

## Increasing the Supply of Solid Organs for Transplantation

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**R**ECENT SUCCESSES IN THE TRANSPLANTATION of solid organs have made it obvious that more organs are going to be needed than are currently being donated.

In the United States last year:

- 5,358 kidney transplant operations were performed, according to information reported to the Health Care Financing Administration, Department of Health and Human Services. Of these, 3,681 involved cadaveric donors.
- Approximately 100 patients underwent cardiac transplantation, including 7 patients who had heart-lung transplant procedures.
- The pioneering transplant team at the University of Pittsburgh carried out 82 liver transplants, almost 4 times the yearly number ever previously possible.

Kidneys have been in short supply since the advent of the transplant era. Even today, many patients must often remain on dialysis when they could be independent if a matched kidney were available for transplantation. There are currently about 65,000 patients on hemodialysis or various forms of peritoneal dialysis. Of course, not all kidney dialysis patients are suitable recipients for renal transplants. However, in 1982 the nation's transplant centers reported that more than 6,720 end-stage renal dialysis patients were wait-listed on kidney transplant registries.

Unfortunately, there is no temporizing mechanism, such as a dialysis procedure, available for someone who is being considered as a candidate for heart or liver transplantation.

The plight of parents seeking donated livers for their children, many suffering from biliary atresia, who would otherwise die without a transplant operation, is perhaps the most recent dramatic manifestation of the dilemmas created by this major accomplishment of modern medicine. Following appeals to the White House for several of these children, the Public Health Service was asked by President and Mrs. Reagan to convene a group of experts to dis-

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cuss ways to increase the supply of organs for transplantation.

Forty-two people—many representing national organizations interested in transplantation—were invited to participate in a Surgeon General's workshop at Project HOPE headquarters, near Winchester, Va., June 7–9, 1983 (see list on page 000). Their task was to seek approaches to help solve the chronic need for donated organs and to pay particular attention to educating the medical community and the general public.

### Current Efforts and Future Needs

At the workshop's first plenary session, Dr. Clive O. Callender of Howard University, Washington, D.C., presented an overview of current attitudes of the American public toward kidney donations, based on a survey (1) conducted earlier in 1983 by the Gallup Organization, Inc. Some of the findings of the survey follow:

- Most Americans (93 percent) have heard or read something about organ transplants. This level of awareness is relatively constant across all demographic groups except that 95 percent of white respondents have heard of organ transplants, compared with 84 percent of black respondents.
- Almost three-quarters (72 percent) of those aware of organ transplantation said that they are very likely to give permission to have the kidneys of a loved one donated after that person's death, and half said that they are very likely to donate their own children's kidneys in the event of accidental death of the child. However, only 24 percent said that they are very likely to want their own kidneys donated after death.
- Those who are most likely to want their own kidneys donated after their death are those who have completed more years of formal education and are in higher income brackets. Blacks are less likely than whites to want their own kidneys donated (10 percent versus 27 percent).

In a pilot project that Callender conducted among blacks in the District of Columbia, he found that the most common reasons blacks donate fewer kidneys than whites were (a) lack of knowledge, (b) religion, (c) fear of complications, and (d) lack of adequate communication between lay persons and health providers (2). He plans a more detailed study of this aspect of attitudes toward organ donation.

Dr. Roger W. Evans reviewed papers (3, 4) developed by the staff at the Battelle Human Affairs Research Centers on the need for and supply of organs and organ donor cards. On the basis of existing epidemiologic information, Evans stated that the need for donor organs far outstrips their supply. On the positive side, he reported, there are clearly more organs available than are being harvested, suggesting that more efficient methods for procurement must be used to lessen the gap between need and supply. He noted the American Medical Association's estimate that as many as 20,000 people who have brain injury, tumor, or infarction of a vessel in the brain die each year in the United States; they are potential organ donors. In the future, he envisioned that the gap between need and supply for heart transplantation will definitely exceed that for kidney transplantation.

Dr. Steven Teutsch of the Centers for Disease Control (CDC) reinforced Evans' contention that more organs are available than are being harvested. He reviewed a pilot study (5) conducted by the CDC to increase the supply of cadaveric kidneys for transplantation in selected hospitals in Georgia. This study used systematic retrieval techniques based on the epidemiologic and public health tools of surveillance and evaluation. As a result, the number of kidneys procured during the 3 years of the study (1976-79) was triple the number procured during the three previous years. Teutsch said that the process was highly labor intensive, but highly productive. He believed that some of the techniques employed in the CDC study could be adapted by other transplant centers.

Despite the emphasis given to donor cards, a Battelle nationwide inquiry (4) of medical and transplant center personnel familiar with organ donation procedures revealed two important dilemmas.

- There is an explicit belief that a greater number of signed donor cards will necessarily increase the supply of donor organs. However, the fact that only a small percentage of donors actually have donor cards raises questions about both current methods of donor card distribution and their overall effectiveness.

- The Uniform Anatomical Gift Act has been adopted in some form by all 50 States and the District of Columbia, and the legislation has been in effect since 1973. Although the act explicitly recognizes donor documents as sufficient legal evidence of a person's donative intent, the vast majority of medical institutions do not allow organ removal without consent of next of kin. In most instances, this policy is based on the realities of our litigious society.

Winifred Mack, president of the North American Transplant Coordinators Organization (NATCO), described the organ procurement process and focused on the duties and responsibilities of the transplant coordinator—a new breed of health professional. She outlined the normal procedure for establishing a local cadaver organ retrieval system, implementing that retrieval process, and working with regional and national resources. Mack reported on NATCO's two new communications efforts:

1. 800-24-DONOR, a national telephone system that directs health professionals to the nearest organ recovery center in the area, and
2. 24-ALERT, a system to disseminate information concerning the need for extrarenal organ donors to procurement programs throughout the United States and Canada. In this system a recorded telephone message, updated usually twice a day, provides a listing of urgently needed livers, hearts, lungs, heart-lung combinations, and pancreata for patients awaiting transplantation at the 18 participating centers. The system operates 24 hours a day and gives details of extrarenal donor requirements including organ needed, blood type, age, geographic recovery area, and 24-hour referral number.

Dr. John Purvis, neurosurgeon from Knoxville, Tenn., presented a glimpse of his personal experiences in educating physicians, including neurologists and neurosurgeons, on brain death. He encouraged transplant surgeons to speak at State medical society meetings so family physicians could "add a face to a name" and be stimulated to participate in the organ retrieval process.

Dr. John C. McDonald, president of the Southeastern Organ Procurement Foundation (SEOPF) described the computer-based organization he heads. SEOPF is a voluntary association of 41 medical institutions in 18 Southeastern States and Puerto Rico, and it has a current computer enrollment of more than 3,000 kidney transplant recipient candidates as well as extrarenal candidates. At present the kidney

efforts of SEOPF are financed by the Social Security Administration; extrarenal efforts are financed by local institutions from varied sources.

Since the beginning, the purpose of SEOPF has been to avoid organ wastage by fostering the proper sharing of organs, quality control, and appropriate preservation and organ retrieval methods. McDonald said that there is a growing number of kidney transplant candidates whose sera are not compatible with those of more than 60 percent of the general population. This incompatibility increases the difficulty of getting a good match. To remedy this, SEOPF has developed a tissue typing tray with special sera. According to McDonald, use of these trays at both the donor's and the recipient's facility has eliminated the necessity of moving the kidney or tissue from the donor to other institutions when there is a high probability of a positive cross-match.

McDonald revealed that there was a wastage of kidneys of 18 to 21 percent in 1981-82. Twelve percent of the kidneys either were obviously diseased or were technically unsuitable for transplantation at the time that they were removed. SEOPF has been trying to reduce the remaining 6 to 9 percent of the wastage that has been attributable to the inability to find an appropriate recipient for the organ or to some misadventure in removal, preservation, or transplantation.

Because other regions of the nation have not developed such a computer-based operation, SEOPF has made its computer hardware and software available to transplant centers outside the SEOPF region under a program called United Network for Organ Sharing, or UNOS. The UNOS program now extends the computer selection network to 59 other transplant institutions. As a result, 93 percent of the continental United States is covered either by SEOPF or UNOS. Efforts are in motion to establish a separate national board of directors for UNOS to develop this system into a true super-network serving the entire nation.

At the conclusion of McDonald's presentation, SEOPF personnel presented a brief demonstration of how a transplant center having an organ available can receive data, from a computer terminal, on patients needing transplants who are registered in the SEOPF computer.

Workshop participants were divided into small groups to pursue answers to seven questions. The charge to the moderators of these discussion groups was to identify specific issues associated with the topics under discussion, rank them, and suggest strategies and initiatives to the Surgeon General for

resolving the high priority issues. The questions and the groups' suggestions, in capsule form, follow:

### Summary of Workshop Reports

*How can existing barriers to the donation of organs for small children be overcome?*

The group addressing this question strongly recommended the establishment of a task force to produce a series of concise working papers that would provide the information base in four specific areas: (a) characterization and quantification of pediatric donors and their families and pediatric recipients; (b) description and assessment of the current organization of health care for transplantation of pediatric patients and the associated organ procurement procedures, systems, and programs; (c) cultural assessment of the family unit in relation to donation of a child's organ; and (d) attitudes and priorities of the public and of health care providers regarding transplantation in relation to other health issues in the pediatric population. The group urged the Surgeon General to request that the Centers for Disease Control generate data on the potential pool of donor children, including the identification of etiologies and number of deaths that could be potentially prevented by transplantation of kidneys, livers, or heart-lung combinations.

*Do barriers exist to obtaining multiple organs from one body? What are they, and how can they be overcome?*

This group believed that lack of professional awareness and communication among procurement coordinators, intensive care nurses, and transplant teams headed the list of barriers. The members recommended that a model project involving several centers be established to demonstrate methods for resolving the complexities of multiple organ procurement, including continuing education geared to professionals and offered in hospitals. It also suggested that a federally funded meeting be held to develop guidelines for donor maintenance and that the Surgeon General convene a panel to devise a coordinated, nationwide system for organ sharing.

*What specific educational measures will encourage the general public to think of the usefulness of organ donation, particularly when a family member is on a respirator and is near death or brain dead?*

Two groups focused on this question. One group felt that top priority should be given to the develop-

ment and implementation of national awareness and education programs geared to the general public and to special target subpopulations whose levels of awareness are known to vary considerably from the norm. Second highest priority should go to the establishment of a national council that would develop and implement such a major awareness and education program. The group strongly urged the Surgeon General to facilitate the convening of an organizing committee, composed of no more than 20 representatives of professional and technical, procedural, and patient-family interests in organ donation and transplantation.

The second group addressing education of the public stated that there was a need for a national

catalyst, such as the Office of the Surgeon General, that could draw together a coalition of all groups concerned with the issues of transplantation to implement a broad public awareness program. The members urged four measures: (a) collect donor profiles to understand better the donor, reasons for giving, peak periods of donation, socioeconomic data, educational levels, and ethnic and religious groups; (b) identify various target groups based on the donor profiles; (c) continue the signing of donor cards as an educational measure in initiating family discussion of the issues; and (d) the Office of the Surgeon General lead in publicizing the definition of brain dead as set forth by the Council of Commissions of Uniform State Laws.

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### Workshop on Organ Transplants—Participants and Support

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Faye G. Abdellah, RN, EdD, Deputy Surgeon General, Chief Nurse Officer, Public Health Service, Washington, D.C.

Michael Batten, White House Aide, Presidential Correspondence, Washington, D.C.

William E. Braun, MD, Chief, Medical Renal Transplantation Service, Cleveland Clinic Foundation.

Berniece Burkhardt, Administrator, The Living Bank, Houston, Tex.

Clive O. Callender, MD, representing the National Medical Association and the National Kidney Foundation. Director, Howard University Transplant Center, Washington, D.C.

Glenna Crooks, PhD, Deputy Assistant Secretary for Health Planning and Evaluation, U.S. Department of Health and Human Services, Washington, D.C.

Donald W. Denny, Director of Organ Procurement, University of Pittsburgh School of Medicine.

William Dolan, MD, representing the American Medical Association. Chief Pathologist, Arlington Hospital, Arlington, Va.

John P. Donica, Director of Public Relations, LeBonheur Children's Medical Center, Memphis, Tenn.

Martin Eichelberger, MD, Director of Trauma Service, Children's Hospital National Medical Center, Washington, D.C.

Roger W. Evans, PhD, Research Scientist, Batelle Human Affairs Research Centers, Seattle, Wash.

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Steven Teutsch, MD, Division of Diabetes Control, Centers for Disease Control, Atlanta, Ga.

Thelma King Thiel, Vice Chairman and Executive Director, American Liver Foundation, Cedar Grove, N.J.

Maxine Turon, Chairman, Children's Liver Foundation, Inc., Maplewood, N.J.

Jane Van Hook, RN, representing the American Association of Critical Care Nurses. Transplant Donor Coordinator, University of Minnesota, Minneapolis.

Ann Vossekuiil and Bryan Vossekuiil, Birmingham, Mich.

William B. Weil, Jr., MD, representing the American Academy of Pediatrics. Department of Pediatrics and Human Development, Michigan State University, East Lansing.

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#### ADMINISTRATIVE SUPPORT

The Children's Liver Foundation Inc., of Maplewood, N.J., and Project HOPE, Millwood, Va., provided administrative support for both the June and September meetings.

In addition, financial support for the June meeting came from the Christian Broadcasting Network, Virginia Beach, Va.; General Dynamics Corporation, St. Louis, Mo.; Grumman Corporation, Bethpage, N.Y.; Mr. Paul Mountcastle, Nashville, Tenn.; Mr. Vernon H. Sharp, Nashville, Tenn.; and Mr. David Whisenant, Dallas, Tex.

Financial support for the September meeting was provided by the Nicolas Goode Foundation, Morning-side, Md.

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*What specific educational measures will encourage members of the medical community, including hospital administrators, to think of organ donation, particularly when a patient is on a respirator and near death or brain dead?*

The group made these four suggestions: (a) collect data about nonparticipating physicians concerning their attitudes, belief systems, and reluctance to participate in organ procurement activities; (b) establish educational programs for the hospital team identified as having a role in organ procurement; (c) include in the curriculums of medical and nursing schools the issue of organ procurement for transplantation; and (d) emphasize the team approach to organ procurement because the physician may not be the most appropriate or effective person to discuss organ donation with prospective families.

*How can we make maximum use of the organs available for transplantation and minimize wastage?*

The Surgeon General was urged by this group to seek agreement of the Joint Committee on Accreditation of Hospitals that accredited hospitals above a predetermined minimum size must develop their own protocols and plans for potential organ donors as a condition for reaccreditation. The group called upon the American Society of Transplant Surgeons to develop a plan to improve interactions between procurement teams and referral hospitals, to improve communications between procurement and transplant teams, and to develop improved practice standards for donor organ removal. The members also urged the Surgeon General to consider in detail the feasibility of regionalizing organ transplant programs, particularly tissue typing laboratories, so that the maximum number of donated organs would be recovered and used.

*What additional information is needed so that better decisions can be made about increasing the supply of donated organs?*

This group believed that a more comprehensive study of physician attitudes might be undertaken to increase the referral of and access to potential organ donors. One way to improve or modify physician understanding and attitudes was through a state-of-the-art letter from the Surgeon General that would inform physicians of the efficacy of various transplants, explain the "extension of care" concept of others in need, describe the organ procurement process so that the hassle of organ procurement is minimized, and clarify the legal matters that may be of concern. Taking public opinion polls of all minorities should be a prerequisite to improve public awareness and education through the use of the mass media, especially television. The group also suggested that prospective data collection should be implemented, through appropriate government agencies, to monitor the effectiveness of various donor recruitment techniques, possible changes in donor sources, and possible changes in the need for various organs.

#### *What actions should follow this workshop?*

The group determined that all of the needs and issues that it developed could be grouped into two general priorities: (a) the need to organize an umbrella organization, federation, or council of interested groups, and (b) the need to define clearly an interactive relationship between the government and the private sector.

Participants in this group believed strongly that a federation of interested groups should be organized within 6 months of the workshop to foster cooperative high-priority activities and programs. They urged the Surgeon General to convene a steering committee and give its members these charges:

- Identify possible participants in the federation,
- Assess the need for and seek sources of funding to support activities of the organization,
- Evaluate the need for involvement of government with health providers and consumers groups, and
- Develop an agenda for the initial meeting of the proposed federation.

After receiving the discussion group reports, I proposed the following plan of action as "doable" in the near future. The progress to date on various tasks is noted.

1. Convene a working group to address the formation of a federation of those organizations and other groups concerned with the substance of the

workshop. The group met September 21-22, 1983, and formed the American Council on Transplantation (ACT). The new national group's interim president is Dr. Gary Friedlaender, an orthopedic surgeon, of the Yale University School of Medicine. He will serve until ACT's first formal meeting which is scheduled for early 1984.

ACT's goal is to increase the availability of organs and tissues for transplantation through post mortem donation and surgical procurement. Its major objectives are the following:

- to motivate the public to donate organs and tissues voluntarily for transplantation,
- to improve donor identification and referral to organ procurement programs by health professionals,
- to promote the effective use of multiple organs and tissues, and
- to ensure equitable access to available organs.

2. Request that one or more of the groups and organizations represented at the workshop submit a proposal to the Public Health Service for the possible funding of a project to address deficiencies in the data bases relating to organ procurement and transplantation. No proposals have been received.

3. Convene a group from the National Institutes of Health, with NIH taking the lead but working with the private sector, to address the maintenance of the body of a potential multiple organ donor and to provide the necessary guidelines according to the best science of the day. The group made its first report on September 21, 1983.

4. Avoid regulatory suggestions and offer an educational alternative to the establishment of organ procurement plans and protocols within hospitals. I have met with representatives of the American Hospital Association, and materials regarding organ removal for transplantation are being prepared.

5. Encourage editorials in specialty journals, appropriate journal articles, and reports on the workshop in suitable publications. I have given a number of radio, television, newspaper, and magazine interviews, and a 30-minute interview tape has been sent to more than 300 radio stations.

6. Make the Surgeon General and willing workshop participants available to speak at meetings of professional societies whose cooperation could help to achieve the goals of the workshop.

7. Begin a dialog with an appropriate national pediatric organization expressing the specific concerns of workshop participants about the unique aspects of pediatric transplantation. Consultation with the American Academy of Pediatrics has taken place, and an AAP committee has been appointed.

8. Arrange for a model or demonstration, using a small controlled population.

## Conclusion

The vigor and dedication that characterize private groups who conduct organ procurement was quite evident at the workshop. What should be the new charge to those working in the field of organ procurement?

As Surgeon General, I believe that the organ procurement effort should remain in the private sector. I do not believe that government should take it over, but I do see that we have a role to act as catalyst. We can convene meetings. We can use our moral suasion, and I intend to do that in the future so that progress is as rapid as possible.

I agree fully with an excerpt from the preamble of one discussion group report: "Individuals and organizations should continue their specialized efforts but need now to identify common interests

and unite in the pursuit of goals that are beyond the ability of any one person or group to accomplish."

## References

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*education courses for three distinct populations—practicing maternal child health nurses, State nurse consultants, and nurse supervisors at county or district levels. The purpose of these courses is to improve the practice of the participating nurses and thereby ultimately to improve the health status of mothers and children in Region IV of the Department of Health and Human Services.*

*Evaluation of the project by its staff after its first 5 years showed that (a) it has provided a series of continuing education courses of high quality; (b) met its goals and objectives; (c) provided continuing education for practicing maternal child health nurses that has improved MCH nursing practice in Region IV; (d) provided continuing education for State nurse consultants that has enabled them to become more effective leaders in their respective States; (e) used previously untapped resources in Region IV to make the concept of regional continuing education in maternal child health nursing a reality; and (f) generated a networking system among State nurse consultants, nurse educators, and nurse leaders in other service-oriented Title V programs that has been most effective in meeting the learning needs of the three distinct populations it serves.*

*The University of Kentucky College of Nursing is in the 7th year of implementing a 7-year federally funded continuing education project. The major goal of MCH (maternal child health) Project 969, which is scheduled to terminate Sept. 30, 1984, is to develop and offer a series of quality continuing*