

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 through 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.1: 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Information Database (CHID) subfile on organ and tissue donation for the purpose of identifying and making available unpublished reports, educational materials, and other "fugitive" literature.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 education 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.

* 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 losses 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 of 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)