation.

I-C.2.Str.4: DOT/DHHS-funded research findings must be submitted to DOT, and made available to the public and to the CHID database (see I-C.2.Str.3).

I-C.3. The DOT should form partnerships with professional organizations to enhance education regarding organ donation in children and youth.

Immediate Action:

I-C.3.Str.1: Identify appropriate organizations which have an interest in donor awareness education directed at children, youth, and young adults and encourage these efforts through provision of materials, resources for presentations, and/or consultation for expanding programs. Specific attention should be directed to the eduction field, minority organizations, and pre-professional groups (medical, nursing, and education students).

I-C.3.Str.2: Undertake efforts through DOT staff and/or OPOs to respond to calls for papers and otherwise get on the agenda for national professional meetings to promote donor awareness education programs.

Intermediate Action:

I-C.3.Str.3: Convene national and/or regional meetings of representatives from education-related and professional organizations (e.g., pediatricians) to provide information, training, and materials to raise the awareness of their members regarding their role in organ donation awareness programs.

I-C.3.Str.4: Generate and make available generic education materials to professional organizations.

I-C.3.Str.5: Establish and maintain a Donor Education Network to facilitate communication and sharing among organizations involved in awareness education to enhance the potential of developing partnership efforts, materials development, and the establishment of an educational materials library.

I-C.4. The DOT should encourage the development of model educational curricula that will teach about organ transplantation and donation.

Immediate Action:

I-C.4.Str.1: Identify and review existing curricula and materials which should be evaluated by interested groups and disseminate the best to appropriate groups for adoption and/or adaption.

Intermediate Action:

I-C.4.Str.2: Work with textbook writers and publishers to get organ and tissue transplantation into textbooks in a variety of appropriate curricular areas. Developers of educational materials should be similarly addressed.

I-C.4.Str.3: Assemble curriculum experts in several academic disciplines to develop a comprehensive model curriculum addressing children from early childhood through high school.

1. The curriculum should be designed so that it can be adopted as a whole by a school system or in component parts - or adapted to meet individual needs.
2. The curriculum should emphasize the integration of organ and tissue donation and be developed for inclusion into subjects usually addressed in existing courses, e.g. study of organ systems in a health science course, study of public policy issues in a social science class.
3. DOT should enlist as a partner in this enterprise a national organization of educators whose advocacy for the curriculum can have a significant impact on its adoption, e.g. National Science Teachers Association, National Education Association, and National Association for Social Studies Teachers.
4. Prior to dissemination, the curriculum should be reviewed by a variety of interested groups, e.g. educators on areas such as religion, minority issues, health, etc.
5. Develop model curricula for inservice and continuing education for teachers (such as curriculum developed by the D.C. Organ Donor Committee for the National Kidney Foundation).

I-C.5. The DOT should require the OPTN to incorporate into its goals and planning process organ donation educational objectives appropriate to youth.

Immediate Action:

I-C.5.Str.1: Include representatives of children, youth, and young adults interests on appropriate UNOS committees.

I-C.5.Str.2: Expand OPO guidelines to include educators and youth representatives on advisory boards.

I-C.5.Str.3: Collaborate with appropriate organizations to implement youth-related educational activities.

Intermediate Action:

I-C.5.Str.4: Organize and disseminate scientific registry data related to children, youth, and young adults.

I-C.6. The DHHS should encourage the Department of Education, the Centers for Disease Control, and other relevant Federal agencies to make organ transplantation and donation education a national objective.

Immediate Action:

I-C.6.Str.1: Form a liaison with HCFA to implement educational requirements as a condition of participation for transplantation organizations within the agency's programs.

I-C.6.Str.2: Form a liaison with the Department of Education to establish organ donation education for children, youth, and young adults as a national priority.

Intermediate Action:

I-C.6.Str.3: Incorporate organ and tissue donation into CDC Teenage Health Teaching Modules, and "Growing Healthy."

I-C.6.Str.4: Encourage the Department of Education and CDC to develop grant programs to encourage innovative education programs at the local level.

I-C.6.Str.5: Appoint ombudspersons to coordinate various Federal efforts to increase donation among children, youth, and young adults.

I-C.7. The Secretary of DHHS, the Surgeon General, and DOT should encourage private, voluntary efforts by youth, student, and community groups to promote organ and tissue donation.

Immediate Action:

I-C.7.Str.1: Explore opportunities for collaboration with insurance companies, public utilities, and other private corporations to educate their customers about organ and tissue donation.

I-C.7.Str.2: Offer awards/recognitions to youth organizations which promote organ donation education.

I-C.7.Str.3: Collaborate with American Red Cross commercial blood donation programs and other appropriate organizations to develop methods for encouraging the completion of donor cards as a part of their operations.

I-C.7.Str.4: Identify recipient and recipient-family support groups (such as TRIO) and donor-family and hospital-based support organizations. Support groups and encourage their involvement in educational activities with children, youth, and young adults.

I-C.7.Str.5: Encourage the establishment of a permanent merit badge for organ and tissue donor awareness among scouting, campfire, and other similar youth organizations.

I-C.7.Str.6: Form a partnership with the American College Health Association to encourage donation among the students they serve.

Intermediate Action:

I-C.7.Str.7: Convene a conference of leading social, religious, and service organizations for youth, including minority youth, to encourage their involvement in stimulating organ and tissue donation among their membership and disseminating innovative program ideas.

I-C.7.Str.8: Support the activities of Teens for Transplants and other organizations whose sole purpose is donation and transplant related projects.

I-C.8. All DHHS Agencies awarding grants and contracts in the area of organ donation education for children and youth should make specific provisions for adequate evaluation of program outcomes.

Immediate Action:

I-C.8.Str.1: Require that applications for grants and contracts include adequate research designs to assess program outcomes.

I-C.8.Str.2: Designate a proportion of grant funds for evaluation.

I-C.9. DOT should reinvigorate efforts to enroll drivers' license applicants as potential organ and tissue donors.

Immediate Action:

I-C.9.Str.1: Review procedures in each State for encouraging the completion of donor cards by drivers' license applicants, the success of these procedures, and factors that discourage or fail to encourage potential donors.

Intermediate Action:

I-C.9.Str.2: Work with the officials of Departments of Transportation and State to develop strategies for increasing the number of completed donor cards by drivers' license applicants, including changes in State law or regulation, staff training for DMV employees, and enhanced public information/education programs. This should include a special focus on student drivers.

I-C.9.Str.3: Develop model legislation to enable the designation of donor status as a permanent part of the driver's license, subject to revision at the time of license renewal.

I-C.9.Str.4: Fund demonstration projects for increasing student enrollment in donation, including programs involving school-based and private driver training programs and the MOTRAIN system.

I-C.10. DOT should seek opportunities for promoting organ and tissue donation through local mass media.

Immediate Action:

I-C.10.Str.1: Identify appropriate celebrity spokespersons to represent its promotional efforts and to serve as role models for children, youth, and young adults.

I-C.10.Str.2: Seek cooperation with the OPTN in the development of mass media campaigns directed toward increasing organ donation awareness among children, youth, and young adults.

Intermediate Action:

I-C.10.Str.3: Expand the DOT grant program to encourage experimental programs that combine local mass media and community organization approaches to increase awareness among children, youth, and young adults; to overcome barriers to donation; and to promote family discussion of the issue.

I-C.10.Str.4: Develop video and/or audio news releases for use by local television and radio news programs.

I-C.10.Str.5: Establish a public relations program to stimulate favorable coverage of organ and tissue donation, with special attention to national youth-oriented publications, college newspapers, and newsletters for social, religious, service, and educational organizations for youth.

I-C.10.Str.6: Develop a program of media training for local OPO officials and other advocates of organ and tissue donation. Special attention should be paid to eliminating medical terminology that reinforces public misperceptions and to develop, instead, more appropriate terminology for specific lay audiences.

WORK GROUP II-A: THE DELIVERY SYSTEM

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RECOMMENDATIONS

II-A.1 Maintain the current approach of organ and tissue donation based on voluntary, altruistic choice and family participation, but continue to explore the potential impact of possible alternative approaches, such as financial incentives and presumed consent.

> II-A.1.Str.1: DHHS should support the collection and further analysis of existing data on the attitudes of the public as well as those involved in the donation process regarding the issues of financial incentives and presumed consent.
>
> II-A.1.Str.2: In addition, DHHS should lead and promote development of a research agenda for alternative approaches to organ acquisition and development of a program of demonstration projects which would include other approaches which might be pursued.

II-A.1.Str.3: The Surgeon General should publicly support and promote the programs of the National Organ Transplant Act including the OPTN and OPOs.

II-A.2. Improve the outcome of requests to families to donate by assuring that the individual responsible for making the request is appropriately trained to make an effective request.

II-A.2.Str.1: HCFA should clarify its regulatory requirements on hospitals to clearly permit hospital protocols to provide that OPOs can be delegated the responsibility to make the donation request of the family.

II-A.2.Str.2: The Division of Organ Transplantation should convene an advisory group to develop standards for individuals making requests for donation.

II-A.2.Str.3: Identify and establish means to eliminate barriers that prevent active participation of neurosurgeons, emergency care physicians, critical care nurses, neurologists, and other related personnel in the organ donation process.

II-A.3. Improve the compliance of hospitals with the current statutory and regulatory requirements of routine inquiry and required referral.

II-A.3.Str.1: HCFA should immediately develop a comprehensive strategy for increasing hospital compliance which includes mechanisms for policy implementation, monitoring, enforcement, and evaluation.

II-A.3.Str.2: HCFA should develop measures of hospital performance for identification and referral of organ and tissue donors and feedback of compliance data to hospitals and OPOs.

II-A.3.Str.3: UNOS should require transplant centers to demonstrate compliance with routine inquiry and required referral as a condition of UNOS membership.

II-A.3.Str.4: DOT shall identify successful routine inquiry and required referral programs, and establish and maintain a clearinghouse that facilitates and promotes these models.

II-A.3.Str.5: DOT, through its grant program, will encourage the development of successful strategies intended to improve routine inquiry and required referral.

II-A.3.Str.6: The DOT grants and contract program should be expanded to include funds to develop model required referral/routine inquiry protocols.

II-A.4. Enhance the effectiveness of decision-making by potential donors.

II-A.4.Str.1: DHHS should publish a compendium of effective State strategies for increasing numbers of individuals choosing to donate their organs and tissues, and disseminate it to State lawmakers for possible State action.

II-A.4.Str.2: HCFA's policies and procedures to implement the Patient Self Determination Act should incorporate organ and tissue donation.

II-A.4.Str.3: DOT should fund a study on how donor cards can become more effective tools for donation. The study should include alternative sites for signing donor cards, ways of increasing family involvement in signing donor cards, and ways of assuring that families and health care providers know that an individual has signed a donor card.

II-A.4.Str.4: The Surgeon General should encourage the use of Durable Powers of Attorney (DPA) to make wishes known about donation and to clarify which family members or other persons should be consulted by providers in making organ procurement decisions.

II-A.4.Str.5: DOT should evaluate the possibility of replacing the current donor card format with a donor DPA.

II-A.4.Str.6: The Surgeon General should encourage the National Commission on Uniform State Laws to establish the legal sufficiency of donor DPAs and to clarify the legal immunity of health care providers in adhering to the terms of the DPA.

II-A.4.Str.7: DOT should explore methods to increase the use of donor DPAs in minority populations.

II-A.4.Str.8: DOT should develop methods for making donor DPAs and other advanced directives known to hospitals and OPOs in the case of nonelective admissions.

II-A.5. Increase the effectiveness of the organ and tissue procurement system.

II-A.5.Str.1: DHHS should widely publicize the results of studies concerning the reasons for widely varying rates of procurement by OPOs.

II-A.5.Str.2: DOT should develop a targeted grant program to assist poorly performing OPOs develop structures that would result in improved performance. Special consideration should be provided to applicants proposing collaboration with hospitals.

II-A.5.Str.3: The Assistant Secretary for Health and the Administrator of HCFA should convene a meeting of representatives from the procurement community to identify, disseminate, and encourage the adoption of successful strategies associated with organ and tissue procurement.

II-A.5.Str.4: AOPO, EBAA, AATB and DOT together should develop standardized policies and procedures to enhance effectiveness and efficiency of procurement.

II-A.5.Str.5: Eliminate the current inconsistencies and confusion in the identification of organ donors by establishing standardized criteria for donor selection.

II-A.5.Str.6: DOT, in conjunction with AOPO, OPTN, and tissue and eye banks, should create a centralized data base on hospital and procurement success rates.

II-A.5.Str.7: DOT should intensively review outlier OPO performance.

II-A.5.Str.8: DOT should gather, disseminate, and support adoption of strategies which are known to provide donor family support, decrease care giver burdens, and increase organ and tissue recovery rates.

II-A.5.Str.9: DOT, in conjunction with professional societies, hospitals, and hospital representatives, should develop strategies to educate and support physicians and nurses in positions of triage and management of potential organ and tissue donors.

II-A.5.Str.10: The Surgeon General should encourage the Secretary of DHHS to have proposed rules governing the policies of the OPTN published within 30 days.

II-A.6. Investigate the competitive and financial disincentives for hospitals to participate actively in the procurement process, including costs associated with medical management of potential donors.

II-A.6.Str.1: HCFA should conduct a study of hospital costs relating to organ donation to ascertain the extent to which unrecovered costs are hindering hospital involvement in organ donation. Examples of such costs are physician services, laboratory tests, and other very extensive services in critical care units to maintain organ viability after brain death pending retrieval.

II-A.6.Str.2: Based upon the study results, HCFA should develop proposals to eliminate such disincentives.

II–A.6.Str.3: The Surgeon General should become apprised of these disincentives and exert leadership to understanding of the organ procurement inhibition arising from the competitive disincentives on trauma centers which regularly furnish organs to competing transplant centers. While hospitals operating these trauma centers are reimbursed for the cost of organ retrieval, they are not compensated for the very large financial losses associated with operating the trauma centers. Negative motivation sets in when trauma personnel of one hospital are expected to extend themselves for retrieval of an organ which has the effect of enhancing the competitive reputation of a transplant center at a rival hospital. This dynamic may be unfortunate, but it exists and materially inhibits organ procurement.

II–A.7. Increase the ability of the hospital to manage brain dead* potential donors and preserve organs prior to recovery in order to provide adequate time to obtain family consent in a sensitive manner.

II–A.7.Str.1: The Secretary of DHHS shall develop an RFP for basic bench research to identify chemical, biological, and other compounds research which will preserve anatomic and physiologic viability of donor organs and tissues prior to recovery but after determination of brain death.

II–A.7.Str.2: The Secretary of DHHS shall initiate multicenter studies on optimal clinical management for patients determined to be brain dead.

II–A.7.Str.3: Required referral protocols should be developed by UNOS and DHHS that will provide OPOs notification as early as possible of a potential organ donor so that the OPO can assist the hospital personnel in appropriate donor management to assure that families are given the opportunity to donate.

II–A.8. Evaluate the extent to which there are financial disincentives for live donation.

II–A.8.Str.1: DOT should expand its analysis of funding sources for living donor expenses.

II–A.9. Encourage cooperative efforts between OPOs, tissue banks, and eye banks.

II–A.9.Str.1: DOT should encourage and facilitate joint public and professional education programs by OPOs, tissue, and eye banks.

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* Until medical certification of brain death, patient management should continue with the goal of patient survival.

II-A.9.Str.2: DOT should encourage and facilitate the publication of joint public relations materials.

II-A.9.Str.3: DOT should encourage cross-training of staffs of OPOs, tissue banks, and eye banks.

II-A.9.Str.4: Encourage where applicable the community-based one number concept.

II-A.9.Str.5: The Surgeon General should work with national groups representing funeral directors, coroners, medical examiners, and emergency medical services personnel to develop guidelines that would facilitate their professional involvement in the donation system.

II-A.9.Str.6: The Surgeon General together with HCFA shall exert leadership to call for professional membership in OPOs' Boards of Directors by community leaders who demonstrate stature, capability, and commitment in enhancing organ availability.

II-A.9.Str.7: Congress should enact legislation that encourages and facilitates cooperative relationships among OPOs, tissue banks, and eye banks that includes promoting single number calling.

II-A.10. Assure equal opportunity for transplants in order to ensure the public's enthusiastic participation in donation.

II-A.10.Str.1: Eliminate the 3-year Medicare eligibility limit for successful transplant patients and extend coverage for payment of immunosuppressive medications for transplant patients to be made coterminous with the period of entitlement.

II-A.10.Str.2: Encourage public and private insurers to offer both coverage and reimbursement for transplant procedures considered to constitute established therapy.

II-A.10.Str.3: Identify medical treatments and social behaviors which prevent or delay onset of end-stage organ failure. Develop strategies for increasing access to such treatments and enhancing such social behaviors.

II-A.10.Str.4: Certificate of Need and OPTN membership approval should require disclosure of strategies that assure access to transplants regardless of ability to pay.

II-A.10.Str.5: DOT will require that the OPTN eliminate all variances in the organ allocation system, except in those cases where the variance assures equitable patient access.

II-A. 11. Provide adequate resources to DOT to successfully carry out its many critical missions.

> II-A.11.Str.1: The Secretary of DHHS should request a FY93 budget of $7 million, including at least $3 million to expand and enhance the grants and contracts program.

WORK GROUP II-B: PROFESSIONAL EDUCATION

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RECOMMENDATIONS

A. GENERAL

For purposes of this series of recommendations health care professionals include the categories as described by Hostetter and Weber in "Increasing Donation by Focusing on the Health Care Environment: Professional Education" (in Background Papers for the Surgeon General's Workshop on Increasing Organ Donation: July 8-10, 1991.) The first category includes "those who are already members of the transplant community, such as transplant physicians and surgeons, clinical transplant coordinators, and organ procurement coordinators." The second category includes "those professionals whose roles bring them into direct contact with the transplant community." Examples here are social workers, critical care physicians and nurses, trauma physicians, neurosurgeons, and neurologists." The third category includes professionals such as clergy, morticians, medical examiners, coroners, and attorneys whose roles, though not directly related to the organ donation and transplantation process, place them in positions to significantly influence individuals' attitudes and decisions related to organ donation.

II-B.1. To begin immediately and continue into the long-term, the Division of Organ Transplantation (DOT) should play a facilitative role with practitioners and educators in each health care profession. Educational goals for organ and tissue procurement (hereafter referred to as "organ") and transplantation learning for health care professionals at all levels of preparation should be defined. In order to ensure preparation of those who will teach undergraduates, special attention should be directed to graduate education in the various professions. Specific educational approaches should be developed which are appropriate for each profession. Evaluation of learning appropriate to the specialty should be included in licensure and certification/recertification requirements. The rapidly changing environment of organ procurement and transplantation requires the continued education of established practitioners at all professional levels.

> II-B.1.Str.1: The Surgeon General should encourage utilization of the existing and proposed curricula developed by UNOS for health professionals.
>
> II-B.1.Str.2: The Surgeon General should encourage the appropriate licensing and certifying agencies to include the field of organ donation and transplant practices in examination development.

II-B.2. In the intermediate term, comprehensive education programs addressing perceptions, attitudes, and knowledge which are barriers to organ procurement should be developed targeting physicians, nurses, and hospital administrators. The foundation for the development of these programs should begin by involving the target audience in the creation, implementation, and distribution of the program. The target audience should identify the content and teaching strategies to be used.

> II-B.2.Str.1: The existing model developed by the American Association of Critical Care Nurses and the National Kidney Foundation to train critical care nurses in the donation process should be used to develop comparable programs for the identified groups.

B. RESEARCH

II-B.3. In order to determine effective educational strategies an understanding of the causes for the present low rate of procurement is needed.

> II-B.3.Str.1: Beginning immediately, conduct research studies to inventory and assess the outcomes of existing formalized educational programs at undergraduate and graduate levels of health professional training. These should include, but not be limited to, academic institutions and professional associations. Publicize the results and promote the utilization of these assessments to develop new more effective programs.
>
> II-B.3.Str.2: Identify the components of OPO programs which lead to successful practices.

II-B.3.Str.3: Study the experience and attitudes of families approached for donation to determine factors which influence their decision to accept or decline the option of donation.

II-B.3.Str.3A: Convene a small group of experts appropriate to each research question. This group or groups will develop the parameters of a study or studies for subsequent use in developing an RFP with funding to be identified by the Surgeon General. Simultaneously, the Surgeon General should publicize the need for research in these areas in appropriate professional journals.

II-B.4. In order to develop more successful educational strategies and operational programs, the Surgeon General should immediately encourage appropriate agencies (for example, AHA, PHS, OPOs) to collaborate with hospitals and OPOs to:

1. Identify all potential organ donors through on-going comprehensive medical chart review.

2. Report data based on the following categories:

    a. Cases referred to the OPOs who became actual donors and those lost. Donor loses would be explained.

    b. Cases not referred to the OPO.

3. Develop strategies that ensure that all identified potential organ donors are referred to the OPO. Determine where and from whom referrals originate and who facilitates or impedes the referral. Identify the cause of donor losses and propose strategies for improvement.

II-B.4.Str.1: The Surgeon General working through appropriate agencies needs to assure that policies exist which allow OPOs to accomplish the actions desired for these recommendations.

II-B.5. In the intermediate term, encourage and solicit publications pertaining to the legal, moral, and ethical issues relating to organ and tissue donation in widely read professional journals. Topics should include but not be limited to the frequency and nature of litigation brought against health care professionals and to the rights of donor families.

II-B.5.Str.1: The Surgeon General's office should take a leadership role to assure the publication of this information.

II-B.6. In order to enhance and promote the professional practice of OPOs, a study should be conducted within the current year to determine marketing-education and training needs. Based on the results of this survey, the curriculum for comprehensive OPO marketing and training should be developed in collaboration with NATCO, AOPO, and UNOS.

II-B.6.Str.1: The Surgeon General should convene a focus group at a convenient time to determine baseline needs.

II-B.6.Str.2: The Surgeon General should form a marketing and training advisory group with representatives including, but not limited to, UNOS, NATCO, and AOPO to develop a content curriculum for the training of OPO personnel.

II-B.7. Beginning immediately, training focusing on ethnic diversity and cultural differences should be conducted for OPO staff and key donor hospital staff to heighten their awareness of these issues.

II-B.7.Str.1: The Surgeon General should identify an advisory group of experienced trainers in the area of ethnic diversity and cultural differences who can develop appropriate training materials.

II-B.8. Beginning immediately, the organ procurement community should establish a relationship with the local medical examiner/coroner's office and coordinate efforts to promote mutual professional education. The learning objective of this mutual education should be the rapid identification of potential donors who may come under the medical examiner/coroner's jurisdiction in order that investigation and clearance for donation can occur in a timely manner.

II-B.8.Str.1: The Surgeon General should, through appropriate publications, express interest and concern for this issue emphasizing that OPOs should be developing relationships within the medico-legal community.

II-B.9. Other groups crucial in the organ donation process should be targeted for educational programs. These groups include the clergy, attorneys, and morticians.

II-B.9.Str.1: The Surgeon General should, through appropriate publications, express interest and concern for this issue. The Surgeon General should encourage the transplant community to develop partnerships with these groups.

WORK GROUP III-A: RE-EXAMINING DONOR CRITERIA: CADAVERIC DONORS

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The objectives pursued by Work Group III-A fell into two categories:

1. Increase organ transplantation activity by increasing the pool of acceptable brain dead cadaveric donors.

2. Increase organ transplantation activity by identifying and utilizing a pool of non-heart beating donors.

The major motivation is to provide safe organs for transplant patients.

RECOMMENDATIONS

III-A.1. The use of donors at both extremes of age is recommended. Specific criteria should be developed for each organ.

III-A.2. It is recommended that HIV-positive donors not be utilized to protect recipients against transmission of this disease.

III-A.3. It is recommended that Hepatitis B surface-antigen-positive donors not be utilized.

III-A.4. It is recommended that there be acceleration and approval of newer more sensitive tests for HIV and Hepatitis B infection on the donor population.

III-A.5. It is recommended that organs and tissues from Hepatitis C positive donors be offered and used selectively.

III-A-6. It is recommended that organs and tissues from systemically infected donors be used selectively.

III-A.7. The medical climate has changed considerably over the past 5 years. We must consider expanding the donor pool in light of severe donor shortages. The use of an expanded pool of donors, e.g., those with diabetes, hypertension, past treatment of cancer, should be considered.

III-A.8. A national study of attitudes toward presumed consent in the U.S.A. should be conducted.

III-A.9. A pilot project of presumed consent within a subpopulation (such as the military) should be conducted. This could be supported by a grant from DOT.

III-A.10. Required referral should be implemented as part of routine hospital accreditation.

III-A.11. A pilot project which eliminates the disincentives associated with organ donation should be conducted under grant or contract from DOT.

III-A.12. A national study of attitudes toward incentives to organ donation in the U.S.A. is needed. The results could lead to a pilot project on incentives.

III-A.13. Stronger liaisons are needed between OPOs and medical examination offices to facilitate the organ donation process.

III-A.14. It is recommended that non-heart beating donors be used for transplantation.

WORK GROUP III-B: RE-EVALUATING DONOR CRITERIA - LIVE DONORS

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RECOMMENDATIONS

The work group recommends that:

III-B.1. The criteria for selection of living donors should consider the physiologic conditions of the donor rather than the chronologic age. Those donors who have health conditions which involve minimal risk of morbidity and mortality may be acceptable. (Policy/Medical criteria)

III-B.1.Str.1: The Surgeon General develop a position paper about living donation that addresses the following:

A. reaffirming living donor transplantation
B. re-evaluation of live donor criteria
    - age
    - unrelated live donor
C. medical risk factors
D. issues of consent (especially for those less than the age of emancipation) (Immediate)

III-B.2. Transplant teams should determine that prospective live donors are competent to consent to or refuse donation, have adequate information to make an informed choice, and can choose voluntarily without coercion or undue influence. Donors below the age of emancipation may be considered with the appropriate safeguards. (Policy/Medical criteria)

III-B.3. Potential live donors receive full and unbiased information about the short- and long-term benefits and risks of donation. (Education)

> III-B.3.Str.1: Overall recommendation for all education recommendations: Federal funds be allocated to establish a national clearinghouse for education related to all aspects of organ donation and transplantation. (short-term within 2-3 years.)

III-B.4. Potential recipients and families receive full and unbiased information about the short- and long-term benefits of all options for transplantation including living related and unrelated donors. (Education)

> III-B.4.Str.1: The Division or Organ Transplantation, in collaboration with Federal agencies and transplant-related health organizations, review educational materials developed for informing patients and families about the treatment therapies for end stage-renal disease. Additionally, the ESRD networks should be required to develop a mechanism for verifying that these materials have been reviewed by patients and families. (ongoing review, ESRD documentation within 1-2 years)

III-B.5. Health care professionals have current information about the appropriate use of live donors for transplantation in order to adequately provide counsel and education to potential recipients and live donors. (Education)

> III-B.5.Str.1: Medical and nursing school curriculum currently being developed by UNOS' Education Committee should incorporate information about the use of live donors. (immediate-ongoing)

III-B.6. Public education should emphasize the potential benefits and minimal risks of living donation. (Education)

> III-B.6.Str.1: Any national campaigns should include information about using live donors for transplantation.

III-B.7. Financial disincentives to live donors should be removed. (Policy/Financial)

> III-B.7.Str.1: A work group comprised of representatives from NATCO and UNOS will study and assess the financial burdens of being a live donor and

develop a set of recommendations and strategies to eliminate financial disincentives to live donation.

III–B.8. Public and private payors should recognize the therapeutic benefits of transplantation with living donors and not discriminate against these procedures. (Policy/Financial)

III–B.8.Str.1: The Surgeon General should encourage the Secretary of Health and Human Services to request HCFA and private payors not to differentiate between donor source for the reimbursement of an approved transplant procedure. (Immediate)

III–B.9. An ongoing program of data collection should be implemented to continue to evaluate the risks and benefits of live donation. (Research/Data)

III–B.9.Str.1: Charge the OPTN Scientific Registry with developing a registry of live donors for long–term follow–up. (Immediate)

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