

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:

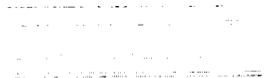
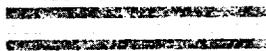
- more than 13 million Americans have kidney and urologic disease today.
- 190,862 Americans were listed in 1989 as having end-stage renal disease.
- 58 million Americans have high blood pressure -- 30 percent of all adults ages 18-74 have high blood pressure; 38 percent of Blacks compared with 28 percent 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 Americans 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.



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.



U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES
PUBLIC HEALTH SERVICE

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

Date

PHS-T810

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

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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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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.