

# **Roles and Training in the Donation Process: A Resource Guide**

**Department of Health and Human Services  
Health Resources and Services Administration  
Health Care Financing Administration**

**The Lewin Group, Inc.**

# **Roles and Training in the Donation Process: A Resource Guide**

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This resource guide and other information and resources on organ donation and transplantation are available on the HHS National Organ and Tissue Donation Initiative Web site at [www.organdonor.gov](http://www.organdonor.gov).

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## PREFACE

Talking to a bereaved family about donating the organs of a beloved family member who has just died is at once an art and a science. Discussing donation and other end-of-life issues with families is not easy. It requires knowledge, flexibility, compassion, and skills. Moreover, timing and coordination of the donation process are vital to obtaining consent for donation.

To address the critical need for organ donors in the United States and realize more of the donor potential in hospitals, the U.S. Department of Health and Human Services' Health Care Financing Administration issued a final rule (42 CFR Part 482, effective August 21, 1998) revising its Medicare and Medicaid Hospital Conditions of Participation to facilitate best practices for increasing organ, tissue, and eye donation. To aid hospitals in identifying potential donors, the rule requires referral of all deaths and imminent deaths to the organ procurement organization (OPO). Recognizing the sensitivity and discretion needed to discuss the option of donation with family members, the rule also requires that those who the hospital designates to initiate donation requests receive training offered or approved by the OPO.

Developed with guidance from donor families and a multi-disciplinary team of transplant and other healthcare professionals, *Roles and Training in the Donation Process: A Resource Guide* offers support to hospitals and OPOs in implementing the training provisions of the rule. As with any education experience, the needs and expertise of learners and educators will vary. For this reason, the guide offers strategies, tools, and resources for training in the donation process, rather than a specific curriculum, methodology, or timeframe. It encourages customized training responsive to the expertise and effectiveness of participants, the objectives and resources of the institutions involved, and the needs of patients and families. In addition, the guide emphasizes the importance of ongoing evaluation and feedback to assess and refine requestor effectiveness and the success of the hospital's donor program.

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# **Roles and Training in the Donation Process: A Resource Guide**

*“My grieving process turned into joy when I learned that there were five people out there who wouldn’t be here if it hadn’t been for him.”* – Suzi Eakle, who donated the organs and corneas of her husband, Bobby Eakle, after he died suddenly of a brain aneurysm. She had no prior knowledge of her husband’s wishes concerning donation.

*“It’s truly a gift of life because if this family had decided no, then I would not be here today.”* – Gloria Brooks, recipient of a liver from Suzi Eakle’s husband, Bobby Eakle.

## **INTRODUCTION**

More than 71,000 Americans are waiting for organ transplants, yet fewer than 22,000 received organ transplants in 1999. Up to 15,000 deaths occur annually that could yield suitable donor organs. Fewer than 6,000 of those deaths result in the donation of an organ.

In response to the need for donors, the U.S. Department of Health and Human Services (HHS) launched the National Organ and Tissue Donation Initiative in December 1997. Its goals are to increase consent to donation, maximize donation opportunities, and learn more about what works to increase donation and improve transplantation through carefully designed research efforts. To promote best donation practices, HHS’ Health Care Financing Administration (HCFA) published a final rule for organ, tissue and eye donation (June 22, 1998, 63 Fed. Reg. 33856) as part of its revised Conditions of Participation (CoP) for Medicare- and Medicaid-participating hospitals. This rule, which took effect on August 21, 1998, contains two key provisions:

- Hospitals must contact their organ procurement organization (OPO) in a timely manner about individuals whose death is imminent or who die in the hospital.
- Only OPO staff or trained hospital staff – referred to as designated requestors – may approach families about organ donation.

A designated requestor is defined in the rule as an individual who has completed a course offered or approved by the OPO and designed in conjunction with the tissue and eye bank community in the methodology for approaching potential donor families and requesting organ donation, though the interpretation of this rule allows for some degree of flexibility. Research confirms the importance of training in approaching families for consent and of collaborative relationships among hospitals, OPOs, and tissue and eye banks.

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has adopted the donation provisions of the CoP rule in its standards for hospitals. Therefore, hospitals accredited

by JCAHO, including hospitals not covered by the CoP rule such as VA and military hospitals, are required by JCAHO to meet its standards for organ, tissue, and eye donation.

A recent report by the American Medical Association's (AMA) Council on Scientific Affairs on the physician's role in organ donation concluded that the CoP requirements encourage health care professional involvement and do not act as a "gag order" prohibiting physicians from discussing donation with family members. The key to success, the authors note, is training:

Discussing severe brain injury, brain death, and organ donation after brain death with families is a specialized form of EOL [end-of-life] decision-making and care in the ICU. Physicians play an important role in caring for patients and families in these circumstances, and the care they provide is enhanced through training and attention to the special issues involved. The Federal COP do not prohibit physician involvement in initiating organ donation requests (provided they are properly trained). In fact, they encourage increased involvement of the medical community (Short, Genel, and Williams, 2000).

In response to requests for guidance from hospitals and procurement organizations, HCFA and the Health Resources and Services Administration (HRSA) convened a workshop on "Roles and Training for the Donation Process" held in Baltimore, Maryland on June 28-29, 1999. The substantial contribution of the workshop participants and planning group formed the core content of this guide. Participants included representatives from the hospital, medical, nursing, medical examiner/coroner, OPO, and tissue and eye bank communities; individuals from recipient and donor family organizations; and specialists in research, education, bereavement, and pastoral care (Appendix H).

In addition, this guide includes examples of innovative programs highlighted by participants in two national forums co-sponsored by HCFA and HRSA titled, "The Challenge of Collaboration: The Hospital Conditions of Participation Technical Assistance Workshop." Due to the enthusiastic response of hospitals and OPOs to the first workshop held on March 6-7, 2000 in Arlington, Virginia, the American Hospital Association, the American Osteopathic Association, and JCAHO joined HCFA and HRSA in co-sponsoring a second workshop on July 20-21, 2000 in Las Vegas, Nevada.

*Roles and Training in the Donation Process: A Resource Guide* ("Resource Guide") is designed as a tool for the donation and hospital communities to develop effective requestor training programs. It does not present or endorse a specific curriculum, but rather suggests topics and resources to consider in developing a training course. As with any good instructional program, curriculum development should take into consideration the existing competencies and learning needs of the trainees.

Chapter 1 reviews principles of patient and family care underlying the donation process. Chapter 2 provides an overview of the donation process, the transplant system, and related legislation. Chapter 3 defines three key overlapping team roles in the donation process – coordinator, requestor, and supporter. Chapter 4 summarizes common elements of requestor

training programs. Chapter 5 discusses feedback and evaluation techniques. Chapter 6 provides examples of innovative donation practices.

In addition, this guide provides tips for initiating review and discussion of donation practices and training. It also includes answers to frequently asked questions about donation. Finally, lists of published studies, training programs, and Internet resources in the appendices provide additional access to resources and strategies for increasing donation and for meeting the CoP requirements and related JCAHO standards.

*Further guidance on implementing the CoP is available at <http://www.hcfa.gov/quality/4a.htm>.*

*For information about the National Organ and Tissue Donation Initiative, visit*

*<http://www.organdonor.gov>.*

## CHAPTER 1: PRINCIPLES OF DONATION

*“Ideally, no matter what a family’s characteristics are, healthcare providers should approach the family with the belief that a donation is possible. In our study, even families who declined donation felt it was right to ask them and valued being able to make the decision. The key is treating every family with respect and care.”* – Holly Franz, Partnership for Organ Donation

Research suggests a relationship between family members’ satisfaction with the quality of care that their loved one received and their willingness to consent to donation. A study by DeJong, Franz, and Wolfe (1998) found that non-donor families were more likely than donor families to report inadequate or insensitive care and poorly-handled donation requests. While the latest national Gallup survey indicates that 85 percent of Americans support organ donation, studies show that only about 50 percent of families consent to donating a loved one’s organs when given the opportunity. A coordinated effort between hospital and OPO staff can improve quality of care and enhance communication with families, two important elements for increasing consent.

This Resource Guide is based on four principles that place organ and tissue donation in the context of patient and family care and end-of-life decision-making. These principles have shaped this guide and are intended to influence the development of training programs.

- Any effort to gain consent for organ and tissue donation must be made in the broader context of providing high quality end-of-life and bereavement care for the family. The needs of the family should mediate the entire organ and tissue donation process.
- Families often require an intensive level of grief care and explanation to completely understand that death has occurred.
- Hospital administrative support for these activities is crucial to their success. Bereavement care is a labor-intensive service that requires staff to have the time and flexibility to identify a family’s needs, and develop an appropriate way to meet them. While these hospital services may not be directly billable, they are critical to delivering high quality care and maintaining positive relations with the community.
- Close collaboration and cooperation among hospitals, OPOs, and tissue and eye banks are necessary for a successful donation process. The experience of several communities indicates that institutions that work together serve donor families better and have higher donation consent rates.

Bereavement care that includes the option to donate among its services can provide substantial support to families experiencing the unexpected loss of a loved one. As defined by the Nebraska Health Systems Acute Bereavement Care training manual, bereavement care includes offering emotional, physical, and spiritual support to families, such as assisting with personal belongings, autopsy options, coroner notification, initiation of the organ and tissue donation process, and providing information related to funeral arrangements.

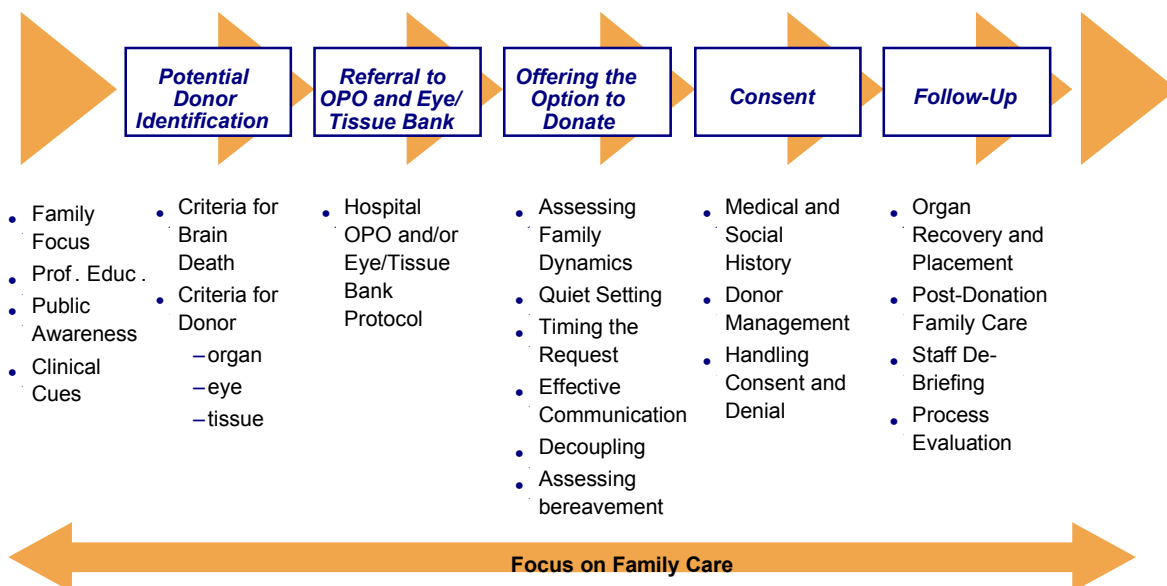
# CHAPTER 2: ORGAN DONATION AND TRANSPLANTATION IN THE UNITED STATES

*“My son has saved six people’s lives. I wish I could save so many lives.”* – Alfredo J. Herrera, M.D., F.A.A.P., a pediatrician from Ellicott City, Maryland, whose 16-year-old son, Christian, became a donor after dying in a car accident. They had discussed donation after Christian had indicated his wish to be a donor on his driver’s license.

## The Organ Donation Process

Preliminary evidence suggests that collaboration and cooperation between hospitals and OPOs is an effective approach for identifying and managing potential donors and for obtaining consent from families. Early studies indicate that donation is most likely to occur when identified best practices are used, such as notifying OPOs as early as possible of deaths and imminent deaths and providing appropriate medical management of the donor. In addition, a 1998 study by Gortmaker et al., which tracked over 700 potential donor cases referred to three OPOs, found that the most successful requests for donation: (1) are made in a private setting, (2) allow the family to comprehend death (particularly brain death) before discussing organ donation (“decoupling”), and (3) involve the OPO transplantation coordinator in the consent process. While each of these three elements significantly and independently enhances the organ donation consent rate, the consent rate is 2.5 times higher when all three elements are present (74 percent) than when none of the elements are present (28 percent) (Gortmaker et al., 1998). All three elements, however, were present in less than one third of all organ donation requests with families (Gortmaker et al., 1998). Exhibit 1 provides a brief overview of the donation process. For more details about the donation process, see Chapter 4: Developing Training Programs.

**Exhibit 1: Overview of the Donation Process**



## **The Organ Transplant System**

In 1984, Congress passed the National Organ Transplant Act (NOTA) to address the need for better coordination and distribution of scarce organs. NOTA established a national task force to study transplantation issues and, in 1986, the national Organ Procurement and Transplantation Network (OPTN). In addition, NOTA created the Scientific Registry of Transplant Recipients (SRTR), a database which has tracked all solid-organ transplants since late 1987. Data from the SRTR support ongoing evaluation and research on transplantation.

The OPTN is charged with operating and monitoring an equitable system for allocating organs, maintaining a waiting list of potential recipients, matching potential recipients with organ donors, and increasing organ donation. The OPTN includes OPOs, transplant centers, hospitals, and other organizations as well as patients, donors, and their families. Both the OPTN and the SRTR currently operate through contracts awarded by HRSA's Division of Transplantation (HRSA/DoT) to the United Network for Organ Sharing (UNOS) in Richmond, Virginia.

When patients are accepted for placement on a transplant program's waiting list, they are registered with the OPTN's centralized computer network, which links all OPOs and transplant centers. When a donor organ becomes available, the OPO enters information about the donor organ into the computer and the computer generates a list of potential recipients ranked according to objective medical criteria (i.e., blood type, tissue type, size of the organ, medical urgency of the patient as well as time already spent on the waiting list and distance between donor and recipient). Each organ has its own specific criteria. The OPO's transplant coordinator then contacts the transplant surgeon caring for the top-ranked patient to offer the organ. If that patient is unable to receive the organ (e.g., if the patient is unavailable or too ill, or if laboratory test results indicate incompatibility between donor and patient), the organ is then offered to the next patient on the list.

OPOs play a key role in procuring and distributing organs. Operating in their designated service area, they facilitate identification and evaluation of potential donors, discuss donation with family members, coordinate procedures for donor management, and arrange for organ recovery, preservation, placement, and transport. In addition, they work with health care professionals and the public to encourage organ donation.

HRSA/DoT, in addition to its oversight of the OPTN and SRTR, is responsible for national coordination of organ donation activities, funding of grants and special initiatives to learn more about what works to increase donation, and technical assistance to OPOs and other transplant-related entities. Moreover, HRSA works closely with HCFA in promoting the effective implementation of the CoP.

HCFA also has several roles in the organ transplant system. HCFA certifies OPOs, specifies their service areas, and provides reimbursement through the Medicare program to OPOs for organ acquisition costs. HCFA certifies OPOs for two-year periods, measuring their performance on five standards based on the number of donors, organs recovered, and organs transplanted relative to their service area population. For certification, OPOs must achieve at least four of the five performance standards. As of July 2000, 59 OPOs had HCFA certification.

In addition, HCFA published a final rule for organ, tissue, and eye donation, effective August 21, 1998, as part of its revised Conditions of Participation for Medicare- and Medicaid-participating hospitals. HCFA based the rule's requirements on similar approaches that have been successful, including Pennsylvania's 1994 "routine referral" law (Pa. Act 102, effective March 1, 1995) requiring hospitals to report all deaths to their OPO. By 1997, the OPO serving the eastern half of Pennsylvania, southern New Jersey, and Delaware had seen a 40 percent increase in organ donors, while for the same period, donation for the entire nation increased by only 7.4 percent. The Council of State Governments published Pa. Act 102 in its 1997 *Suggested State Legislation*. HCFA recognized that full implementation of the CoP donation provisions could take up to a year, although it expected hospitals to make progress toward implementation during the phase-in period.

Finally, HCFA's Medicare program provides insurance coverage for most Americans with permanent kidney failure, paying for dialysis treatment and transplantation through the End Stage Renal Disease (ESRD) program. ESRD is unique, in that it is the only disease-specific condition that qualifies someone for Medicare coverage, regardless of age. With various restrictions, Medicare also covers liver, lung, heart, and heart-lung transplants, in addition to pancreas transplants when performed simultaneously with or after a kidney transplant. In addition, it provides immunosuppressive drug coverage for up to three years post-transplant.<sup>1</sup>

## Legislative Framework

The following section briefly summarizes key legislation relevant to the donation process.

**Uniform Anatomical Gift Act (UAGA) of 1968 (and 1987 amendments):** To foster uniformity in donor designation procedures, the UAGA establishes procedures for making anatomical gifts. A competent adult may make an anatomical gift by completing and signing a document of gift. These gifts are irrevocable upon the donor's death and no additional consent is legally necessary. The UAGA also imposes an affirmative duty on emergency personnel and hospitals to determine an individual's donative intent. The 1987 amendments were intended to strengthen the legislative language and increase the potential for donor intent to be considered an advance directive. All 50 states and the District of Columbia have enacted the UAGA in some form; fewer have adopted the 1987 amendments.

**Uniform Determination of Death Act (UDDA) of 1980:** Many state laws regarding the determination of death are based on the UDDA, which lawmakers designed to provide a comprehensive and medically sound basis for determining death in all situations. The UDDA states that an individual is dead if he has sustained either irreversible cessation of circulatory and respiratory functions or irreversible cessation of all functions of the brain, including the brain stem, as determined in accordance with accepted medical standards. As of February 2000, 42 states had adopted the act. Hospital policy may dictate additional practice requirements for evaluation and pronouncement of brain death.

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<sup>1</sup> For individuals whose immunosuppressive coverage is due to expire in 2000, Congress has mandated an additional 8 months of coverage.

**National Organ Transplant Act of 1984 (NOTA):** Among its provisions, NOTA created the national Organ Procurement and Transplant Network (OPTN), established federal grants for OPOs, and created a national Scientific Registry of Transplant Recipients. NOTA also made it illegal to buy and sell organs and tissues. Agencies are allowed to recover the “reasonable” costs associated with procurement, but those costs are not passed on to donor families.

**Omnibus Budget Reconciliation Act of 1986 (42 U.S.C. Sec. 1320b-8):** This act added new organ procurement and allocation requirements under Section 1138 of the Social Security Act, including the recommendation of NOTA’s Task Force on Organ Transplantation to require all hospitals participating in Medicare or Medicaid to institute a “required request” policy. Specifically, the act required hospitals to have written protocols for encouraging organ and tissue donation by identifying potential donors and referring them to an organ procurement organization and assuring that families of potential donors are made aware of the option of organ and tissue donation and their option to decline. By 1995, all 50 U.S. states and the District of Columbia had enacted required request legislation. Typically, states require hospital administrators, or their designees, under certain conditions, to request the next of kin to consent to the gift of all or part of a decedent’s body for transplantation or other purposes.

**The Federal Patient Self Determination Act of 1991:** This act amends federal Medicare and Medicaid statutes to require hospitals and other health care providers to maintain written policies and procedures regarding five issues. Among its provisions, the health care provider:

- Must provide written information to the patient regarding the patient’s rights under state law to make decisions concerning medical care, including the right to formulate advance directives.
- Must document in the individual’s medical record whether the individual has executed an advance directive.
- May not discriminate against an individual based on whether he or she has executed an advance directive.
- Must comply with state laws respecting advance directives.
- Must have a policy for educating hospital staff and the community on issues concerning advance directives.

*Periodic updates on legislation and regulations regarding organ donation and transplantation can be found on the HRSA/DoT Web site at <http://www.hrsa.dhhs.gov/osp/dot>. Federal legislative updates can be found at <http://www.transweb.org/news/news.htm> or at <http://thomas.loc.gov>.*

## **Data on Donation and Transplantation**

The OPTN collects information from OPOs, transplant centers, and histocompatibility laboratories on the characteristics of potential organ recipients and available organ donors to facilitate matching for transplantation. Data on cadaveric and living donors include demographics, documentation of consent, donor serology, and organ recovery and preservation. Data on transplant candidates include demographics, waiting times, histocompatibility (e.g., ABO blood group), and patient status codes reflecting the degree of medical urgency. The SRTR collects post-transplant information pertaining to organ recipients such as patient and graft survival at discharge, six months, and one year post-transplant, and annually thereafter. UNOS makes national, regional, and center-specific data available to the public through annual and periodic publications and on the Internet at *www.unos.org*.

The United States Renal Data System (USRDS) is a national data system which collects, analyzes, and distributes information about end-stage renal disease, a substantial contributor to the demand for transplantation. Kidney transplants account for more than half of all transplants performed in the United States. Dialysis centers are required by regulation to assure that all patients in the facility are assessed for and fully informed about their suitability for transplantation as part of the patient's long-term care plan. The USRDS is funded directly by HHS' National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) in conjunction with HCFA. The USRDS Coordinating Center operates under a contract with the Minneapolis Medical Research Foundation. In addition, NIDDK funds the National Kidney and Urologic Diseases Information Clearinghouse established in 1987 to increase knowledge and understanding about diseases of the kidneys and urologic system among patients and their families, health care professionals, and the general public.

Trade associations such as the American Association of Tissue Banks and the Eye Bank Association of America collect data on procurement and transplantation from their member organizations. Requests for data can be made directly to these organizations.

*For more information about the data sources described above, see Appendix C: Internet Resources.*

## CHAPTER 3: TEAM ROLES IN THE DONATION PROCESS

*“The process of donation begins with the incident causing the death and continues through the bereavement. Every health care professional who interacts with the family is part of the process and every step impacts on the family’s ultimate decisions regarding donation.”* – Margaret B. Coolican, RN, MS, CDE, National Donor Family Council

*“The care we receive throughout the whole donation experience enhances or destroys our sense of trust. Accountability and cooperation of all health care professionals will solidify confidence in the donation process.”* – Vicki Crosier, National Donor Family Council

The consensus of several studies and the multi-disciplinary group of professionals who contributed to this guide support the assertion that a team approach is most effective for obtaining consent for donation. While the various tasks in the donation process may be filled by a combination of hospital (e.g., physicians, nurses, social workers, and pastoral care providers), OPO and tissue and eye bank personnel, three key roles in this process can be identified – coordinator, requestor and supporter. Various combinations of staff will fill these roles, as determined by the particular situation and setting. For example, while one person may have primary responsibility for discussing organ donation with the potential donor family, several people may play supporting roles in the process.

It is important to note that although differentiation is made among the roles of coordinator, requestor, and supporter in this Resource Guide, they are all part of the requesting team and, as such, are considered under the “designated requestor” umbrella for purposes of the CoP. According to the CoP, any individual who provides information to the family about donation, informs the family of its donation options, or makes the request for donation must be either an organ procurement representative or a designated requestor. The individual must be a trained designated requestor even if the individual is acting in a supportive or collaborative role with the OPO in performing any of these functions, though those individuals in supporter and collaborative roles may be trained less intensively than those in requestor roles. Whenever possible, the OPO representative and a designated requestor (such as someone from the hospital staff who has established a rapport with the family) should work together to coordinate the approach to the family. Different levels, types, and intensities of training may be appropriate for the differing roles, but all individuals acting in these roles must be trained.

These three roles provide a framework for tailoring training programs while providing maximum flexibility for OPO, eye/tissue bank, and hospital collaboration. These roles may be more or less strictly defined, but the team approach should always be emphasized. In addition, all three roles share a responsibility for providing bereavement and other end-of-life support to families.

Finally, in order for the donation process to be effective, the performance of those offering the option should be systematically tracked and evaluated to ensure quality bereavement services are being offered to families and consent rates are at optimal levels. Doing so also provides the opportunity to identify best practices and incorporate these practices into improved training programs.

## **Coordinator**

The coordinator's role is to oversee the entire donation and/or bereavement care process from beginning to end. He or she maintains contact with all those involved in the process, and ensures that all aspects of the process are carried out in accordance with relevant policies and protocols and in consort with institutional priorities and philosophies.

## **Requestor**

The requestor's role is to empower the family to make decisions. When the time is appropriate, the requestor is the individual who will offer the option of donation to the family, or discuss donation with them, but does not necessarily manage the entire process.

## **Supporter**

The supporter's role is to provide assistance as needed to the requestor, the coordinator, and anyone else involved in the donation process. Individuals who have a significant role in the care of the patient or the patient's family are in the supporting role.

Each of the three roles has implications for education and training. For example:

- Consent is linked to many aspects of care, not just the actions of the person who offers the donation option. Therefore, all individuals involved in the care of both the potential donor and the family must understand that a family's assessment of the care provided to a loved one could affect its willingness to donate.
- Individuals in supporter roles may need less intensive training than individuals in requestor roles. For example, hospital staff may be trained about the purpose of conducting the medical and social history without being trained to perform them. However, everyone involved in the consent process should have some level of training.
- Persons who offer the donation option must be able to explain to bereaved families that death has occurred, either by brain or cardiopulmonary criteria. Training should prepare them to be sensitive to families who may not be able to fully listen and absorb information during a time of crisis.

*Further clarification of the relationship among the OPO, the eye and tissue bank, and the hospital can be found in the "Hospital Conditions of Participation for Organ Donation, Questions and Answers" at <http://www.hcfa.gov/quality/4a1.htm>.*

## CHAPTER 4: DEVELOPING TRAINING PROGRAMS

*“Organ donor families have their own stories. Each story is different and special. But what is common to all is the uncommon generosity of the human spirit, often in a time of grief and tragedy, to rise above personal self-concern to help others in need of transplantation, in need of life.”* – Rear Admiral Kenneth P. Moritsugu, M.D., M.P.H., Deputy Surgeon General of the United States, who donated the organs and tissues of both his wife and a daughter after they lost their lives in separate automobile accidents within a five-year period. Their donations saved and enhanced the lives of 13 people.

Research indicates that the readiness of hospital staff to handle requests for donation has an impact on donation rates. In their study of 1,061 critical care nurses and physicians from 28 hospitals in four separate regions of the United States, Evanisko et al. (1988) found that the greater the percentage of staff who had received training in organ donation, the higher the hospital’s donation rate. In hospitals with high rates of organ donation, 52.9 percent of staff had received training. In contrast, in hospitals with low rates of organ donation, 23.5 percent of staff had received training. While 94 percent of the critical care staff said they support organ donation, and 98 percent said involved staff should be trained in how to approach families properly, less than one-third reported having received training in explaining brain death or requesting donation. Siminoff, Arnold, and Caplan (1995) found that health care professionals with more positive attitudes about donation and their role in the procurement process were more likely to request donation and to have greater success in obtaining consent.

Training programs may emphasize all or part of the donation process. They may be used to enhance support for donation or to generate specific improvements in the donation process. For example, additional training in the clinical cues for, and determination of, brain death can increase early notification of imminent death cases to the OPO, an important factor in donation.

While training programs on the donation process will share many common elements, individuals, institutions, and communities are best served by programs tailored to meet their unique needs and circumstances. Various levels of training intensity may be needed to match the role each individual has in the donation process. For example, different individuals may be responsible for notifying the OPO of deaths and imminent deaths, managing the care of the potential donor to preserve organs for donation, explaining brain death to the family, offering the family the option to donate, obtaining a medical and social history of the potential donor, testing tissue samples, and providing counseling and support to the family. Different approaches may be used to match the background, competencies, and learning styles of trainees, ranging from experiential programs that emphasize role playing, observation, and practice, to self-guided education programs over the Internet. Moreover, training programs may take place on or off-site, and may be conducted as a one-time session or as a series of sessions over a period of time.

The most successful programs will ensure that there is as much buy-in and input as possible from all concerned parties, including hospital and procurement organization administrators and staff, patients and families, and training program participants. Ideally, training will be incorporated as an essential and ongoing component of the individual’s official duties. All concerned parties

will benefit from immediate and ongoing feedback on the effectiveness of the training program in building knowledge and skills in the donation process; developing more supportive attitudes toward donation; enhancing sensitivity and cultural competency in working with families; improving compliance with regulations and protocols; and increasing referrals, requests for donation, and consent. Training has the potential to pay off not only in improved donation practices but also in better patient and family care and higher customer satisfaction.

Two key principles should be incorporated into any training program. First, training programs should emphasize the importance of demonstrating respect for patients, potential donors, and their families at all times. All families and individuals, especially those dealing with the death of a loved one, deserve to be treated with care and sensitivity. Moreover, families offered the option of donation are more likely to give consent if they believe that they and their loved one are being treated appropriately and respectfully. Second, training programs should promote team approaches to donation. Collaboration among all individuals involved in the donation process is critical not only for ensuring that procedures are followed but also for obtaining consent from families.

Many OPOs, tissue and eye banks, and other health and professional organizations have developed programs that can be used or adapted to train designated requestors and others involved in the donation process. Appendix A provides tips for developing an effective training program. Exhibit 2 provides several examples. Finally, Appendix E provides a matrix of training programs used throughout the country.

## **Exhibit 2: Selected Examples of Training Program Models**

***“Making the Critical Difference.”*** American Association of Critical Care Nurses and the National Kidney Foundation. The AACN and NKF designed this program to motivate and prepare critical care nurses to participate in the organ and tissue donation process. NKF can be reached at (800) 622-9010, or at [www.kidney.org](http://www.kidney.org).

***Southwest Transplant Alliance Training.*** Southwest Transplant Alliance. This training has two components, one geared specifically to physicians and another geared toward nurses and others. STA can be reached at (214) 522-0255.

***Designated Requestor Training Materials.*** Indiana Organ Procurement Organization. This set of materials includes three parts: “No Easy Answers” videotape, training presentation, and a quick reference guide. IOPO can be reached at (317) 685-0389.

***“Interviewing Families About Organ and Tissue Donation: A Professional Approach.”*** Verble, Worth, and Verble. VWV’s training programs teach individuals how to communicate more effectively, including offering the option of donation to grieving families. Verble, Worth, and Verble, a performance management consulting firm based in Lexington, Kentucky, can be reached at (606) 254-0883.

For additional training models, see Appendix E: Matrix of Training Programs.

## Selecting Trainees

*“If we offer to the people something of which we ourselves do not approve, how can we afterwards defend our work? Let us raise a standard to which the wise and honest may gladly repair.”* – President George Washington in a speech at the Constitutional Convention

A key step in developing training programs is to identify appropriate candidates for training. When selecting these individuals, it is important to recognize that not everyone is willing or suited to work with families during a time of crisis. In particular, early identification of those individuals who have the most potential to be successful requestors and coordinators can save time, money, and frustration. For example, when LifeSource, the OPO for Minnesota, North Dakota, South Dakota, and portions of Wisconsin, worked with a Level II trauma center to train 80 nursing staff to be “Certified Designated Requestors” (CDRs), it found that the absence of input from nursing staff prior to training led to greater variability in performance and commitment. Feedback from CDRs revealed that some felt uncomfortable with providing the option of donation, while others exhibited ambivalence toward the donation program in general. The program also noted that a collaborative approach (OPO staff and CDRs) resulted in a 90 percent consent rate throughout 1999, compared with a only 50 percent consent rate for CDRs who approached families on their own. After consulting with its Nurse Practice Board and multidisciplinary Donation Committee, the trauma center elected to recertify just 30 of the CDRs to give each CDR greater opportunity to be involved in the donation process. In addition, it instituted a continuing education program on best donation practices throughout the hospital.

Desirable personal qualities for those individuals working directly with families include:

- Proactive support of organ, tissue, and eye donation
- Capacity for compassion
- Good listening and communication skills
- Patience
- Self-confidence and assuredness
- Capability as a problem solver
- Willingness to monitor and improve one’s own performance

## Understanding the Organ Donation Process

Each of the three main roles requires an understanding of all or part of the donation process. Knowledge of organ, eye, and tissue donation is important so that those involved in the process will be able to answer accurately and confidently any questions that the family might have. The amount and depth of training individuals receive will depend on their role and on the unique circumstances of the hospital, OPO, and eye and tissue bank relationship.

The material provided in this section represents the most basic level of information about the organ donation process. The sequence of activities may vary depending upon the specific setting and case. An individual’s progress from injury to brain death to donation, for example, can take place over several hours or even several days. While nearly all cadaveric donations are

from deceased individuals who were brain dead and on a ventilator, less than 1 percent of all cadaveric donors each year are “non-heart-beating donors” (individuals whose deaths are determined by cessation of heart and respiratory function rather than loss of whole brain function). More information on this type of donation is available in two recent studies published by the Institute of Medicine (see Appendix C: Internet Resources).

The donation process requires concurrent application of medical practice and bereavement care, as recognized by the AMA Council on Scientific Affairs’ report on the physician’s role in organ donation. After noting the critical importance of the “structure, process, sequence, timing and coordination of the donation process,” it underscores the need to respect potential donors and their families throughout the donation process, “Although the goal of increasing the consent rate and procuring more organs is desirable, the more important goal is the implementation of a process that focuses on the families of potential donors. When the focus is on the process and not on the outcome, either decision becomes acceptable, simultaneously preserving and promoting the goals of families and the organ donation system” (Short, Genel, and Williams, 2000).

### **The Organ Donation Process:**

- 1. Identifying a Potential Organ Donor.** Most potential organ donors have suffered an unforeseen accident or illness (e.g., stroke or motor vehicle accident) resulting in irreversible damage to the central nervous system. Among cadaveric donors in 1998, cerebrovascular disease/stroke and head trauma accounted for 88 percent of all causes of death. At the hospital, the patient may be placed on a ventilator to provide support for breathing and respiratory function. If the patient is brain dead, the ventilator and other medical support help maintain organ viability while the family decides about donation.
- 2. Notifying the Organ Procurement Organization (OPO).** The hospital notifies its OPO in a timely manner of all imminent deaths and deaths in the hospital. Timely notification of imminent death is critical to allow families sufficient time to make informed decisions about donation while the potential donor’s organs are still viable. Imminent death is defined under hospital policies devised in conjunction with its OPO and generally includes a severely brain-injured individual on a ventilator. OPO staff gather information needed for a preliminary assessment of the patient’s medical suitability as an organ donor.
- 3. Declaring Brain Death.** Brain death is the irreversible loss of all brain function, including the brain stem. Initial requirements for determining brain death include clinical or radiographic evidence of a catastrophic cerebral event consistent with brain death, exclusion of medical conditions that may confound clinical assessment, and confirmed absence of drug intoxication, poisoning, or neuromuscular blockade. Repeated clinical evaluation is recommended. The clinical examination should be consistent with absence of all brain stem, cranial nerve, motor and autonomic responses (no movement or autonomic response to painful stimulation, no breathing with apneic oxygenation, no brain stem reflexes).

Diagnostic tests, such as cerebral angiogram, cerebral blood flow scan, and electroencephalography (EEG), are used to confirm brain death in settings where the clinical examination is considered insufficient, such as the presence of sedatives (e.g. pentobarbital) or other conditions that impede the clinical examination. Declaration of brain death should

be performed by a physician with the requisite training, skills and experience, and must be done in accordance with state laws and sound medical practice. Hospital policy may dictate additional practice requirements.

4. **Requesting Consent.** A trained OPO staff member and/or a hospital's designated requestor approach the patient's family members for consent to donate their relative's organs, generally after hospital staff have explained the diagnosis of brain death and given the family sufficient time and support to absorb this information.<sup>2</sup> A family may refuse to give consent, or it may give consent for donation of all or only some organs and/or tissues. A release from the medical examiner or coroner also may be required for donation to proceed. Once the consent forms are signed and witnessed, all hospital costs from this point are paid by the OPO, not the family. Only now is the patient considered a "donor."
5. **Evaluating the Donor's Medical Suitability.** Under the CoP requirements, the OPO determines medical suitability for organ donation (and for eye and tissue donation if the hospital has made no alternative arrangements). For legal liability purposes, most medical and social histories are conducted by organ, tissue, or eye bank staff who are specifically trained to complete this task. The questions included in the medical and social history are very carefully worded, and are designed to elicit any critical information related to the potential donor that may eliminate him or her from consideration based on a medical or behavioral circumstance. (See Appendix F: Donor Medical History and Behavioral Risk Assessment Rationale for an example provided by LifeNet.)

In addition, staff conduct a review of the donor's organ systems; evaluate the donor's body for markings, tattoos, and evidence of intravenous drug use; conduct initial serology testing and tissue typing; and note the findings from the medical and social history. Hospitals, OPOs, and eye and tissue banks have developed protocols to facilitate this process. Training programs can incorporate these protocols into the curriculum.

6. **Providing Donor Management.** Donor management techniques (e.g., medications, respiratory care, fluid resuscitation) to optimize oxygenation of organs, maintain hemodynamic stability, and sustain fluid and electrolyte balance must be initiated to ensure the integrity of the organs and tissues for transplantation. A study by Hauptman and O'Connor (1997) noted that without aggressive support, cardiac arrest occurs in 20 percent of potential donors within 6 hours after the declaration of brain death and in 50 percent of donors within 24 hours. In their article on the role of critical care nurses in organ donation, McCoy and Argue (1999, p. 51) state, "a collaborative effort between the nurse and the procurement coordinator will help maintain the stability of the donor's condition and contribute to timely completion of diagnostic studies."

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<sup>2</sup> According to the UAGA of 1968 and subsequent amendments, hospitals, OPOs, and eye and tissue banks have the authority to act on an advance directive if the potential donor is listed in a state donor registry, has a positive indication on his or her driver's license, or has indicated his or her wishes using some other valid piece of donor documentation. At this time, however, the advance directive is rarely acted upon without the option of donation being offered to the next of kin before donation procedures are implemented. See "Legislative Framework" in this Resource Guide for more information.

Staff should become familiar with their hospital's donor management practices and understand the necessity of preserving organ function until surgical removal from the donor. A common training technique in donor management is to develop a separate booklet outlining very specifically what procedures should be implemented at appropriate points in the process. An excellent tool is the "Critical Pathway for the Organ Donor," developed by UNOS, which outlines standards of care for each phase of the donation process (see *Critical Care Nurse*, "Organ Donation Issue," April 1999 or go to [www.aacn.org/aacn/aacnsite.nsf/htmlmedia/critical\\_care\\_nurse.html](http://www.aacn.org/aacn/aacnsite.nsf/htmlmedia/critical_care_nurse.html)).

7. **Recovering Organs.** Organs are recovered in a sterile surgical procedure while the donor is on a ventilator. When organs are removed, they are flushed with a solution that helps preserve them until they are transplanted. After flushing, they are placed in sterile bags in a cooler with ice and transported to various transplant centers where patients awaiting a transplant who have been matched to the organs through a national database receive them. Tissue recovery may occur after the removal of organs.
8. **Making Funeral Arrangements.** The disposition of the body follows hospital guidelines and the wishes of the family. The donation does not preclude an open-casket viewing of the body. The funeral director should be contacted regarding details of the funeral arrangements.
9. **Ensuring Follow-Up.** Without revealing recipients' identities, OPOs generally send letters to donor families within a few weeks of the donation telling them about the recipients who received the gift of their loved one's organs. Recipients and donor family members who want to correspond can do so with the assistance of the OPO, but the names of donors, donor family members, and recipients are kept confidential. In some cases, when all parties agree, donor family members and recipients exchange names and have the opportunity to meet. Many OPOs offer grief support-group services to organ and tissue donor families. In addition, a number of OPOs conduct donor recognition ceremonies to publicly recognize the generosity of those who have given the gift of life and sponsor the participation of donors and donor families in national donor recognition ceremonies hosted by HHS in Washington, DC and by the National Kidney Foundation at its U.S. Transplant Games. Finally, OPOs often provide feedback to hospital staff and others (e.g., medical examiners/coroners, emergency response personnel) regarding the positive impact their efforts have had on the lives of recipients and donor families alike.

*For more information about matching donors to recipients and other details about the organ allocation process, visit the UNOS Web site at [www.unos.org](http://www.unos.org).*

## **Requesting Tissue and Eye Donation**

According to the American Association of Tissue Banks, "tissue transplants make possible skin grafts for thousands of critically burned patients; donated corneas avert or correct blindness; and tens of thousands of patients benefit from donated bone, cartilage and tendons used to reconstruct and rehabilitate" (American Association of Tissue Banks, 2000). The American Red Cross estimates that 150,000 people a year have the quality of their lives improved by bone transplants (American Red Cross, 2000). Furthermore, the members of the Eye Bank

Association of America reported a total of 45,765 corneal transplants in 1999 (Eye Bank Association of America, 2000).

The CoP requires hospitals to have an agreement with their OPO and an agreement with at least one tissue bank and at least one eye bank to cooperate in the retrieval, processing, preservation, storage and distribution of tissues and eyes. In the absence of separate arrangements between the hospital and a tissue bank and an eye bank, the OPO is required to identify and refer potential tissue and eye donors using protocols developed in consultation with the tissue and eye banks. In addition, the CoP requires that the family of each potential donor be informed of its options to donate tissues and eyes as well as organs.

As in the organ donation process, procurement personnel evaluate the medical suitability of the potential tissue donor by testing for diseases and by obtaining a medical and social history. According to the LifeLink Foundation, tissue donation does not interfere with an open casket funeral since skin is removed in a thin, split-thickness layer, from areas such as the back, buttocks, and back of the thighs. Moreover, prosthetic devices are used to replace bone or an eye that has been removed (LifeLink Foundation, 2000).

It is essential that hospitals, OPOs, tissue banks, and eye banks work together to optimize both organ and tissue donation and to educate and train staff. Due to differences in donation and transplantation criteria for solid organs as compared with tissues and eyes, the potential for tissue donation is generally higher than it is for organ donation. For example:

- Most tissues can be recovered from donors as long as 12-24 hours after cardiac cessation when the body is kept cool. Optimally, corneal tissue should be removed within the first few hours after death.
- Cornea, eye, and tissue donation do not require intact cardiovascular function, so donor maintenance requirements are not the same as for organs.
- Requests for cornea, eye, and tissue donation are most often done over the telephone.
- Family concerns may be different depending on the type of donation (e.g., concerns about disfigurement).

## **Working with Medical Examiners, Coroners, and Funeral Directors**

In their policy statement on donation, the National Association of Medical Examiners and principal national transplant organizations recognized that, “medical examiner/coroner cases constitute the single greatest source for healthy organs and tissues” (UNOS, 1996). They also asserted that organ and tissue donation is compatible with the appropriate preservation of forensic evidence and should not compromise the quality practice of forensic medicine. Medical examiners and coroners (ME/Cs) are responsible for investigating sudden or violent deaths and for providing accurate, legally defensible determinations of the manner and cause of these deaths. For cases that fall under the ME/C’s jurisdiction, donation cannot proceed without the ME/C’s consent to release the case for donation.

A number of ME/Cs across the country have become active in working with hospitals, procurement agencies, funeral homes, and district attorneys offices to facilitate and promote organ and tissue recovery. For example, the Cook County Medical Examiner's Office in Illinois instituted a new protocol that resulted in a 100 percent release of potential donation cases. Moreover, the local organ and tissue recovery agency, Regional Organ Bank of Illinois, now informs Cook County ME/Cs of the donation wishes of the deceased's family.

In Massachusetts, where hospital emergency departments must report all deaths to the Office of the Chief Medical Examiner (OCME), a routine referral program requires emergency departments to make just one call to the OCME and to obtain the telephone number of the next of kin. The OCME then ensures timely notification to the organ and eye/tissue procurement agencies. In each donation case, medical examiners gather forensic evidence during the procurement process. A full-time donation coordinator at the OCME provides the hospital with monthly reports of the emergency department's donation efforts and gives hospital staff feedback on cause of death. Since the program began in 1997, ME/C denials for donation have been eliminated and donation of organs and tissues has increased statewide (M. Christie, personal communication, June 20, 2000).

Families often rely upon the expertise and guidance of funeral directors in making decisions concerning final arrangements for their loved ones, including, in some instances, donation. It is important for hospitals, OPOs, eye and tissue banks, ME/Cs and other concerned parties to develop good communications with individuals in the funeral industry to address any concerns that may arise. Organ and tissue donation should not be considered an obstacle to embalming or open casket viewing. Organizations such as the International Cemetery and Funeral Association and the National Funeral Directors Association have developed educational materials on donation for the public and for their members.

## **Documenting the Donation Process**

Proper documentation of the donation process is essential. Documentation helps assure that proper procedures are followed, provides a basis for quality improvement efforts, and serves as evidence of compliance with HCFA and JCAHO requirements. Documentation should be as explicit and simple as possible, while still serving to collect all necessary information. Documentation procedures and responsibilities will vary for each hospital, OPO, and eye/tissue bank. Training should identify who is responsible for documenting each component of the donation process and include instruction in locating and completing the appropriate documentation. Copies of documentation forms and procedures can be included in a training program packet. See Exhibit 3 for an example of the types of documentation that may be required.

### **Exhibit 3: Nebraska Health System's Acute Bereavement Packet \***

Documentation forms and related materials include:

1. A flow chart for acute bereavement services in the Nebraska Health System.
2. A clinical abstract for autopsy.
3. An authorization for autopsy and final disposition of deceased patient's form.
4. A deceased patient information form to be completed on every death.
5. A funeral home information form.
6. A consent for disposition of body/products of conception form.
7. An organ and tissue donation consent form.
8. A pamphlet providing questions and answers about autopsy developed by the Nebraska Health System and the University of Nebraska Medical Center.
9. A pamphlet on dealing with grief.
10. An acute bereavement services phone number list.
11. A sympathy card from the University of Nebraska Hospital staff.

\* For more about Nebraska Health System's Acute Bereavement Service, see Chapter 6.

## **Working with Families**

Working with families is an important part of patient care, regardless of the potential for donation. Ensuring that potential donor families have all they need to make donation decisions is a critical part of the donation process. Individuals and teams who approach families about donation must receive training to equip them to work with families in a respectful and caring fashion, to provide families with the facts and support they need, and to use best practices to obtain consent. In addition, individuals who offer the option of donation must have the ability and willingness to spend considerable time with family members.

### ***Understanding families in the acute stage of loss***

Family members facing the loss of a loved one may experience a range of emotions, including anger, grief, guilt, confusion, fear, and powerlessness. They may abruptly change attitudes about organ and/or tissue donation and the provision of medical care within short windows of time. Reactions will vary among individuals and as a function of cultural, ethnic, and other influences. Moreover, these emotions and reactions may hinder the ability of family members to process information about the situation at hand. How families are treated at this time is likely to play a role in their donation decision and in their ultimate satisfaction with that decision. Many families find solace in their decision to donate and provide the gift of life to others.

### ***Maintaining respect for the family***

All individuals involved with the donation process must have a fundamental respect for the bereaved family members and the difficulty of their situation. Individuals working with the

family must maintain the focus of supporting the family through the situation and serving their needs, rather than the needs of themselves, the hospital, the OPO, or the eye and tissue bank.

### ***Developing communication skills***

An individual offering the donation option should be comfortable discussing sensitive issues and responding to a family going through the grieving process. Role-play and other practice and feedback activities are useful training tools to improve communication skills. In addition, persons who offer the option of donation must be comfortable with their own attitudes towards death and must not be afraid of approaching and interacting with a family in crisis. Training must emphasize that death is the focal event and that donation figures among the possible end-of-life decisions for the family. Finally, training should prepare individuals to answer questions and address misconceptions that families have about death and the donation process (see Appendix B: Frequently Asked Questions). Many families, for example, may not understand that donation does not jeopardize a potential donor's quality of care, does not disfigure the body, and does not cause the surviving family to incur more expenses. Moreover, nearly all religions support donation.

### ***Getting to know the family***

The ability to effectively communicate with families in crisis is greatly enhanced if the team identifies important background information about the family prior to an initial discussion. Conducting a background assessment of the family by speaking to physicians, nurses, and staff who have interacted with or observed the family can help in adapting the approach and style of communication, allowing the requesting team to be more focused on the family's needs and to target discussion about organ and tissue donation more effectively.

### ***Assessing family dynamics and modifying approaches***

Individuals involved in making the donation request should recognize that family dynamics and decision-making may change with the arrival or departure of family members and that a change in communication styles may be necessary to maintain good rapport with the family. Knowledge of the family structure (e.g., identification of the key decision makers) and orientation of the potential donor within that family structure can alter how, when, and with whom the requesting team introduces the topic of organ and/or eye and tissue donation. Individuals who offer the donation option, that is, OPO staff and/or designated requestors, should be practiced in adjusting their approach throughout an interaction with a family. Videotaped role-play activities built into a training program are an effective instructional aid for developing this skill.

As described above, the grieving process is usually not linear. Helping a family handle this crisis means being prepared for families to "backtrack" to earlier stages of understanding and acceptance of death. For example, a discussion of brain death may need to occur several times throughout the interaction with a family and the information may need to be presented in multiple ways for the family to ultimately understand the situation. It also is important to give families time to absorb the reality that brain death has occurred and to verbalize that understanding before making a request for donation.

### ***Being sensitive to cultural, religious, and spiritual influences***

Those offering the option of donation to a family must be sensitive to the family's unique cultural, religious, and spiritual background, perspectives, and values. People tend to respond more positively to individuals that they feel they can trust or with whom they can identify. To enhance their rapport with families, some programs have adopted a range of approaches, for example, training hospital chaplains or mothers of donors as designated requestors, hiring OPO staff who speak in the native language of persons with limited-English proficiency, or developing a specific minority requestor program. Examples of some of these specialized approaches, including Albany Medical Center's "MOD Squad" (Mothers of Donors), Lifelink of Georgia's Designated Minority Requestor Program, and Nebraska Health System's Acute Bereavement Service, are described in Chapter 6: Innovative Practices. Care should be taken, however, not to make assumptions about family preferences. Moreover, the absence of a designated requestor of the same cultural, religious, or racial or ethnic background as the family should not be used as an excuse to avoid discussing the donation option with the family.

### ***Providing ongoing support and care***

Family care does not end with the decision to donate or not to donate. Assistance with personal belongings, funeral arrangements and other practical matters may be needed. In addition, families may be offered additional emotional support such as referrals for counseling and support groups. While the names of donors and recipients are kept confidential, donor families also may want basic information about the people who received their loved one's organs and tissues and how they may eventually develop lines of communication with the recipients. These are effective tools in the healing process both for donor families and transplant recipients.

## CHAPTER 5: FEEDBACK AND EVALUATION

*“I haven’t failed, I’ve found 10,000 ways that don’t work.”* – Benjamin Franklin

*“The danger in communication is the illusion that it has been accomplished.”* – George Bernard Shaw

Evaluation of the donation process is necessary to ensure that the process is effective, that regulatory and other requirements are being met, and that areas in need of improvement are identified. If an opportunity to donate has been missed, or nearly missed, it is important to know precisely why and to identify ways to improve in the future. Using continuous quality improvement measures to track various aspects of the donation process (e.g., referral of deaths and imminent deaths, potential donors based on death record reviews, number and type of organs and tissues donated, individual and hospital-specific consent rates) and to provide feedback to participants and management can increase both the effectiveness of the donation process and customer satisfaction. Exhibit 4 provides an example of a collaborative initiative between an OPO and hospitals in its service area to document and provide feedback on CoP implementation.

### **Exhibit 4: Mid-South Transplant Foundation and Service Area Hospitals Collaborate to Provide Feedback and Documentation of Donation Process**

**Activity:** Mid-South Transplant Foundation (MSTF), the OPO covering Western Tennessee, Eastern Arkansas, and Northern Mississippi, worked closely with the Medical Records Department, the Quality Improvement Coordinator, and the Compliance Officer of each hospital in its service area to design a “Notification of Death” (NOD) form tailored to each institution. After comparing the NOD forms and the hospital’s death list, MSTF provides each facility with a monthly written report of its compliance with the CoP. If performance problems are identified, a walk-through in-service, specifically designed to address problem areas, is available. This technique allows hospital staff to review the proper steps in the referral/donation process in their own timeframe. As each participant completes the in-service, a post-test is available. MSTF reviews the tests and returns them to the Nurse Manager with a certificate of completion for each participant.

**Results:** This feedback and documentation process has benefited both MSTF and the hospitals:

1. The NOD is now part of the patient’s medical record, so it is readily available to surveyors.
2. The NOD provides timely feedback on where additional in-service education is needed.
3. These activities keep the lines of communication open between each hospital and MSTF.
4. MSTF assists area hospitals in data collection for site surveys.
5. The NOD provides information to help develop plans for increasing routine referral.
6. The certificates of completion document staff participation in continuing education.

For more information, contact Connie B. Poteet, RN, Hospital Development Coordinator, Mid-South Transplant Foundation, at (877) 228-5433 or (901) 328-4452.

The performance of those offering the donation option should be systematically tracked and evaluated to ensure quality bereavement care is being offered to families and consent rates are at optimal levels. Doing so provides the opportunity to identify best practices and incorporate these practices into improved training programs. When performance does not meet standards or expectations, the OPO, the eye/tissue bank, and/or the hospital, as appropriate, must be willing to take corrective action, such as retraining, limiting the involvement of certain individuals in the donation process, or instituting changes in procedures. For ongoing quality improvement, it is arguably as important to recognize and thank individuals and teams for their role in contributing to a more effective donation process as it is to take corrective action when problems are found.

Some of the commonly used approaches to providing feedback include:

### **Conducting case reviews**

A post-donation case review, through a feedback session, debriefing, morbidity and mortality conference or grand rounds, allows staff from the hospital, OPO, and/or eye and tissue bank to review aspects of a particular case where there was potential for donation and to gain insight into the overall strengths and weaknesses in the donation program. Medical record reviews conducted by the hospital and/or procurement agency often provide very useful information for this feedback process. In response to the CoP, for example, Donor Alliance of Colorado and multidisciplinary Donation Resource Teams (DRTs) in two hospitals developed a new continuous quality improvement process to increase referrals, approaches by trained staff, and informed decision-making by families. On a monthly basis, the DRTs review death reports, assess the accuracy of documentation, identify approaches by non-trained staff, and review data on referrals and donations. When deficiencies are found, a Performance Improvement Activity Sheet is used to initiate corrective action. Between the first quarter of 1998 and the fourth quarter of 1999, one of the two hospitals increased its compliance with routine referral from 70 percent to 100 percent and its designated requestor approaches from 29 percent to 90 percent. The second hospital went from no routine referral documentation to 95 percent compliance, while its designated requestor approaches increased from 24 percent to 79 percent.

### **Generating written reports**

Written reports produced on a routine basis (e.g., monthly or quarterly) help hospital and procurement staff to spot strengths and weaknesses in the donation process and to document compliance with HCFA and JCAHO donation requirements. For example, the Lifeline of Ohio Organ Procurement Agency spoke with surveyors for JCAHO and the American Osteopathic Association and with hospital survey readiness staff to prepare a Survey Readiness Notebook. The notebook includes hospital policies and procedures, three consecutive years of hospital referral data and donor activity, a list of trained designated requestors, consent rates, an overview of training and refresher training activities, hospital death and release of body forms, and other materials.

## **Conducting medical record reviews**

McNamara, Franz, Fowler, et al. (1997) make several recommendations for quality improvement initiatives based on medical record reviews. They suggest that OPO staff provide feedback from medical record reviews to key hospital staff concerning practice improvements. In addition, they recommend that hospitals use information from medical record reviews to assess the hospitals' performance in the organ donation process, identify areas where performance can be improved, and monitor the effectiveness of the implemented changes. To aid in implementing the CoP, for example, Our Lady of the Lake Regional Medical Center in Baton Rouge, Louisiana created a task force with staff from the eye bank and from the medical center's education, quality assurance, patient care services, and medical records departments. The task force developed a mortality audit tool to record deaths, referrals, completion and documentation of consent forms, and other measures. Each month, the audit tool is compared to an automated mortality report. Results are used to refine the donation process, including the continuing education of hospital staff.

## **Listening to donor and non-donor families**

Feedback both from donor and non-donor families provides critical information on the family's perception of the requesting team's actions. A common method of obtaining donor and non-donor family feedback is to conduct a survey of families after an appropriate amount of time has passed since their interaction with the requesting team. (Surveying should occur only if permission for follow-up contact has been granted by the family at the time of the event.) Appropriate steps should be taken to protect families in this process. If the hospital has an Institutional Review Board (IRB), for example, the survey instrument and the process for surveying should be reviewed by the IRB. Appendix G includes a sample cover letter and survey from the Northeast Organ Procurement Organization and Tissue Bank and a sample survey from Lifelink of Georgia.

## **Communicating among hospital, OPO, and eye/tissue banks**

As mentioned elsewhere in this Resource Guide, healthy communication among the hospital, OPO, eye bank, and tissue bank facilitates optimal care of the potential donor family and higher rates of consent. Each locality should determine the most effective method of inter-organizational communication.

## CHAPTER 6: INNOVATIVE PRACTICES

*“Quality is never an accident; it is always the result of intelligent effort.”* – John Ruskin

*“An optimist sees an opportunity in every calamity; a pessimist sees a calamity in every opportunity.”* – Sir Winston Churchill

Below are additional examples of innovative donation practices that could be incorporated into a training program. The programs highlight a range of approaches, including instituting continuous quality improvement, providing bereavement care, and utilizing minority requestors and mothers of donors to talk with bereaved families about donation. This list of programs is not meant to be exhaustive but to stimulate creative and more effective approaches to donation.

### **California Transplant Donor Network and John Muir Medical Center**

To implement the requirements of the CoP, the California Transplant Donor Network (CTDN) and the John Muir Medical Center (JMMC) worked together to meet with individuals from throughout the hospital, review and revise brain death and organ donation policies, update forms, and provide in-service education and designated requestor training. CTDN, JMMC, and the local tissue bank conducted meetings and in-service programs with trauma physicians, neurosurgeons, the Nursing Council, the Nursing Directors Council, and the Pastoral Care Department. One physician requested and received training as a designated requestor. In addition, CTDN and JMMC revised expiration-related forms to include documentation of referral and outcomes. CTDN provides monthly reports to JMMC’s ICU manager, Quality Assurance Department, and Donor Council on compliance with the CoP, and performs quarterly medical record reviews to determine organ potential. Each quarter, the Donor Council, an interdisciplinary team of professionals from nursing, ICU, ER, OR, respiratory therapy, medical imaging, pastoral care, social services, and organ and tissue procurement, reviews progress on implementing the CoP and makes recommendations for improvement.

As a result of these efforts, from 1998 to 1999, hospital potential donor referrals to the OPO increased from 88 percent to 95 percent and consent for organ donation jumped from 53 percent to 74 percent. CTDN credits the success of these efforts to the early involvement of a broad spectrum of personnel in both critical and non-critical care areas of the hospital whose input enabled CTDN and JMMC to identify the hospital’s needs and to enlist the assistance of hospital staff to best meet those needs.

For more information, contact Helen Christensen, Hospital Development Coordinator, CTDN, at (415) 837-5886, extension 330, or Vivian Brailoff, Director of Critical Care Services, JMMC, at (925) 947-4466, extension 35454.

## **Pacific Northwest Transplant Bank and Portland Veterans Affairs Medical Center**

To improve its compliance with the CoP and JCAHO standards, the Portland Veterans Affairs Medical Center (PVAMC) chartered an interdisciplinary Performance Improvement (PI) team in May 1999. The 14-member team included nursing and administrative representatives from medicine and surgery wards/units, decedent affairs, and the PVAMC's liver transplant program. Together, the PI team and the Pacific Northwest Transplant Bank (PNTB), the local OPO, reviewed and revised existing donation policy; incorporated donation policy requirements into orientation and annual competencies; developed a computerized, interactive teaching module; and provided training on all shifts. They enlisted and trained designated requestors to add to the existing trained requestor pool and listed the requestors' names in the hospital's electronic phone book. Finally, the PI team enlisted Quality Management (QM) to conduct death reviews to document compliance with internal policies. PNTB now performs the chart reviews on a quarterly basis.

Progress in complying with the revised donation policy was substantial. In 1997 and 1998, donation had been considered in only 33.9 percent and 28 percent of deaths, respectively, as evidenced by a completed "certificate of request for donation" in the medical record. During the first half of 1999, completed certificates of request rose to 50.9 percent of reviewed charts and reached 95 percent by the final quarter of 1999. Over the same period, referral calls rose from 54.7 percent of all hospital deaths to 84.7 percent.

PNTB and PVAMC credit this success to the commitment of hospital management who chartered a PI team with the authority to assure compliance with policies. The PI team achieved compliance with the donation policy through concise policy revision, a standardized death packet, education (at orientation and ongoing) of nursing and administration staff, a committed trained requestor pool, and timely review of data to allow continuous evaluation and improvement.

For more information, contact Chris Shaw, RN, Procurement Coordinator, PNTB, at (503) 494-5560, or Roberta Ruimy, MA, Transplant Specialist, PVAMC, at (503) 721-7860.

## **Lifeline of Georgia's Designated Minority Requestor Program**

Cultural, social, religious, and other differences between the individual offering the option of donation and the potential donor family may result in subtle barriers that can adversely influence a family's decision to donate. By having someone of the same cultural, social, or religious background offer the option of donation, some of these obstacles may be overcome. LifeLink of Georgia initiated the Minority Requestor Program in 1995 to help alleviate barriers for families who may have such concerns about organ, tissue, and eye donation. Support for the program initially came from the Carlos and Marguerite Mason Trust, but as the program continued to prosper, LifeLink of Georgia included the program as part of its procurement costs. In the four years following implementation of LifeLink of Georgia's Minority Requestor Program, the

number of African-American organ donors nearly tripled, rising to 170 donors between 1995 and 1999 compared to a total of 62 African-American organ donors during the previous four years.

For more information, contact Bobbi Beatty, Vice President and Executive Director of MDEP, 3715 Northside Parkway, 100 Northcreek, Suite 300, Atlanta, Georgia 30327. She may be reached by telephone at (404) 266-8884, via fax at (404) 266-0592, or by e-mail at [Bobbi@lifelinkfound.org](mailto:Bobbi@lifelinkfound.org).

## **Albany Medical Center's "MOD Squad"**

Mothers of Donors, known as the "MOD Squad," is a pilot program of the Center for Donation and Transplant ("the Center") in Albany, New York. Used in the pediatric population over the past two years, the MOD Squad comprises a small group of volunteer mothers who have each experienced the loss of a child. These volunteers are screened and trained, in coordination with OPO staff, to approach parents of children who may be potential donors and to offer the families emotional support, education, and general assistance. MOD Squad members respond 24 hours a day to help families facing the loss of a loved one.

The MOD Squad began as a bereavement group composed of mothers who had lost their children and had donated their children's organs. Recognizing the need to support families in a time of crisis, the director of the Center collaborated with the mothers to create the MOD Squad program. Between October 1997 and July 1999, the MOD Squad interacted with 22 families who were offered the option of donation. Over this period of time, the MOD Squad achieved a consent rate of 90 percent, compared to an overall rate for the Center of 64 percent.

From a financial perspective, the Center has not incurred significant costs related to the MOD Squad because of its volunteer nature. A grant awarded in 1999 by HRSA's Division of Transplantation, however, allows the Center to offer stipends to the mothers to cover travel costs and other expenses associated with being on call.

In addition, the grant funding is enabling the Center to expand and implement the MOD Squad initiative into two other regions of New York State and to offer MOD Squad support to more families facing the loss of a loved one. The program evaluation will provide a rigorous qualitative and quantitative examination of the effectiveness of the program in relation to the consent rate. Findings from this evaluation are expected to improve understanding of the salient social support factors related to the consent decision-making process. Finally, the MOD Squad grant initiative will focus on creating new and refining existing educational materials that will be made available to other organ procurement centers desiring to implement such a program.

Information about the expansion and evaluation of the MOD Squad program under the HRSA/DoT grant may be obtained from Elizabeth A. Pease, Project Coordinator, Center for Donation and Transplant, 218 Great Oaks Boulevard., Albany, NY 12203. She may be reached by telephone at (518) 262-8744.

## **Nebraska Health System's Acute Bereavement Service**

The Nebraska Health System (NHS) established its Acute Bereavement Service to add structure and constancy to the requesting procedure to ensure that potential donor families are approached in an appropriate and caring manner. Specifically, the purposes of NHS's Acute Bereavement Service are:

- To ensure support and comfort to the families and friends of dying patients during the initial time of grief and loss.
- To ensure that the option for tissue and organ donation and autopsy is presented for each death.
- To ensure compliance with regulatory requirements for reporting deaths to the county coroner and the OPO.

A relatively small group of individuals trained in both bereavement care and organ and tissue donation participate in the Acute Bereavement Service. They include chaplains, nurse resource coordinators, and organ recovery staff. These individuals are primarily responsible for helping families through the grieving process and offering them the option of donation. By establishing a specialized service for these purposes, NHS has been able to increase and maintain high levels of compliance with routine referral requirements.

Staff receive training in a comprehensive policy and procedures manual unique to NHS which outlines the responsibilities of various staff in specified bereavement situations (e.g., the nursing staff in an intra-uterine fetal death or infant death). The manual is detailed and presented in a step-by-step fashion for all those involved in the process. According to the NHS Acute Bereavement Care training manual, "Acute Bereavement Service provides NHS with the opportunity to ensure that the surviving relatives of all deceased patients are provided with a consistent level of care, guidance, and support during the initial stages of death."

The program measures its success by tracking the percent of all hospital deaths referred to the OPO. From May to June 1999, NHS reported 100 percent of hospital deaths to the OPO, followed by referral rates of 98.1 percent from July to September and 99.5 percent from October to December. In addition, Acute Bereavement Service staff are conducting an evaluation of services by soliciting feedback from families and nurses. Final results are pending. Data derived from evaluations of the program have helped to bolster support among physicians and hospital administrative staff. This support was a key factor in the expansion of the Acute Bereavement Service when two area hospitals – University and Clarkson Hospitals – merged together to become NHS.

For further information on NHS' Acute Bereavement Service, contact Kathy Menke, Community Relations, at (402) 559-5274 or Reverend Deborah Boucher-Payne, Pastoral Care, at (402) 552-3323.

## **APPENDIX A**

### **TIPS FOR BUILDING AN EFFECTIVE TRAINING PROGRAM**

# TIPS FOR BUILDING AN EFFECTIVE TRAINING PROGRAM

## GETTING STARTED:

- Select a team or committee to complete the following review. Ideally this team will include staff and administrators from the hospital, OPO, and tissue and eye banks. Hospital personnel may include staff from the emergency department, intensive care unit, operating room, respiratory therapy, neurology, neurosurgery, cardiology, laboratory, medical records, risk management, quality assurance, patient/customer services, mental health services, pastoral care, and ethics committee.
- Incorporate additional input from patients, families, and relevant community parties, such as emergency response personnel, medical examiners, coroners, and funeral directors.
- After completing the assessment, develop an action plan to identify the steps that need to be taken for your institution to develop a more effective donation training program. Anticipate potential barriers to the implementation of the action plan and take steps to address them.

## 1. ASSESS TRAINING NEEDS

- Gather and review donation training materials, including those currently used by the hospital, OPO, and tissue and eye banks:
  - Do training materials incorporate current protocols, procedures, and best practices?
  - Are the materials appropriate for training goals and intended audience?
  - What deficiencies exist in training content or presentation?
- Discuss previous donation training experiences:
  - What aspects of training have worked and what aspects have not worked and why?
  - What are staff attitudes toward training?
  - Who are the hospital's successful requesters? How is success defined?
- Identify specific training needs and goals:
  - What is the purpose and expected outcomes of the training?
  - Is there sufficient institutional buy-in and support?
  - Are continuing education and training considered part of the staff's official duties?
  - Which hospital staff have contact with potential donor families?
  - What roles (e.g., requestor, coordinator, supporter) and functions will hospital staff have?
  - How will the training enhance teamwork and institutional collaboration?

## **2. IDENTIFY FAMILY NEEDS**

- Discuss end-of-life and bereavement care issues:
  - What mechanisms currently exist to support families in crisis?
  - What are the roles fulfilled by hospital and procurement staff to support families?
  - What changes and improvements should be considered?

## **3. EXAMINE CURRENT DONATION PRACTICES**

- Is the hospital fully compliant with current HCFA regulations and JCAHO standards, including the timely referral of all deaths and imminent deaths to the OPO?
- Are there formal policies for determining brain death and for withdrawal of supportive measures? Are these policies being followed?
- Are best practices being used to request donation from family members (e.g., quiet, private setting, “decoupling” of the explanation of brain death from the subsequent discussion of donation, team approach, respect and sensitivity to family needs, cultural competency)?
- Are optimal donor management practices being used to maintain organ and tissue viability?

## **4. CUSTOMIZE THE TRAINING PROGRAM**

- Select appropriate training elements to meet identified needs.
- Identify individuals from the hospital, OPO, and community to assist in the design and implementation of the training program, e.g., experts in bereavement, death and dying, neuroscience, donor management, organ and tissue procurement, risk management, quality assurance, cultural diversity, pastoral care, ethics, and funeral services.

## **5. DEVELOP FEEDBACK AND EVALUATION MECHANISMS**

- Conduct medical record reviews to evaluate success and identify missed opportunities.
- Identify or develop tools to evaluate satisfaction with, and success of, the training program and to track individual requestor performance.
- Institute measures (e.g., written reports, debriefings, newsletter articles) to provide regular feedback on the donation process and outcomes to administrators, staff, and the community.

## **APPENDIX B**

### **FREQUENTLY ASKED QUESTIONS**

## **FREQUENTLY ASKED QUESTIONS**

### **What organs and tissues can be donated after death?**

The heart, kidneys, pancreas, lungs, liver and intestines all can be transplanted, as can blood vessels, bone, cornea, heart valves, skin, tendons, and other tissues.

### **Will the decision to donate my loved one's organs affect the quality of medical care he or she receives at the hospital?**

No. Every effort is made to save the person's life before donation is considered.

### **Will donation disfigure my loved one's body?**

No. Families may proceed with funeral services, included an open-casket viewing if desired.

### **Are there any costs to my family for donation?**

No. All costs for donation are ultimately paid by recipients and their health insurance. The patient's family pays only for the medical care provided before death and funeral expenses.

### **Are organs sold?**

No. The National Organ Transplant Act (Public Law 98-507) makes it illegal to sell human organs and tissues. Violators are subject to fines and imprisonment.

### **Should some people rule themselves out as donors due to age or medical history?**

No. Testing is used to make sure only healthy organs or tissues are transplanted. If organs or tissues can't be transplanted, they may help others through medical education and research.

### **How are organs distributed?**

Patients are matched to organs based on a number of factors including blood and tissue typing, medical urgency, time on the waiting list, and geographical location.

### **Do religious groups support organ donation?**

Yes, nearly all U.S. religions support donation as a gift of life to fellow human beings.

### **How many people are currently waiting for organ transplants?**

By August 2000, more than 71,000 people were on the OPTN waiting list for transplantation. Additional data on donation and transplantation can be found at [www.unos.org](http://www.unos.org).

### **Can I donate my body to medical science?**

Yes. If you wish to donate your entire body for research or education, you should contact the facility of your choice directly (e.g., medical or dental school) to make arrangements.

Additional questions and answers can be found at <http://www.organdonor.gov/faq.html>, <http://www.transweb.org/myths/myths.htm>, <http://www.lifelineofohio.org/faq.htm>, and [http://www.nceyebank.org/2\\_ml10.htm](http://www.nceyebank.org/2_ml10.htm).

## **APPENDIX C**

### **INTERNET RESOURCES**

## GOVERNMENT RESOURCES

**U.S. Department of Health and Human Services (HHS).** Division of Transplantation, Health Resources and Services Administration. The Division provides federal oversight and funding support for the nation's organ procurement, allocation, and transplantation system; coordinates national organ and tissue donation activities; and administers the national bone marrow program.

<http://www.hrsa.gov/osp/dot>

**Food and Drug Administration.** FDA's Center for Biologics Evaluation and Research is responsible for ensuring the safety, efficacy, potency, and purity of biological (e.g., tissue) and related products intended for use in the diagnosis, treatment, prevention or cure of diseases in humans as well as the safety of the nation's supply of blood and blood products.

<http://www.fda.gov> (click on "Biologics")

**Health Care Financing Administration.** HCFA administers the Medicaid and Medicare programs and the State Children's Health Insurance Program. HCFA guidance on the Conditions of Participation for organ, tissue, and eye donation includes the June 1998 Federal Register notice, HCFA regional coordinator contacts, questions and answers, and interpretive guidelines for surveyors.

<http://www.hcfa.gov/quality/4a.htm>

**National Organ and Tissue Donation Initiative.** The U.S. Department of Health and Human Services has undertaken this initiative to ease the critical shortage of organ donors. Its goals are to increase consent to donation, maximize donation opportunities, and learn more about what works to increase donation and transplantation through carefully designed research efforts.

<http://www.organdonor.gov>

**National Institute of Allergies and Infectious Diseases.** NIAID, among its many activities, supports studies aimed at improving immunosuppressive therapies, further developing reagents needed for precise tissue matching, defining the genetic regulation of the immune response, and understanding the molecular mechanisms that control immune system genes. NIAID is participating in the first NIH cooperative clinical trial in kidney transplantation, designed to translate developments in basic research into new therapies to prevent graft rejection.

<http://www.niaid.nih.gov>

**National Institute of Diabetes and Digestive and Kidney Diseases.** NIDDK conducts and supports basic and clinical research on kidney disease and other diseases affecting public health.

<http://www.niddk.nih.gov>

The National Kidney and Urologic Diseases Information Clearinghouse

<http://www.niddk.nih.gov/health/kidney/nkudic.htm>

The United States Renal Data System

<http://www.usrds.org>

## ORGANIZATIONAL RESOURCES

**American Association of Tissue Banks.** AATB is a scientific, not-for-profit, peer group organization founded in 1976. Its mission is to facilitate the provision of high quality transplantable human tissue in quantities sufficient to meet national needs.

<http://www.aatb.org>

**American Hospital Association.** The AHA is a not-for-profit association of health care organizations founded in 1898. It provides national advocacy for its members, which include 5,000 hospitals, health care systems, networks, and other providers of care.

<http://www.aha.org>

**American Medical Association.** The AMA, a voluntary national membership organization of physicians, launched its national “Live and Then Give” campaign in 1998 to promote physician-patient discussions about donation, expanding on a campaign initiated by the Texas Medical Association, the TMA Alliance and the Texas Transplant Society. The AMA has provided educational materials to state medical societies and their alliance organizations of member spouses. The campaign also encourages physicians, their families and staff to sign donor cards.

<http://www.ama-assn.org>

**American Osteopathic Association.** The AOA is the national professional organization for osteopathic physicians in the United States. In addition, the AOA is the recognized accrediting authority for colleges of osteopathic medicine, osteopathic postdoctoral training programs and osteopathic continuing medical education.

<http://www.aoa-net.org>

**American Red Cross Tissue Services.** American Red Cross Tissue Services supplies one-quarter of the nation’s tissue for transplantation through its network of 15 tissue centers nationwide and promotes donation through its Transplant Awareness Program.

<http://www.redcross.org/tissue>

**American Society of Minority Health and Transplant Professionals.** ASMHTP’s mission is to promote organ and tissue donation and transplantation among minorities and to serve in a national advisory capacity for research and education on these and other health related issues.

<http://www.lifegift.org/asmhtp.htm>

**American Society of Transplantation.** AST is an organization of transplant professionals dedicated to research, education, advocacy and patient care in transplantation science and medicine.

<http://www.a-s-t.org/index.htm>

**American Society of Transplant Surgeons.** ASTS promotes and encourages education and research in organ and tissue transplantation to facilitate progress in the saving of lives and to enhance the quality of lives of patients afflicted with end-stage organ failure.

<http://www.astso.org>

**Association of Organ Procurement Organizations.** APOPO is a private, non-for-profit professional organization representing the nation's organ procurement organizations.

<http://www.aopo.org>

**Coalition on Donation.** The Coalition on Donation is an alliance of voluntary, professional health, science, and transplant patient groups formed to educate the public about organ and tissue donation, correct misconceptions about donation, and create a greater willingness to donate.

<http://www.shareyourlife.org>

**Eye Bank Association of America.** EBAA is a not-for-profit organization of eye banks dedicated to the restoration of sight through the promotion and advancement of eye banking.

<http://www.restoresight.org>

**Joint Commission on Accreditation of Healthcare Organizations.** JCAHO, an independent, not-for-profit organization, evaluates and accredits more than 19,500 health care organizations in the United States, including hospitals, health care networks, managed care organizations, and health care organizations that provide home care, long term care, behavioral health care, laboratory, and ambulatory care services.

<http://www.jcaho.org>

**National Kidney Foundation, Inc.** NKF is a voluntary health organization that seeks to prevent kidney and urinary tract diseases, improve the health and well being of individuals and families affected by these diseases, and increase the availability of all organs for transplantation.

<http://www.kidney.org>

**National Minority Organ and Tissue Transplant Education Program.** National MOTTEP educates minority communities about organ and tissue transplantation and empowers minority communities to develop transplant education programs to address the shortage of donors.

<http://www.nationalmottep.org>

**North American Transplant Coordinator's Organization.** NATCO is a professional society of transplant coordinators, including clinical and organ and tissue recovery coordinators, as well as specialists in public and professional education.

<http://www.natco1.org>

**South-Eastern Organ Procurement Foundation.** SEOPF's mission is to enhance the donation, procurement, and transplantation of organs and tissues through scientific studies and professional education.

<http://www.seopf.org>

**TransWeb.** TransWeb is a nonprofit educational web site based at the University of Michigan Medical Center featuring news and events, information about donation, and resource links.  
<http://www.transweb.org>

**Transplant Recipients International Organization, Inc.** TRIO is an independent, not-for-profit, international organization committed to improving the quality of life of transplant candidates, recipients, their families and the families of organ and tissue donors.  
<http://www.trioweb.org>

**United Network for Organ Sharing (UNOS).** UNOS provides information for professionals, patients, donors, and recipients on OPTN policies and data on donation and transplantation.  
<http://www.unos.org>

## LEGISLATIVE UPDATES

**Division of Transplantation, Health Resources and Services Administration**  
<http://www.hrsa.dhhs.gov/osp/dot> (click on “Legislative and Regulatory Activities”)

**Thomas Congressional Internet Service.** A free federal legislative information resource.  
<http://thomas.loc.gov>

**TransWeb**  
<http://www.transweb.org/news/news.htm>

## FAMILY RESOURCES

**National Donor Family Council.** The Council provides information and support to donor families and professionals. Materials include the *For Those Who Give and Grieve Book*, 3<sup>rd</sup> ed., the *For Those Who Give and Grieve Newsletter*, the *Donor Family Connection Newsletter*, *Brain Death: A Simple Explanation*, 2<sup>nd</sup> ed., and the *National Communications Guidelines* to assist professionals in facilitating communication between donor families and transplant recipients.  
<http://www.kidney.org/recips/donor> or call the NDFC at 800-622-9010

**Transplant Recipients International Organization, Inc.** TRIO is an independent, not-for-profit, international organization committed to improving the quality of life of transplant candidates, recipients, their families and the families of organ and tissue donors.  
<http://www.trioweb.org>

## PROFESSIONAL RESOURCES

**Critical Care Nurse: Organ Donation Issue.** This April 1999 issue published by the American Association of Critical Care Nurses includes the “Critical Pathway for the Organ Donor” developed by UNOS, which outlines standards of care for each phase of the donation process.  
[www.aacn.org/aacn/aacnsite.nsf/htmlmedia/critical\\_care\\_nurse.html](http://www.aacn.org/aacn/aacnsite.nsf/htmlmedia/critical_care_nurse.html)

**United Network for Organ Sharing.** UNOS publications include the *Organ Procurement Coordinator’s Handbook*, the *UNOS Organ Procurement, Preservation and Distribution in Transplantation* reference manual, *Donation and Transplantation Nursing Curriculum*, *Vital Connections Emergency Physician Kit*, *Organ and Tissue Donation: A Reference Guide for Clergy*, *Brain Death Video*, and the “*In Symphony...*” booklet and poster on the donation process.  
[www.unos.org](http://www.unos.org) (click on “Resources”) or call UNOS at 804-330-8541

## MINORITY RESOURCES

**American Society of Minority Health and Transplant Professionals.**  
<http://www.lifegift.org/asmhttp.htm>

**Journal for Minority Medical Students.** Winter 1998, Vol. 10, No. 2. *Special Topic: Donations & Transplants* and *The Black Bag: Health, Hope, and the Gift of Life*.  
[http://www.spectrumunlimited.com/html/our\\_publications\\_\\_journal\\_for\\_.html](http://www.spectrumunlimited.com/html/our_publications__journal_for_.html)

**National Institute of Allergy and Infectious Diseases.** Minority programs and initiatives.  
<http://www.niaid.nih.gov/facts/mwhhp1.htm>

**National Minority Organ and Tissue Transplantation Education Program.** Minority-focused educational materials include an 11-minute video, *How Do You Say Thank You? An African American Perspective on Organ and Tissue Donation*.  
<http://www.nationalmottep.org> or call National MOTTEP at 1-800-393-2839

**Office of Minority Health Resource Center.** HHS’ OMH-RC serves as a national resource and referral service on minority health issues. OMH-RC’s May 1998 *Closing the Gap* newsletter (<http://www.omhrc.gov/ctg/organ.pdf>) is dedicated to the subject of organ donation, including articles and facts about minority donation.  
<http://www.omhrc.gov>

**United Network for Organ Sharing.**  
Minority Affairs Committee  
[http://www.unos.org/About/Frame\\_About.asp?SubCat=Committees](http://www.unos.org/About/Frame_About.asp?SubCat=Committees)

## **RELIGIOUS VIEWPOINTS**

For information on various religious viewpoints on solid organ and tissue donation, visit:

<http://www.robi.org/donrel.htm> (Regional Organ Bank of Illinois)

[http://www.transweb.org/qa/qa\\_txp/faq\\_religion.html](http://www.transweb.org/qa/qa_txp/faq_religion.html) (TransWeb)

## **FREQUENTLY ASKED QUESTIONS**

Frequently asked questions can be found on many donation and transplantation Web sites, e.g.:

<http://www.lifelineofohio.org/faq.htm> (Lifeline of Ohio)

[http://www.nceyebank.org/2\\_ml10.htm](http://www.nceyebank.org/2_ml10.htm) (North Carolina Eye Bank, Inc.)

<http://www.organdonor.gov/faq.html> (HHS)

<http://www.transweb.org/myths/myths.htm> (TransWeb)

## **INSTITUTE OF MEDICINE REPORTS ON DONATION AND TRANSPLANTATION**

Non-Heart-Beating Organ Transplantation: Practice and Protocols (2000)

<http://www.nap.edu/catalog/9700.html>

Extending Medicare Coverage for Preventive and Other Services (2000)

<http://www.nap.edu/catalog/9740.html>

Organ Procurement and Transplantation: Assessing Current Policies and the Potential Impact of the DHHS Final Rule (1999)

<http://books.nap.edu/catalog/9628.html>

Non-Heart-Beating Organ Transplantation: Medical and Ethical Issues in Procurement (1997)

<http://www.nap.edu/catalog/6036.html>

Xenotransplantation: Science, Ethics, and Public Policy (1996)

<http://www.nap.edu/catalog/5365.html>

## APPENDIX D: MATRIX OF RELEVANT CITATIONS

Article	Organ Donation/ General	Donation Process	Family Needs	Hospital Staff Readiness	Brain Death	Roles and Responsibilities	Tissue Donation	Grieving	Program Model	Racial/Ethnic Issues
American Association of Tissue Banks. Facts about organ & tissue donation. 2000. Retrieved July 21, 2000 from the World Wide Web: <a href="http://www.aatb.org">http://www.aatb.org</a>							X			
American Red Cross. What is tissue donation? 2000. Retrieved July 21, 2000 from the World Wide Web: <a href="http://www.redcross.org/tissue">www.redcross.org/tissue</a>							X			
Beasley CL. After a decade of progress, a need to re-energize the organ donation movement. <i>Nephrol. News Issues</i> . 1997; 11(2): 56-7.	X									
Beasley CL. Maximizing Donation. <i>Transpl. Rev.</i> 1999; 13(1): 31-39.				X						
Beasley CL, Capossela CL, Brigham LE, Gunderson S, Weber P, Gortmaker SL. The impact of a comprehensive, hospital-focused intervention to increase organ donation. <i>J. Transpl. Coord.</i> 1997; 7(1): 6-13.		X	X						X	
Beyer MC, Zanetos MS. Factors influencing response to organ/tissue donation requests: implications for educational programs. <i>Dialysis and Transplant.</i> 1992; 21(12): 794-805.		X								
Buckley PE. The delicate question of the donor family. <i>Transplantation Proceedings.</i> 1989. 21(1):1411-1412.			X							
Burris GW, Jacobs AJ. A continuous quality improvement process to increase organ and tissue donation. <i>J. Transpl. Coord.</i> 1996; 6(2): 88-92.				X						
Committee on Suggested State Legislation. Amendments to the Uniform Anatomical Gift Act [Pa. Act 102]. In: <i>Suggested state legislation</i> . Lexington, KY: The Council of State Governments, 1997: 56: 123-136.	X									
Cumberland BG, De Wit RJ, Kootstra G. Organ and tissue procurement rates improve after professional healthcare education by hospital development coordinators and time sensitive requesting. <i>Transplant Proc.</i> 1995; 27(5): 2957-8.		X								
Cutler JA, David SD, Kress CJ, Stocks LM, Lewino DM, Fellows GL, Messer SS, Zavala EY, Halasz NA. Increasing availability of cadaveric organs for transplantation by maximizing the consent rates. <i>Transplantation.</i> 1993; 56(1): 225-228.		X								

Article	Organ Donation/ General	Donation Process	Family Needs	Hospital Staff Readiness	Brain Death	Roles and Responsibilities	Tissue Donation	Grieving	Program Model	Racial/Ethnic Issues
Davies C. Brain stem death and organ donation. <i>Nurs. Crit. Care.</i> 1996; 1(6): 286-91.					X					
DeJong W, Franz HG, Wolfe SM, Nathan H, Payne D, Reitsma W, Beasley C. Requesting organ donation: an interview study of donor and non-donor families. <i>Am. J. Crit. Care.</i> 1998; 7(1): 13-23.			X							
Douglass GE, Daly M. Donor families' experience of organ donation. <i>Anaesthesia and Intensive Care.</i> 1995; 23(1): 96-98.			X					X		
Duckworth R, Sproat GW, Morien ML, Jeffrey TB. Acute bereavement services and routine referral as a mechanism to increase donation. <i>J. Transpl. Coord.</i> 1998; 8(1): 16-8.			X					X		
Ehrle RN, Shafer TJ, Nelson HR. Referral, request, and consent for organ donation: Best practice – a blueprint for success. <i>Critical Care Nurse.</i> 1999; 19(2) 21-33.						X				
Evanisko MJ, Beasley CL, Brigham LE, Capossela C, Cosgrove GR, Light J, Mellor S, Poretzky A, McNamara P. Readiness of critical care physicians and nurses to handle requests for organ donation. <i>Am. J. Crit. Care.</i> 1998; 7(1): 4-12.			X							
Eye Bank Association of America. Eye Bank Association of America releases 1999 statistical report [Announcement]. March 23, 2000. Retrieved July 21, 2000 from the World Wide Web: <a href="http://www.restoresight.org/public/strptrls00.pdf">http://www.restoresight.org/public/strptrls00.pdf</a>	X	X								
Featherstone K. Nurses' knowledge and attitudes toward organ and tissue donation in a community hospital. <i>STNS J. Trauma Nurs.</i> 1994; 1(2): 57-63.				X						
Franz HG, DeJong W, Wolfe SM, Nathan H, Payne D, Reitsma W, Beasley. Explaining brain death: a critical feature of the donation process. <i>J. Transpl. Coord.</i> 1997; 7(1): 14-21.			X		X					
Gallagher CM. "Hear a just cause, O Lord, attend to my cry": organ donation and pastoral care. <i>J. Pastoral Care.</i> 1997; 51(2): 213-21.						X				
Garrison RN, Bentley FR, Raque GH, Polk HC, Sladek LC, Evanisko MJ, Lucas BA. There is an answer to the shortage of organ donors. <i>Surgery, Gynecology, and Obstetrics.</i> 1991; 173(5): 391-396.	X	X								

<b>Article</b>	<b>Organ Donation/ General</b>	<b>Donation Process</b>	<b>Family Needs</b>	<b>Hospital Staff Readiness</b>	<b>Brain Death</b>	<b>Roles and Responsibilities</b>	<b>Tissue Donation</b>	<b>Grieving</b>	<b>Program Model</b>	<b>Racial/Ethnic Issues</b>
Gortmaker SL, Beasley CL, Brigham LE, Franz HG, Garrison RN, Lucas BA, Patterson RH, Sobol AM, Grenvik NA, Evanisko MJ. Organ donor potential and performance: size and nature of the organ donor shortfall. Crit. Care Med. 1996; 24(3): 432-9.	X									
Gortmaker SL, Beasley CL, Sheehy E, Lucas BA, Brigham LE, Grenvik A, Patterson RH, Garrison N, McNamara P, Evanisko MJ. Improving the request process to increase family consent for organ donation. J. Transpl. Coord. 1998; 8(4): 210-7.		X								
Gravel MT, Szeman P. Increasing referrals and donations using the Transplant Center Development Model. J. Transpl. Coord. 1996; 6(1): 32-6.									X	
Hauptman PJ, O'Connor KJ. Procurement and allocation of solid organs for transplantation. N. Engl. J. Med. 1997; Feb 6; 336(6): 422-31.	X	X								
Helmimski F. Formalities, good faith, and tissue donation. Mayo Clinic Proceedings. 1994; 69(10): 985-986.							X			
Hong BA, Kappel DF, Whitlock ME, Parks-Thomas TD, Freedman BK. Using Race-Specific Community Programs to Increase Organ Donation among Blacks. Amer. J. Publ. Health. 1994; 84(2): 314-315.										X
Kappel DF, Whitlock ME, Parks-Thomas TD, Hong BA, Freedman BK. Increasing African American Organ Donation: The St. Louis Experience. Transpl. Proc. 1993; 25(4): 2489-2490.										X
Klieger J, Nelson K, Davis R, et al. Analysis of factors influencing consent rates. Journal of Transplant Coordination. 1994; 4: 132-134.		X								
LifeLink Foundation. About tissue donation. 2000. Retrieved July 21, 2000 from the World Wide Web: <a href="http://www.lifelinkfound.org/tdonation.html">http://www.lifelinkfound.org/tdonation.html</a>							X			
Lindsay KK. Assisting professionals in approaching families for donation. Crit. Care Nurs. Q. 1995; 17(4): 55-61.						X				
Lundin T. The stress of unexpected bereavement. Stress Medicine. 1987. 3: 109-114.								X		

Article	Organ Donation/ General	Donation Process	Family Needs	Hospital Staff Readiness	Brain Death	Roles and Responsibilities	Tissue Donation	Grieving	Program Model	Racial/Ethnic Issues
McCoy J, Argue PC. The role of critical care nurses in organ donation: A case study. <i>Critical Care Nurse</i> . 1999; 19(2):48-52.		X				X				
McNamara P, Beasley C. Determinants of familial consent to organ donation in the hospital setting. <i>Clin. Transpl.</i> 1997; 219-29.			X							
McNamara P, Franz HG, Fowler RA, Evanisko MJ, Beasley CL. Medical record review as a measure of the effectiveness of organ procurement practices in the hospital. <i>Jt. Comm. J. Qual. Improv.</i> 1997; Jun; 23(6): 321-33.	X								X	
National Donor Family Council of the National Kidney Foundation. "Bill of Rights for Donor Families." NKF. 1994.			X							
National Donor Family Council of the National Kidney Foundation. Brain death: a simple explanation. 2nd edition. 1998. [Also available in Spanish].					X					
National Donor Family Council of the National Kidney Foundation. For those who give and grieve: a book for donor families. 3rd edition. 1997.			X					X		
National Minority Organ and Tissue Transplant Education Program, Nicholas Green Foundation. How do you say thank you? An African American perspective on organ & tissue donation (video, running time: 11 minutes).	X							X		X
Niles PA, Mattice BJ. The timing factor in the consent process. <i>J. Transpl. Coord.</i> 1996; 6(2): 84-87.		X								
Osterweis M, Soloman F, Green M, eds. Bereavement: Reactions, Consequences, and Care. Washington DC: National Academy Press. 1984.								X		
O'Brien RL, Serbin MF, O'Brien KD, Maier RV, Grady MS. Improvement in the organ donation rate at a large urban trauma center. <i>Arch. Surg.</i> 1996; 131(2): 153-9.				X						
Peele AS, Devney P. Educating health care professionals in the process of organ and issue donation. <i>Crit. Care Nurs. Clin. North Am.</i> 1994; 6(3): 575-80.		X								
Pelletier M. The organ donor family members' perception of stressful situations during the organ donation experience. <i>Journal of Advanced Nursing.</i> 1992; 17(1): 90-97.			X							

Article	Organ Donation/ General	Donation Process	Family Needs	Hospital Staff Readiness	Brain Death	Roles and Responsibilities	Tissue Donation	Grieving	Program Model	Racial/Ethnic Issues
Pelletier M. The needs of family members of organ and tissue donors. <i>Heart and Lung</i> . 1993; 22(2): 151-157.			X				X			
Politoski, G, Boller J. Making the critical difference: An innovative approach to educating nurses about organ and tissue donation. <i>Crit Care Nurs</i> . 1994; 6(3): 581-585.			X			X				
Pritchard JG, Bale RM, Abou-Samra M, Dial LK, Horton MD. Severe cerebral injury and brain death: management of the patient's family. <i>Journal of Family Practice</i> . 1985; 21(5): 341-348.					X					
Ptacek JT, Eberahard TL. Breaking bad news: a review of the literature. <i>Journal of the American Medical Association</i> . 1996; 276(6): 496-502.								X		
Radecki CM, Jaccard J. Psychological aspects of organ donation: a critical review and synthesis of individual and next of kin donation decisions. <i>Health Psychology</i> . 1997. 16(2): 183-195.	X		X							
Redfern SM. Organ donation ... how do we ask the question? <i>Collegian</i> . 1997; 4(2): 23-5.		X						X		
Reitz NN, Callender CO. Organ donation in the African-American Population: A fresh perspective with a simple solution. <i>J. Natl. Med. Assoc</i> . 1993; 85(5): 352-358.										X
Riker RR, White BW. Organ and tissue donation from the emergency department. <i>Journal of Emergency Medicine</i> . 1991; 9(6): 405-410.	X						X			
Riley LP, Coolican MB. Needs of families or organ donors: facing death and life. <i>Critical Care Nurse</i> . 1999; 19(2): 53-59.			X					X		
Roark D. The need for increasing organ donation among African Americans and Hispanic Americans: an overview. <i>J. Emerg. Nurs</i> . 1999; 25(1): 21-7.										X
Savaria DT, Rovelli MA, Schweizer RT. Donor family surveys provide useful information for organ procurement. <i>Transp Proc</i> . 1990; 22(2): 316-317.			X							
Shafer TJ, Kappel DF, Heinrichs DF. Strategies for success among OPOs: a study of three organ procurement organizations. <i>J. Transpl. Coord</i> . 1997; 7(1): 22-31.		X								X

Article	Organ Donation/ General	Donation Process	Family Needs	Hospital Staff Readiness	Brain Death	Roles and Responsibilities	Tissue Donation	Grieving	Program Model	Racial/Ethnic Issues
Shirley S, Cutler J, Heymann C, Hart M. Narrowing the organ donation gap: Hospital development methods that maximize hospital donation potential. J. Heart Lung Transpl. 1994; 13(5): 817-823.									X	
Short P, Genel M, Williams MA. The physician's role in organ donation. Action of the AMA House of Delegates 2000 Annual Meeting: Council on Scientific Affairs Report 6 recommendations Adopted as Amended in lieu of Substitute Resolution 519 (I-99) and Remainder of Report Filed.						X				
Siminoff LA, Arnold RM, Caplan AL. Health care professional attitudes toward donation: effect on practice and procurement. J. Trauma. 1995 Sep; 39(3): 553-9.				X						
Sullivan J, Seem DL, Chabalewski F. Determining brain death. Critical Care Nurse. 1999; 19(2): 37-46.	X				X					
Sutton RB. Supporting the bereaved relative: reflections on the actor's experience. Med. Educ. 1998; 32(6): 622-9.			X					X		
Taylor P, Young K, Kneteman N. Intensive care nurses' participation in organ procurement: impact on organ donation rates. Transplant Proc. 1997; 29: 3646-3648.						X		X		
Thall CR, Jenson G, Wright C, Baker S, Meade R. The role of hospital-based family support teams in improving the quality of the organ donation process. Transplantation Proceedings. 1997. 29: 3252-3253.						X				
United Network for Organ Sharing. Medical examiners & coroners resource: how to develop and enhance a relationship with your death investigation specialist. 1996.	X	X				X				
van Dalen J, Blok GA, Kranenburg J, Haase B. European Donor Hospital Education Program. Transplant Proc. 1996; (1): 398-9.									X	
Wight C. Two initiatives designed to maximize the potential for organ donation from intensive care units. Ann. Transplant. 1998; 3(2): 13-7.									X	
Wight C, Jager K, Blok G, van Dalen J, Cohen B. Overview of the European Donor Hospital Education Program. Transplant Proc. 1996; (1): 422-3.									X	

Article	Organ Donation/ General	Donation Process	Family Needs	Hospital Staff Readiness	Brain Death	Roles and Responsibilities	Tissue Donation	Grieving	Program Model	Racial/Ethnic Issues
Wijdicks EF. Determining brain death in adults [see comments]. <i>Neurology</i> . 1995; 45(5): 1003-11. [Comment: <i>Neurology</i> . 1995; 45(5): 1012-4; Comment: <i>Neurology</i> . 1996; 47(1): 309-10.]					X					
Williams MA, Suarez JI. Brain death determination in adults: more than meets the eye [editorial, comment]. <i>Crit Care Med</i> . 1997; 25(11): 1923-4.					X					
Practice parameters for determining brain death in adults (summary statement). The Quality Standards Subcommittee of the American Academy of Neurology. <i>Neurology</i> . 1995; 45(5): 1012-4.					X					

## APPENDIX E: MATRIX OF TRAINING PROGRAMS

Author, year	General Description	Stage of Process	Target Audience	Content	Logistics of Training	Personnel Conducting Training
Alabama Organ Center (1999) 205/731-9200	Outline for Designated Requestor Program	<ul style="list-style-type: none"> <li>• Potential donor identification</li> <li>• Referral</li> <li>• Request</li> <li>• Consent</li> <li>• Follow-up</li> </ul>	Hospital staff	Legal issues; brain death (definition, legal issues, causes); donation process, including identification and referral, logistics of the request, donor management, recovery, and post-event; public attitudes regarding brain death; decoupling; minority issues; issues with declining and consenting	Not specified	OPO staff
American Association of Neurological Surgeons, Congress of Neurological Surgeons, & United Network for Organ Sharing (1993) 804/330-8541 (UNOS)	“Vital Connections: Neurosurgery and Transplantation... A Critical Link” is a resource for neurosurgeons on brain death and donation.	<ul style="list-style-type: none"> <li>• Potential donor identification</li> <li>• Referral</li> <li>• Request</li> <li>• Consent</li> </ul>	Hospital staff	Understanding shortage of donors; referral of donors; donor criteria; OPOs; neurosurgeons’ role in organ donation; diagnosis of brain death; legal aspects of cadaveric organ donation; referral and donation process; communicating with the family; religious and cultural issues	Format: binders, videos	Self
Beacham, Cleveland Eye Bank (1999) 216/844-3937	The goal of the packet is to train designated requestors for eye and tissue donation as required by the HCFA regulation revising the Conditions of Participation for Medicare- and Medicaid-participating hospitals.	<ul style="list-style-type: none"> <li>• Potential donor identification</li> <li>• Referral</li> <li>• Request</li> <li>• Consent</li> <li>• Follow-up</li> </ul>	Hospital staff	HCFA regulation; hospital policy (individualized or LifeBanc); family approach; logistics of request; documentation requirements; consent; follow-up with family	Time: approximately 5 hours  Format: lecture, conversation modeling, role playing	Not specified

Author, year	General Description	Stage of Process	Target Audience	Content	Logistics of Training	Personnel Conducting Training
Burgess, Regional Organ Bank of Illinois (ROBI) (1998) 312/431-3600	<p>The correspondence outlines ROBI's plan for hospital staff training in the process of organ/tissue donation. The hospital staff receive the same training as internal OPO staff.</p> <p>Two types of training are involved, one for those hospitals with organ potential (organ &amp; tissue), and one for those hospitals that have no organ potential (tissue only).</p>	<ul style="list-style-type: none"> <li>• Potential donor identification</li> <li>• Referral</li> <li>• Request</li> <li>• Consent</li> <li>• Follow-up</li> </ul>	Hospital staff	Organ donation process; brain death; communication skills; grief process; family issues; legal consent; informed consent; telephone consent; cultural sensitivity; coordination with coroner/medical examiner's office; funeral arrangements; proper paperwork handling	<p>Time: Organ and tissue training: 8 days plus rotation or procurement observation</p> <p>Time: Tissue-only training: 5 days plus observation and call center shift</p> <p>Format: training modules, video role play, practice training, written exam, observation of procurement process, clinical rotation</p>	OPO staff
Donor Network of Arizona (1999) 602/222-2200	The Donor Network of Arizona runs a family approach workshop for medical professionals.	<ul style="list-style-type: none"> <li>• Potential donor identification</li> <li>• Referral</li> <li>• Request</li> <li>• Consent</li> </ul>	Healthcare professionals	Legislation regarding donation; what can be donated/how it is used; the need for donation; donation criteria; organ allocation policies and procedures; common fears and misconceptions; obstacles to donation; key elements to family conversation	<p>Time: 4.5 hours</p> <p>Format: lectures, handouts</p>	OPO staff

Author, year	General Description	Stage of Process	Target Audience	Content	Logistics of Training	Personnel Conducting Training
Ohio Valley LifeCenter (1999) 513/558-5555	A program developed by LifeCenter, the OPO in Cincinnati. The stated goals of the program are to increase donations by making sure all families of potential donors are approached about their donation options, educate staff about the pertinent regulations, and train staff to talk to families about tissue and eye donation. LifeCenter conducts requests related to organ donation, whereas hospital staff conduct the requests related only to eye and tissue donation.	<ul style="list-style-type: none"> <li>• Potential donor identification</li> <li>• Referral</li> <li>• Request</li> <li>• Consent</li> <li>• Follow-up (limited)</li> </ul>	Hospital staff	(Focus of training is on eye and tissue donation because OPO handles the organ donations) Legislation regarding donation; donor identification/referral; brain death; decoupling; logistics of request; consent; myths/fears	Format: lecture	OPO staff
Indiana Organ Procurement Organization (1999) 317/685-0389	The training consists of three separate parts: “No easy answers,” an instructional video covering difficult family situations, a step-by-step Designated Requestor Training Presentation, and the Designated Requestor Quick Reference Guide.	<ul style="list-style-type: none"> <li>• Potential donor identification</li> <li>• Referral</li> <li>• Request</li> <li>• Consent</li> <li>• Follow-up</li> </ul>	Hospital staff	Donor criteria; referral; logistics of the request; decoupling; family emotional challenges; family questions/concerns; legal issues; who should approach family; cultural issues; follow-up, including donor family communication with recipient family, and documentation	Format: presentation/lecture; video; follow-up “reference guide”	Hospital education staff
Knapik, The Lions Eye Bank for Long Island (1999) 516/465-8430	The “Designated Requestors Workshop” is a “prepackaged workshop” that can be utilized by hospitals that wish to train staff to become requestors. The packet includes pre-workshop preparation, the workshop itself, and a consent assessment tool used to determine certification.	<ul style="list-style-type: none"> <li>• Potential donor identification</li> <li>• Request</li> <li>• Consent</li> <li>• Follow-up</li> </ul>	Hospital staff	Donor criteria; legal issues; cultural sensitivity; communication skills; consent paperwork; follow-up procedures	Time: 6-8 hour workshop  Location: centrally-located hospitals with large conference rooms  Format: lecture, presentation, role play	Hospital education staff

Author, year	General Description	Stage of Process	Target Audience	Content	Logistics of Training	Personnel Conducting Training
Life Connection of Ohio (1999) 419/893-1618	A formal donor requestor training program in Ohio.	<ul style="list-style-type: none"> <li>• Potential donor identification</li> <li>• Referral</li> <li>• Request</li> </ul>	Hospital staff	Reasons donation is important; regulations; routine notification checklist; designated in-hospital requestor checklist; consent and autopsy form review; approaching families; decoupling, team approach; donation process review; role-play/skills practice; post-test; evaluation	Time: 1 hour, 2 hours, or 4 hours long, depending on experience of requestor; annual review and proficiency sessions required  Format: lectures, videos, handouts, tests	Not specified
LifeNet (1998)  Leslie (1999) 757/464-4761	LifeNet's "Credentialed Requestor Workshop" is a training program designed to meet the clinical and information needs of the health care provider involved in the organ procurement and donation process; the roles and responsibilities of the requestor, ethical, legal, and cultural issues are presented.	<ul style="list-style-type: none"> <li>• Potential donor identification</li> <li>• Referral</li> <li>• Request</li> </ul>	Hospital staff (ER and ICU), and clergy	Brain death/non-beating heart donation; donation process; roles of the requestor; ethical, legal issues; cultural, religious issues; bereavement and care of the family; logistics of requesting	Time: 2 full days  Format: lecture and discussion format; videos; presentations from donor families and recipients; scenarios and role play	OPO staff
Mississippi Lions Eye and Tissue Bank (1999) 601/841-3422	"What on Earth am I Gonna Say? Offering the Option of Donation to Families in Grief" is a program designed to give doctors and nurses a foundation from which to present the option of tissue donation to families.	<ul style="list-style-type: none"> <li>• Potential donor identification</li> <li>• Referral</li> <li>• Request</li> <li>• Consent</li> </ul>	Physicians and nurses	Donor criteria; why donations are important; legal issues; examples of inappropriate requesting methods; traits of requestors; approach to request; steps to take if consent given or not given	Time: 1 lecture—few hours long  Format: lecture with slides, handouts, question/answer period	OPO staff

Author, year	General Description	Stage of Process	Target Audience	Content	Logistics of Training	Personnel Conducting Training
NorthEast Organ Procurement Organization and Tissue Bank (1998) 860/545-2256	“Offering the Option of Organ and Tissue Donation” is a concise training session for hospital staff.	<ul style="list-style-type: none"> <li>• Potential donor identification</li> <li>• Referral</li> <li>• Request</li> <li>• Consent</li> </ul>	Hospital staff	Evolution, need, and benefit of organ and tissue donation; organ and tissue donation process; psychosocial factors that impact organ and tissue donation; self-perceptions of feelings, attitudes, and apprehensions related to the sudden death of a loved one; needs of the potential donor family; personal anxieties that may impact discussion with families	Time: 2 hours Format: lecture, slides, handouts, question/answer period	OPO staff
Peterson, Southwest Transplant Alliance (1996) 214/522-0255	A training/reference manual for critical care nurses training to become “nurse liaisons,” individuals responsible for requesting donation gifts. The manual is developed by the Southwest Transplant Alliance, an OPO.	<ul style="list-style-type: none"> <li>• Potential donor identification</li> <li>• Referral</li> <li>• Request</li> <li>• Consent</li> <li>• Follow-up</li> </ul>	Critical care nurses	Role of the liaison nurse; donor criteria; referral; brain death; family approach and obtaining consent; “Family Bill of Rights;” medical/social history of donor; donor evaluation/management; organ placement/UNOS; operating room procedure	Format: lecture, some literature review	OPO staff
Politoski and Boller (1994)  American Association of Critical Care Nurses (AACN) and National Kidney Foundation Workshop Booklet, 3 <sup>rd</sup> Ed. (1997) 800/899-2226	An intensive workshop designed to motivate and prepare critical care nurses to participate in the organ/tissue donation process.	<ul style="list-style-type: none"> <li>• Potential donor identification</li> <li>• Referral</li> <li>• Request</li> <li>• Consent</li> <li>• Follow-up</li> </ul>	Critical care nurses	Personal feelings on death/dying and organ/tissue donation; referral, family responses to donation; barriers to participation in donation; potential roles of the nurse in donation: <i>Initiator, Facilitator, Supporter</i> ; understanding brain death; communication skills	Time: 8 hour continuing education workshop Format: workshops, videos, simulation exercises, lecture/presentations, group discussions/role playing	OPO staff trained to use the program, aided by local AACN and NKF affiliates

Author, year	General Description	Stage of Process	Target Audience	Content	Logistics of Training	Personnel Conducting Training
Rutigliano, Rochester Eye and Human Parts Bank, Inc. (1999) 716/272-7890	The packet is a self-study guide for hospitals and their educators in response to new state and federal requirements for recertification of designated requestors. The focus is on tissue and eye donation only. A recertification test is provided at the end of the packet, which the requestor completes and sends to the OPO.	<ul style="list-style-type: none"> <li>• Potential donor identification</li> <li>• Referral</li> <li>• Request</li> <li>• Consent</li> <li>• Follow-up</li> </ul>	Hospital staff	Terminology; transplantable tissue; donor criteria; legal issues; consent; paperwork; referral; preparation of body/recovery procedures; family approach; best practices; cultural and religious issues	Format: reading through materials, self-test	Self
Schaefer, The Lions Eye Bank of Oregon (1999) 503/413-7523	A requestor training course developed through a joint effort of The Lions Bank of Oregon and the Pacific Northwest Transplant Bank. The focus of the course is more on family concerns of organ and tissue donation and less on process.	<ul style="list-style-type: none"> <li>• Potential donor identification</li> <li>• Referral</li> <li>• Request</li> <li>• Consent</li> <li>• Follow-up</li> </ul>	Hospital staff	Emphasis on family right to choose; donor criteria; referral; post-event procedures; family issues during request (pain and suffering, disfigurement, additional cost); transplantable organs and tissues; “Family Bill of Rights”	Format: presentation/lecture, videos, recipient and/or donor family speakers, role play	Staff from the Pacific NW Transplant Bank and Lions Eye Bank of Oregon
Southwest Transplant Alliance (1999) 214/522-0255	This binder of information includes physician-oriented information on tissue /organ donation.	<ul style="list-style-type: none"> <li>• Potential donor identification</li> <li>• Referral</li> <li>• Request</li> <li>• Consent</li> </ul>	Physicians	Referral; regulations; legal issues; brain death; dealing with families in crisis; tissue donation	Format: binder of information	Self

Author, year	General Description	Stage of Process	Target Audience	Content	Logistics of Training	Personnel Conducting Training
TransLife Organ, Tissue & Transplant Services (1998) 407/303-2474	“Requestor Training I” held at Orlando Regional Medical Center. Staff attend a short session and an educator must “okay” each staff member for each of a checklist of steps. An article on the timing of the consent process is also distributed.	<ul style="list-style-type: none"> <li>• Potential donor identification</li> <li>• Referral</li> <li>• Request</li> <li>• Consent</li> </ul>	All ICU staff	Donor criteria; referral, communicating with physician and family; confirmation of brain death, assess family’s understanding of brain death, introduce option of organ donation and introduce TransLife coordinator; possible family questions	Time: 30 minute sessions  Format: lectures, handouts	OPO staff
Verble, Worth, and Verble (1999) 606/254-0883	“Interviewing Families About Organ and Tissue Donation: A Professional Approach” is a research-based workshop aimed at providing procurement professionals and hospital personnel information regarding clearly defined roles and a systematic method for the donation request process.	<ul style="list-style-type: none"> <li>• Request</li> <li>• Consent</li> </ul>	Procurement and Hospital personnel	Personal feelings/concerns about organ donation; successful donation request models (hospital-level); communication skills in a “typical” donation conversation; obtaining and relaying information effectively; cultural considerations; telephone consent; dealing with family/personal dynamics	Time: 2 days  Format: presentations, demonstrations, large and small group discussion, and modeling, role-play  Enrollment is limited to 24 participants	Verble, Worth, & Verble staff

## **APPENDIX F**

### **DONOR MEDICAL HISTORY AND BEHAVIORAL RISK ASSESSMENT**

## **APPENDIX G**

### **FAMILY FEEDBACK SURVEYS**

## **APPENDIX H**

### **EXPERT PANEL AND WORKSHOP PLANNING GROUP**

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