New York Alliance for Donation and New York State Nurses Association

# Think, Care, Act: The Role of the Nurse in Organ and Tissue Donation

# **NYSNA Continuing Education**

This continuing education course is offered free of charge to registered nurses practicing in New York State through a generous grant from the New York Alliance for Donation.

The New York State Nurses Association is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

This program has been awarded 3.4 CHs through the New York State Nurses Association Accredited Provider Unit.

The New York State Nurses Association is accredited by the International Association for Continuing Education and Training "IACET" and is authorized to issue the IACET CEU.

The New York State Nurses Association is authorized by IACET to offer 0.3 CEUs for this program.

In order to receive contact hours/CEUs, participants must read the course material, pass an examination with at least 70%, and complete an evaluation. Contact hours/CEUs will be awarded for this online course until April 9, 2018.

All American Nurses Credentialing Center (ANCC) accredited organizations' contact hours are recognized by all other ANCC accredited organizations. Most states with mandatory continuing education requirements recognize the ANCC accreditation/approval system. Questions about the acceptance of ANCC contact hours to meet mandatory regulations should be directed to the Professional licensing board within that state.

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NYSNA wishes to disclose that no commercial support or sponsorship has been received.

#### **How to Take This Course**

Please take a look at the steps below; these will help you to progress through the course material, complete the course examination and receive your certificate of completion.

#### 1. REVIEW THE OBJECTIVES

The objectives provide an overview of the entire course and identify what information will be focused on. Objectives are stated in terms of what you, the learner, will know or be able to do upon successful completion of the course. They let you know what you should expect to learn by taking a particular course and can help focus your study.

#### 2. STUDY EACH SECTION IN ORDER

Keep your learning "programmed" by reviewing the materials in order. This will help you understand the sections that follow.

#### 3. COMPLETE THE COURSE EXAM

After studying the course, click on the "Course Exam" option located on the course navigation toolbar. Answer each question by clicking on the button corresponding to the correct answer. All questions must be answered before the test can be graded; there is only one correct answer per question. You may refer back to the course material by minimizing the course exam window.

# 4. GRADE THE TEST

Next, click on "Submit Test." You will know immediately whether you passed or failed. If you do not successfully complete the exam on the first attempt, you may take the exam again. If you do not pass the exam on your second attempt, you will need to purchase the course again.

#### 5. FILL OUT THE EVALUATION FORM

Upon passing the course exam you will be prompted to complete a course evaluation. You will have access to the certificate of completion **after you complete the evaluation**. At this point, you should print the certificate and keep it for your records.

# **Course Objectives**

Upon completion of this course, the learner will be able to:

- Discuss the need for organ and tissue donation.
- Discuss challenges regarding organ and tissue donation.
- Describe the process of organ transplantation for the organ recipient.
- Identify the benefits of organ and tissue transplantation on the recipient.
- Discuss the laws and regulations that impact organ and tissue donation.
- Distinguish between circulatory death and brain death and how they relate to organ and tissue donation.
- Identify critical aspects of the authorization process.
- Discuss the role of the registered nurse in organ and tissue donation including referral, donor management, recovery, and aftercare.

#### **About the Authors**

This education project is jointly sponsored by the New York State Nurses Association and the New York Alliance for Donation. The project has also been supported with funding from the New York State Department of Health. The sponsors of the program worked collaboratively to develop the materials presented and would like to thank the following individuals who worked as an expert panel to develop the curriculum.

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#### Introduction: The Need for Donation



She was such a wonderful woman...she had primary biliary cirrhosis...she had been waiting for a liver for years and was doing fairly well, but then suddenly her health started deteriorating. She just got sicker and sicker...she was so sick...fading away, really. The wait was unbearable...You get so close to these patients. Her family was starting to give up...the entire team was distraught—the physicians, the secretary, the surgeons, the nurses, the coordinator, the social workers—the entire team was getting desperate. We kept saying, "We have to get her a liver tonight!" But still she waited; no matching liver became available.

These are the words of Maureen, a registered nurse for over 25 years, who works on a liver transplant team in a large metropolitan medical center. Having committed her professional life to organ and tissue donation, she is clearly passionate about organ and tissue donation and the patients who need them.

The patient kept saying, "I feel so bad because I'm waiting for someone to die." But we kept saying to her, "No, you're waiting for someone to donate!" Still she got sicker and weaker. But then, just at the 11th hour, she got a liver! It was just sheer luck! Although the recovery took time because she had been so sick, she's now doing beautifully. Ultimately, it was a gratifying experience.

This was a good outcome, according to Maureen. But she and many nurses continue to struggle with frustration related to organ and tissue donation. The solution seems so simple for patients who are awaiting transplant. Many people hope until the last moment and the organ doesn't come.

An average of **21 people** die each day while awaiting transplantation (Organdonor.gov, 2015). Many of these patients would live if all medically suitable potential donors or their families say "yes" to donation.

According to the United Network for Organ Sharing (UNOS), as of January, 2015, there were more than 123,500 individuals waiting for a life-saving organ transplant across the United States. As of January, 2015, the list included 1,001 children younger than 18 years of age. The need for kidneys tops the list, followed by liver and heart. Transplant hospitals place individuals on the national waiting list after they are given careful medical evaluations. Each month, approximately 500 people in the United States are added to the national waiting list.

Nearly 29,000 Americans (about 79 each day) receive organ transplants every year, with the vast majority, nearly 23,000, receiving a transplant from a deceased donor.

There is a particularly urgent need for minority organ donation. The need for transplant in minority populations is disproportionately high, due to the frequent incidence of conditions such as high blood pressure or diabetes, both of which can lead to the need for a kidney transplant. While skin color is not a barrier when it comes to organ donations and transplants, the odds of a transplant being successful are much greater when a minority recipient receives an organ from a minority donor (New York Alliance for Donation, 2015). As of January, 2015, approximately 35,000 African-Americans, 20,000 Latinos, 8,000 Asians, and over 2,000 other non-Caucasians were on the waiting list. However, in 2013, only about 1,370 African-Americans, 1,111 Latinos, 189 Asians, and less than 140 other non-Caucasians donated organs at the time of their death (UNOS, 2015).

More than 10,300 New Yorkers are on the national waiting list for transplantation; this list includes approximately 3,700 Caucasians, 3,600 African-Americans, 2,000 Latinos, 1,000 Asians, and 80 other non-Caucasian individuals (UNOS, 2015a).

In 2013, 9,171 people died in the United States under conditions that made them medically suitable, potential organ donors. However, only 8,268 of those who died in 2013 became organ donors (UNOS, 2015b).

In 2013, of the 574 individuals who died in New York State who could have potentially become organ donors, only 356, or 62%, actually donated their organs. This is significantly below the national average of 76% (UNOS, 2015b).

The value of donation does not only translate into saved lives. The following two stories are from New York residents who chose to donate the organs of their loved ones. More can be read at <a href="https://www.donormemorial.org">www.donormemorial.org</a>.

# Dale Brachtenbach, Organ Donor 1949 - 2004

My dad loved life to the fullest. He raised me to be the best I could. His entire world revolved around my needs and happiness. When I was a little girl he would take me on vacations to Florida or we would go to Canada for a weekend just to get away. My dad and I also became a foster family for nearly 20 greyhounds in about a six-year period. He spent many weekends going to pick up retired greyhounds from tracks to give them a chance at a happy home life. We actually had four greyhounds of our own. My dad had the biggest heart I know of. He was and still is my world. With my parents being divorced it was he who got custody. I am happy to say that I was with my dad until the very end and he is now my guardian angel. He was the greatest man in my life and am proud to call Dale Brachtenbach my father. He was wonderful, and was taken from me entirely too early. He was only 55 when he passed away from a cerebral hemorrhage. I chose to give his gift of life to others; he was a giving man and would have done the same. My father will forever be the greatest man and influence on my life. The grieving has not gotten easier; it's just one more day to deal with a great loss. I love him more than life itself. I am proud of my father and I know he is proud of me.

#### Maryann Drago, Organ Donor 1969 - 2002

Maryann was a wonderful person and the best sister. She was very outgoing and loved by everyone. She loved to go out and sing Karaoke, even though she wasn't the best of singers. At parties she never sat down. She loved to do every dance from the Macarena to the Chicken Dance! On my wedding video you actually see her more than you do me! She worked as a teacher at a day care center and was just about to get a promotion. She had a son named C.J. He was nine when she passed away. About a year and a half before she passed away, she married a man named Michael. She was very happy. . . On April 10, 2002, at the age of 32, this all changed. My sister suffered from a severe asthma attack. She stopped breathing, and went into cardiac arrest. Two days later she was pronounced brain dead. It was so sudden and devastating to my whole family. We were all in total agreement in the decision of donation. My sister would have wanted to help other people; that was just the kind of person she was. That decision has helped me cope with a lot of pain and grief. I know that while I was crying for the loss of my sister, my friend, others were crying tears of joy, for the new life of their loved one. I know that they appreciate the gift of life and hope they live life to the fullest everyday. There is not a day that goes by that I do not think of my sister. I love her very much and am very thankful for the time I had with my big sis!

# **Facts About Organ and Tissue Donation**

There are many myths and misconceptions about organ and tissue donation. Here are some facts to remember:

- One deceased donor potentially can provide one heart or two heart valves, two lungs, two
  kidneys, one liver or multiple liver segments, one pancreas, one intestine, two corneas, bones,
  including whole joints, connective tissues, skin, and blood vessels (Center for Donation and
  Transplant [CDT], 2004; Finger Lakes Donor Recovery Network [FLDRN], n.d.; New York
  Alliance for Donation [NYAD], n.d.).
- Although there was a 59% increase in the rate of organ donation between 1990 and 1999, the
  need for organs clearly exceeds available donor organs (Molzahm, Starzomski, & McCormick,
  2003). The waiting list for those awaiting transplantation has doubled in 10 years (UNOS, 2011).
- Large hospitals are the best source for organ donations; 80% of organ donations come from 20% of hospitals (Joint Commission, 2004).
- Hospitals vary in their success rates relative to the obtaining of authorization for donated organs and tissues: from over 90% to less than 10% (Joint Commission, 2004).
- Organs are allocated based on the urgency of medical need, not according to a patient's
  financial, political, social, or celebrity status. The length of time it takes to receive a transplant is
  based on medical criteria such as blood type, height and weight, and time spent waiting. The
  most important factor that affects length of time waiting is a lack of organ donors (CDT, n.d.a;
  NYAD, n.d.).
- Donation is consistent with the life-preserving traditions of major religions (CDT, n.d.b; NYAD, n.d.). For a listing of the positions of major religions relative to organ and tissue donation go to http://www.alliancefordonation.org/sites/alliancefordonation.org/files/2014\_Religious%20Views%2 0on%20Donation.pdf
- Donation is not discussed until all efforts to save a life have failed. If someone is sick, injured, and admitted to a hospital, the first priority is to save that person's life. If all possible efforts to save a patient's life have failed and two physicians have certified that brain death has occurred, a family is then asked about giving the gift of life through organ and tissue donation (CDT, n.d.c, FLDRN, n.d.; NYAD, n.d.).
- Donation is a sterile surgical procedure. Open-casket funerals are not affected by donation (CDT, n.d.a; NYAD, n.d.).
- Donor families incur no expense for donation (CDT, n.d.a; NYAD, n.d.).
- Experience shows that families are more willing to donate a loved one's organs and tissues if
  they have had prior conversations about donation with the deceased. Talking to one's family
  allows this decision to be made easily and with the knowledge that a loved one's wishes are
  being carried out when that time comes (New York Organ Donor Network, 2005).
- Donor families say donation helps with their grieving.
- Transplantation is no longer considered experimental. It is desired treatment for thousands with end-stage organ disease. Each year, more than 600,000 Americans receive tissue transplants and more than 25,000 receive organ transplants. In 2013, there were 28,954 organ transplants from both deceased and living donors in the United States (UNOS, 2015b).

| • | Tissue donation can give the gift of sight, save burn victims from disfigurement and death, provide relief from amputation, and grant other life-enhancing assistance. Almost one million corneal transplants have been performed since 1961. People from the age of nine days to 103 years have had their eyesight restored due to the donation of corneas. In 2013, 48,229 corneal transplants were performed in the U.S, (Eye Bank Association of America, 2015). |
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# The Benefits of Transplantation

The benefits of transplantation are numerous. Donated organs can make the difference between life and death for those awaiting transplantation.

| Organ/Tissue  | Medical Application  | Benefit to Recipients   |
|---|--|---|
| Heart   | Transplant from non-living donor.  | Treatment of end stage organ failure due to: Cardiomyopathy; coronary artery disease; congenital and valvular disease.                                      |
| Lung  | Transplant from living and non-living donor.   | Treatment of end stage organ failure due to: Congenital diseases; emphysema; COPD; cystic fibrosis; pulmonary fibrosis.                                     |
| Liver   | Transplant from living and non-living donor.   | Treatment of end stage organ failure due to: Cirrhosis; acute hepatic necrosis; metabolic diseases; malignant neoplasm.                                     |
| Kidney  | Transplant from living and non-living donor.   | Treatment of end stage organ failure due to: Diabetes; sickle cell anemia; polycystic kidneys; scleroderma; congenital and metabolic disorders.             |
| Pancreas  | Transplant from living* and non-living donor.  | Treatment of end stage organ failure due to: Diabetes; pancreatic cancer; bile duct cancer.   |
| Intestine   | Transplant from living* and non-living donor.  | Treatment of end stage organ failure due to: Crohn's Disease; functional bowel problem.   |
| Eye   | Replace diseased or damaged tissue.  | Prevention of blindness; restoration of vision; reconstruction of the orbit.  |
| Musculoskeletal And<br>Connective Tissue  | Reconstruction related to trauma, tumors, degenerative diseases, hip revision, spinal fusion, repair of jaw. | Prevention of amputation; promotion of healing; prevention of collapse of bone; reduction of pain and nerve damage; restoration of mobility; dental repair. |
| Skin  | Treatment of burns, reconstructive surgery.  | Promotion of healing of burns; restoration of continence; enhancement of function and structure of soft tissue.   |
| Source: New York Alliance for Donation, <u>www.alliancefordonation.org</u> (n.d.) |  |   |
| *Living donors may donate a portion of the organ/tissue noted.                    |  |   |

# **Transplant Statistics**

| Types of Transplants, Nationwide and in New York - 2013 |          |          |
|---|----------|----------|
|   | National | New York |
| Kidney transplants                                      | 16,895   | 1,176    |
| Liver transplants                                       | 6,455    | 358      |
| Heart transplants                                       | 2,531    | 162      |
| Lung transplants  | 1,923    | 51       |
| Kidney-pancreas transplants                             | 762      | 25       |
| Pancreas transplants                                    | 256      | 21       |
| Intestine transplants                                   | 109      | 9        |
| Heart-lung transplants                                  | 23       | 0        |
| TOTAL:  | 28,954   | 1,802    |

Source: UNOS (2015c)
Note: Numbers reflect transplants from both living and deceased donors.

| Nationwide Transplants by Donor Type - 2013 |          |        |
|---|----------|--------|
|   | Deceased | Living |
| Kidney transplants                          | 11,163   | 5,732  |
| Liver transplants                           | 6,203    | 252    |
| Heart transplants                           | 2,531    | 0      |
| Lung transplants                            | 1,992    | 1      |
| Kidney-pancreas transplants                 | 761      | 1      |
| Pancreas transplants                        | 256      | 0      |
| Intestine transplants                       | 108      | 1      |
| Heart-lung transplants                      | 23       | 0      |
| All Organs                                  | 22,967   | 5,987  |
| Source: UNOS (2015c)                        |          |        |

| Continuous Organ Function - Nationwide |                       |
|--|-----------------------|
|  | Longest Survival Rate |
| Kidney                                 | 34 years              |
| Kidney/Pancreas                        | 14 years              |
| Pancreas/Liver                         | 16 years              |
| Liver                                  | 27 years              |
| Heart                                  | 22 years              |
| Heart/Lung                             | 15 years              |
| Lung (double)                          | 10 years              |
| Lung (single)                          | 6 years               |
| Source: UNOS An                        | nual Report, 1999     |

| One-Year Survival Rates       |       |
|-------------------------------|-------|
| Kidney (deceased donor)       | 96.3% |
| Kidney (living donor)         | 98.5% |
| Pancreas                      | 97%   |
| Liver (deceased donor)        | 88.4% |
| Liver (living donor)          | 91.0% |
| Heart                         | 87.9% |
| Heart/Lung                    | 80.5% |
| Lung                          | 81.6% |
| Source: UNOS Annual Report, 2 | 2011  |

# Laws and Regulations

#### **Anatomical Gift Act**

The federal Uniform Anatomical Gift Act was enacted in 1968 to establish consistency in laws governing organ and tissue donation throughout the United States. The act ensures that anatomical gifts can cross state lines and that there is compliance with the wishes of donors. Individual states also have adopted Anatomical Gift Acts that govern the process by which individuals donate their organs, tissues, eyes, and bodies. In general, the law allows any competent individual who is 18 years old or older to execute an anatomical gift. Gifts from minors require the authorization of parents or legal guardians. The execution of the gift may occur before or after death; age or medical history should not affect the execution of an anatomical gift.

In New York, the Uniform Anatomical Gift Act is found in Public Health Law, Article 43. New York State also has an Organ and Tissue Donor Registry (1-866-NYDONOR) from which certified organ procurement organizations (OPOs) and state-licensed tissue and eye banks can access information at the time of a referral from a hospital.

#### Health Insurance Portability and Accountability Act

The Health Insurance Portability and Accountability Act (HIPAA) was enacted in 2003. Despite this safeguard for private health information (PHI), hospitals may and should disclose PHI to OPOs, according to the Privacy Rule (*Code of Federal Regulations*) (45 CFR §164.512):

A covered entity (hospital) may use or disclose PHI to OPO's or other entities engaged in the procurement, banking or transplantation of cadaveric organs, eyes, or tissue for the purpose of facilitating organ, eye or tissue donation and transplantation.

Procurement and banking activities are not considered health care and the organizations that perform such activities are not considered health care providers for the purposes of this rule.

#### Centers for Medicare and Medicaid

As a condition of participation in the Medicare program, the Centers for Medicare and Medical Services (CMS) (2005) require hospitals to report all deaths to the OPO in its region.

In 1998, CMS published the final rule (42 CFR §482) that imposes several requirements for hospitals that are designed to increase organ donation. One of these requirements is that a hospital **must** have an agreement with the OPO describing how the hospital will contact the OPO in a timely manner about individuals who die or whose death is imminent in the hospital. The OPO will then determine the individual's medical suitability for donation.

The hospital also must have 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, providing that the agreement does not interfere with organ donation (Medicare and Medicaid Programs; Conditions for Coverage for Organ Procurement Organizations, 2005).

This federal regulation requires hospitals to ensure, in collaboration with the OPO, that the family of every potential donor is informed of its option to donate or not to donate organs or tissues. It also requires that the person initiating the request for organ/tissue donation must be employed by the OPO or trained by the OPO. This person is known as a "Designated Requestor."

Hospitals must work with the OPO and at least one tissue bank and one eye bank to educate staff on donation issues, review death records to improve identification of potential donors, and maintain potential donors while necessary testing and placement of organs and tissues take place (Medicare and Medicaid Programs; Conditions for Coverage for Organ Procurement Organizations, 2005).

OPOs and tissue and eye banks provide hospitals with information and guidance about the donor process and submit routine compliance reports to them. Each OPO or tissue or eye bank has contracts with hospitals within its geographic region. Such consultative services and partnerships ensure a smooth donation process and increase the number of lives saved every year through organ donation.

#### Joint Commission

As part of its 2011 Comprehensive Accreditation Manual for Hospitals, the Joint Commission has a standard that addresses hospital's responsibilities for organ and tissue donation and procurement. These standards require hospitals, with participation from their medical staff, to implement policies and procedures for procuring and donating organs and other tissues. Some of the performance elements to achieve the Joint Commission standard are (Joint Commission, 2011):

- The hospital has a written agreement with an OPO and follows its rules and regulations.
- The hospital develops, in collaboration with the designated OPO, written procedures for notifying the family of each potential donor of the opportunity to donate or decline to donate organs, tissues, or eyes.
- This notification is made by an organ procurement representative or the hospital's designated requester.
- Written documentation by the hospital's designated requester must show that the patient or family accepts or declines the opportunity for the patient to become an organ or tissue donor.
- The hospital's staff exercises discretion and sensitivity to the circumstances, beliefs, and desires of the families of potential donors.

# **Transplant Recipient Process**

#### Organ Allocation

The transplant center is responsible for placing someone on the national waiting list. The transplant center's medical profile on the candidate is stored in the Organ Procurement and Transplantation Network (OPTN) database. When a donor becomes available, the computer compares candidates on the list and ranks them according to medical criteria.

Organs recovered in New York are first allocated to recipients that are a perfect match anywhere in the United States. After which, depending on the organ, priority is given to recipients within the State of New York. Next they are offered to recipients outside of New York State. The national organ sharing policies are established by the national OPTN.

#### Candidate Ranking

A variety of factors influence the match of donor organs to candidates on the waiting list. The rankings are affected by tissue match, blood type, severity of medical condition, immune status, and time waiting for transplant.

If the match is for a heart, heart-lung, liver, lung, or pancreas transplant, the potential recipient's distance from the donor hospital is also considered, because these organs cannot survive outside of the body for very long. All ranking and matching processes are carried out without reference to gender, socioeconomic, or celebrity status. Organs often go to recipients with similar ethnic or racial background, as they have similar cell lines and this will increase the rate of successful transplantation. There is, however, no preferential treatment for any race or ethnicity.

#### Recipient Selection

The Organ Procurement Organization (OPO) is responsible for placing all pertinent donor information into a computerized database. When this has been completed, an electronic list will be produced, with the highest ranking potential recipient on top. The local OPO will then discuss the potential recipient with the transplant center, and the final selection of recipient will be made.

In order for the patient on the list to receive the donated organ, several factors are considered:

- 1. The patient has to be available and willing to be transplanted immediately.
- 2. The patient has to be healthy enough to undergo major surgery.
- 3. Laboratory tests measuring the compatibility between donor and recipient must show that the recipient will not reject the organ.

If the first patient is unable to receive the organ, the organ is then offered to the next patient on the list. Once the patient is selected and contacted and all testing is complete, surgery is scheduled and transplantation takes place.

# **Challenges to the Donation Process**

Despite the laws and regulations governing organ and tissue donation and despite the efforts to increase donation, a number of complex reasons contribute to the shortage of donations. According to Molzahn, Starzomski & McCormick (2003) some of these reasons are public misperceptions about organ donation; ethno-cultural traditions; healthcare organizations' lack of commitment to the donation process; and healthcare professionals' negative attitudes, lack of knowledge, and discomfort about the donation process.

## **Public Misperceptions**

In a 2001 Health Canada poll, 19% of respondents said they believed that potential donors might be declared dead prematurely so their organs and tissues could be used for transplant. Nearly one quarter believed that organ donation procedure disfigures the body (Molzahn, Starzomski, & McCormick, 2003). According to Exley, White, and Martin (2002), studies of families who refused to grant authorization for donation revealed a number of beliefs and social attitudes, particularly doubts about the exact moment of death and the need for the body to remain intact.

There is a misperception among the general population that healthcare providers are less likely to try to save one's life if it is known that the person has agreed to be an organ donor. These individuals may not be aware that the healthcare team trying to save lives is completely separate from the transplant team (United States Department of Health and Human Services [USDHHS], n.d.).

Fueled by news reports about high-profile organ donation recipients, there is some public opinion that celebrities or the "rich and famous" receive preferential treatment on the waiting list for organs. This certainly can affect one's willingness to donate (USDHHS, n.d.).

#### **Ethno-Cultural Traditions**

Organ donation rates vary among ethnic and cultural groups. Essential to understanding the differences in donation rates is the well-documented disparity in the access and quality of healthcare services for racial and ethnic minorities (Institute of Medicine, 2002).

According to the U.S. Department of Health and Human Services Web site (<a href="www.organdonor.gov">www.organdonor.gov</a>), some diseases of the kidney, heart, lung, pancreas, and liver that can lead to organ failure occur more frequently among ethnic minority populations. For example, Native Americans are four times more likely than Caucasians to suffer from diabetes. African Americans, Asian and Pacific Islanders, and Latinos are three times more likely than Caucasians to suffer from kidney disease. Many African Americans have hypertension, which can lead to kidney failure. Some of these diseases are best treated through transplantation: others can only be treated through transplantation (USDHHS, n.d.).

The rate of organ donation among minorities does not keep pace with the number needing transplants. Although minorities donate in proportion to their share of the population, their need for transplants is much greater. African Americans, for example, are about 13% of the population. They represent about 17% (UNOS, 2015) of donors, and about 37% of those waiting for kidneys (UNOS, 2015a). African Americans make up 35% of persons with end-stage renal disease (ESRD). The average wait for a suitable kidney for Caucasian patients is 1,310 days; for African American patients the average wait is 1,831 days (UNOS, 2015d).

The lower rate of African American organ donations has been attributed to a lack of awareness about transplantation, distrust of healthcare providers, and religious beliefs (Molzahn, Starzomski, & McCormick, 2003). In an Institute of Medicine's (IOM) 2002 report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, other factors were identified, including personal bias on the

part of caregivers. This bias, which may be unconscious, contributes to "institutional racism" and unequal treatment. Clearly, this is a vicious cycle in which this unequal treatment of racial and ethnic minorities fuels the mistrust that some minorities have toward healthcare providers.

Asian Americans also have a lower rate of organ donation. It is important to remember that Asians encompass a wide range of cultures and that these ethnic groups may be quite diverse. Overall, Asian Americans believed that the body should remain intact in order to reunite with the spirit after death. They have concerns about possible lack of respect of the body after death.

There also is a misperception that racial discrimination favors Caucasians as donor recipients, so minorities should refuse to donate. Matching donor organs to potential recipients requires genetic similarity, however. Generally, people are genetically more similar to people of their own ethnicity or race than to people of other races. Therefore, matches are more likely and timelier when donors and potential recipients are members of the same ethnic background (USDHHS, n.d.).

Minority patients have to wait longer for matched kidneys and therefore may be sicker at the time of transplant or may die while waiting. By diversifying the donor pool with more donated organs from minorities, finding a match will be quicker and the waiting time will be reduced (USDHHS, n.d.; Joint Commission, 2004).

Regardless of race or ethnicity, one screening criterion for organ donation is the individual's ability to pay for the surgery and follow-up medication therapy. This requires either health insurance or enough wealth to pay out of pocket. According to the Joint Commission (2004), when insurance coverage for immunosuppressive therapy runs out, some patients become non-adherent because they cannot afford the medication therapy. The transplanted organs then are rejected and the patients once again are on the waiting list.

The IOM (2002) report recommends the following in order to achieve equal health care in the U.S.:

- A more diverse healthcare workforce;
- Improved cultural competency among healthcare providers and the OPOs;
- Health education to improve the overall health knowledge of the public; and
- Improved access to health care for racial and ethnic minorities.

The Minority Organ and Tissue Transplant Education Program (MOTTEP) is a national organization that aims to increase awareness and acceptance of organ donation to minority communities, as well as to provide health education which may help to prevent the diseases that precipitate the need for organ transplantation. MOTTEP's efforts have helped to increase minority donation rates. In 2003, donation rates increased by 13% among Latinos and 11% among African Americans (Joint Commission, 2004).

# Healthcare Facilities' Commitment to the Donation Process

According to the Joint Commission's (2004) *Healthcare at the Crossroads: Strategies for Narrowing the Organ Donation Gap and Protecting Patients*, hospitals that create a culture in which organ and tissue donation is a priority and who work collaboratively with their regional OPOs have a higher success rate for donation. Hospitals with a low rate of donation are not necessarily unsupportive of organ donation, but tend to reflect the facility's focus on other organizational priorities (Joint Commission, 2004).

#### Attitudes of Healthcare Professionals

Healthcare professionals may have a lack of knowledge about the organ donation process in general and, more specifically, about identifying potential organ donors, identifying brain death, and referring potential donors (Molzahn, Starzomski, & McCormick, 2003). In their review of the literature, Molzahn, Starzomski,

and McCormick (2003) found that nurses also may have the perception that transplants were offered to persons whom they believed to be unsuitable candidates for transplant and may be uncomfortable about how and when to approach family members regarding donation. Healthcare providers identified "negative personal experiences" as a reason for not supporting organ donation; these "negative personal experiences" were not defined.

In research cited by Molzahn, Starzomski, and McCormick (2003), focus groups of healthcare providers had a lower rate of signed organ donation cards than did focus groups of consumer groups. The reasons for these lower rates are presumably related to healthcare professionals' perceptions of the organ donation process.

In addition, the organ donation process may raise issues for healthcare professionals regarding their own mortality. Denial of one's own death may be a factor in the misconceptions of healthcare professionals that can impact on their perceptions of the donation process.

# **Case Studies: Organ and Tissue Donation**

Mr. Peters is a 55-year-old male who presents to the emergency department (ED) of a hospital with the chief complaint of gastrointestinal (GI) distress for approximately one week. His past medical history is unremarkable. While in the ED, GI diagnostics are ordered and Mr. Peters is admitted for a GI workup.

The following three situations all utilize the above scenario as the starting point. They are intended to demonstrate that organ and tissue donation may be made from any unit of the hospital.

# <u>Situation 1: Emergency Department Death – Tissue and Eye Donation</u>

While in the ED, Mr. Peters experiences a sudden onset of massive headache, hyperemia, hypertensive crisis, and cardiac arrest. The patient is coded, but ultimately is pronounced dead. The family is notified. The ED staff initiates morgue care procedures according to hospital policy and procedure and the patient is transferred to the morgue.

The ED staff refers the death to OPO donation hotline number and informs the family about the need to make end-of-life decisions. The OPO staff person approaches the family with the option of donating Mr. Peters' tissue and eyes (the organs have been ruled out because the patient was not on a ventilator at the time of death). The family agrees to the donation and identifies a funeral home. Recovery staff then contacts the ED staff and request that the patient be held for donation. Recovery staff then also contact the medical examiner regarding autopsy and it is decided that the autopsy will be completed post-recovery. The recovery agency contacts the medical examiner when the recovery process is complete and identifies the tissues recovered.

The funeral home is instructed by the recovery agency to pick up the body at the medical examiner's office. The recovery agency transfers the donor from the morgue to the operating room for eye and tissue recovery.

# Situation 2: Medical-Surgical Unit Death – Tissue and Eye Donation

Mr. Peters receives a GI consult in the ED and laboratory and diagnostic tests are ordered. He is transferred to a medical unit in stable condition. Over the course of the next three days, Mr. Peters complains of increasing headache, blurred vision, a slight change in gait, and a slight change in speech patterns. His blood pressure is slightly elevated and his heart rate is slightly increased but in normal sinus rhythm.

On the fourth day of his admission, Mr. Peters is found comatose. His pupils are sluggish and there is minimal response to external stimuli. A short time later, Mr. Peters' heart stops. He is coded and ultimately pronounced dead. The family is notified, morgue care is initiated, and the body is transferred to the morgue.

The medical unit staff refers the death to the OPO donation hotline number and the donation and recovery process continues as in Situation 1.

#### Situation 3: Critical Care Unit Death – Organ, Tissue and Eye Donation

Mr. Peters codes in the ED. He is resuscitated and placed on a ventilator. He is admitted to the critical care unit (CCU) and is diagnosed with a cerebral hemorrhage with a subdural hematoma. He scores 4 on the Glasgow Coma Scale and it appears that brain death is imminent.

The OPO is contacted by the CCU nurse regarding Mr. Peters and his medical status. The OPO reviews the patient's medical record and identifies him as a possible candidate for donation. On his sixth day in the hospital, Mr. Peters is declared brain dead. The OPO staff approaches Mr. Peters' family about the opportunity for organ, tissue, and eye donation. The family provides authorization and are informed about the timeline required for donation evaluation, including serology testing, additional lab work, cardiac catheterization, chest X-ray, bronchoscopy, identification of potential organ recipients, time of actual organ recovery, time of actual eye and tissue recovery, and time of release to funeral home. The family is assisted in saying their final goodbyes in the CCU and is escorted from the unit by OPO staff.

The donor evaluation is completed, organ recipients are identified and the organs are accepted by the respective centers. Transportation arrangements are finalized. The donor is transferred to the operating room (OR) for organ recovery. After the organ recovery, the eye and tissue recovery teams complete eye and tissue recovery. The tissue recovery team reconstructs the donor's body in preparation for the funeral home and morgue care is completed. The tissue recovery team notifies the funeral home, which picks up the body and transports it for funeral preparation.

#### The Referral Process

As stated previously, the Center for Medicare and Medicaid (CMS) requires all U.S. hospitals to adopt routine notification policies so every death can be evaluated for potential donation. Hospitals are required to notify their federally designated OPOs of all deaths and all imminent deaths. The initial referral to the OPO usually is made by a physician, nursing supervisor, ED nurse, or intensive care unit (ICU) nurse.

The first step in making a referral is to ensure the medical chart is available so the patient's diagnosis and background can be discussed. The following information will typically be needed:

- The patient's name, age, sex, race, medical/social history, current diagnosis, unit where the patient expired, and the date and time of death.
- More detailed information to determine if there are conditions that would preclude donation, such as current hospital course, blood culture results, and medications the patient received.
- Name and phone number of patient's next of kin.

The Hospital Conditions of Participation for Medicare and Medicaid made clear that it is the OPO's responsibility to request organ and tissue donation from the family of the patient.

# **Pathways to Donation**

Organ donation most often occurs when a patient is declared brain dead, though organ donation after circulatory death (DCD) is becoming more frequent. Tissue donation is an option for patients that suffer from either circulatory death or brain death.

#### Brain Death

- Patient maintained on ventilator, heart beating
- Candidate for organ and tissue donation
- Tissue recovery follows organ donation

# Circulatory Death

- Patient has no cardiac or respiratory activity
- Consideration of DCD should be given to all patients in whom life-sustaining therapy is being
  withdrawn and whose death is expected to be imminent. The decision to withdraw lifesustaining treatment should be made independently of any decision to donate organs or
  tissue (Dunne & Doherty, 2011).
- Body must be kept cool before tissues are recovered

Organs from DCD considered suitable for transplantation include the kidneys, liver, pancreas, lung, and tissue (cornea, bone, skin, and heart valves) (Dunne & Doherty, 2011).

# Clinical Triggers

Imminent death is a term that applies to patients who are on a ventilator and have had an insult or injury to the brain. When a patient is on a ventilator and appears to have irreversible loss of brain function, death is considered to be imminent and the OPO should be notified immediately. The OPO must be notified before the patient is removed from the ventilator.

# Early referrals are important because:

- The patient's family must be given time to be educated about donation, discuss the opportunity, and make an informed decision; and
- The patient's stability must be maintained so that donation is medically possible if the family gives authorization.

## Brain Death

In most cases, in order to be an organ donor, the patient must have been declared brain dead and remain connected to a ventilator. Patients may be declared brain dead after suffering head trauma, anoxic injuries, cerebral bleeds, or brain tumors. All of these are injuries or insults to the brain that will cause swelling and ultimately cut off all blood flow to the brain, causing death. Brain death can be declared by a physician according to practice parameters approved by the American Academy of Neurology's *Practice Parameters: Determining Brain Death in Adults* (1994). In New York State, a second physician must certify the time of death, according to 10 NYCRR 400.16: Determination of Death. Many hospitals in New York State have updated their policies to reflect the *Guidelines for Determining Brain Death* set forth by the New York State Department of Health and the Task Force on Life & the Law in November, 2011 available at

https://www.health.ny.gov/professionals/hospital administrator/letters/2011/brain death guidelines.pdf.

Current standards for making a diagnosis of brain death require:

- (1) Identification of the suspected cause of the coma;
- (2) Determination that the coma is irreversible;
- (3) Performance of a clinical examination; and/or
- (4) Interpretation of appropriate neurodiagnostic and laboratory tests.

The clinical examination includes an evaluation of overall responsiveness, brain-stem reflexes, and apnea testing. The patient should be deeply comatose, with no response to painful or verbal stimuli, including decorticate or decerebrate posturing (Henneman & Karras, 2004). Other reflexes corresponding to connections between various nerves originating in the brain stem are also tested. Among these are: coughing or gagging in response to suctioning the airway, constriction of the pupil in response to light, blinking in response to touching the cornea, grimacing or movement in response to pressure above the eye, and moving the eyes when head is rotated (doll's eyes phenomenon) or when the ears are flushed with ice water.

Physicians specializing in neurology, neurosurgery, critical care medicine, or who are privileged by the hospital to perform such examinations and who are not members of a transplant team, usually are responsible for the clinical exam.

Nurses may have several responsibilities related to the detection and declaration of brain death. The nurse may be the first to recognize a patient's lack of responsiveness as a sign of brain death and to relay these findings to the physician. The nurse may assist in the collection of data to confirm brain death, in addition to observing and caring for the patient. Although the physician may give a patient's family a thorough explanation of brain death, the family may need clarification and may direct questions to the nurse. Reinforcement and clarification of medical information that has been given to the patient's family may be required. The nurse must have a clear understanding of brain death in order to support the family's decision (Veijo, Ehrle, Shafer, & Nelson, 1999). Protocols related to brain death declaration are in place at each institution and nurses should be familiar with them.

#### Circulatory Death

In some instances, a person may donate organs after circulatory death has occurred. For organ donation after circulatory death (DCD) to occur, the following circumstances must exist:

- A patient has suffered devastating and unrecoverable brain damage resulting in ventilator dependency;
- The family has decided to withdraw mechanical ventilation; and
- Death from cardiac and respiratory arrest will occur within one hour following withdrawal of mechanical support.

In this situation, organ recovery would occur only after support is withdrawn and after circulatory death is pronounced. This type of donation is increasing and hospitals and OPOs should have specific protocols and policies that apply to them.

Tissue and eye donation may occur after either brain death or circulatory death. Unlike organ donation, patients do not need to be maintained on ventilators for tissue or eye donation to occur. Consequently, there are more opportunities for patients to become tissue donors after death. Tissue procurement occurs in a sterile, operating room environment. Every effort is made to complete the procurement as soon as possible after death.

#### Living Donors

In addition to donations from persons who have suffered brain death and circulatory death, donations can also be made from living donors. Living donors increase the supply of available organs. According to the United Network for Organ Sharing (2015), of the nearly 29,000 organ transplants in the U.S. in 2013, nearly 6,000 were living donor transplants (UNOS, 2015b).

The donor often is a family member (parent, sibling, child, or other relative) of the person needing the organ, but an organ donated by an unrelated person (spouse, friend, etc.) can also be utilized if a match is obtained. Among the organs that a living donor can provide are:

- A single kidney;
- One lobe of the lung;
- A segment of the liver;
- A portion of the pancreas; or
- A portion of the intestines.

The needs of living donors and their families are significantly different from those of patients who have suffered brain death or circulatory death. Living donations are coordinated by the center doing the transplant. More information about living donation is available at <a href="https://www.transplantliving.org">www.transplantliving.org</a>.

# **Role of the Registered Nurse**

As with all aspects of health care, nurses are intimately involved in the process of organ and tissue donation; nurses are advocates, educators, counselors and supporters in this process. It can be a challenging role for the nurse to be an advocate for patients who are waiting for transplantation, as well as advocating for grieving families of potential donors who must make a decision that is right for that family (Norris & House, 1991).

Nurses often are the first healthcare professionals to recognize a potential organ donor. They are critical in the effort to remove the discrepancy between the number of potential donors and actual donors. Identifying a patient as a potential donor and then contacting the local OPO according to the hospital's policy are two simple steps nurses can take to significantly improve the number of organs available (Norris & House, 1991).

Ensuring that the option of organ or tissue donation is offered to families is truly part of a nurse's role as patient advocate. Every family has the right to be informed of donation as a choice. This is a decision they have the right to make, along with decisions about autopsies and funeral arrangements. It is the nurse's responsibility to act as an advocate for the family by actively participating with the OPO to support this opportunity. While federal law requires that OPO staff actually discuss donation with the families, nurses can facilitate and lay the groundwork for this discussion.

This is easier said than done, however. Many healthcare professionals are reluctant to discuss this opportunity with the family of a potential donor because of their personal fears and misconceptions, as well as a common human refusal to deal with the issue of one's own mortality.

In reality, organ donation may well be the only positive event experienced by the family during this period of grieving and loss. It can provide the family with positive feelings regarding the opportunity to help save the life of another human being. Studies have shown organ donation is a positive part of the normal grief process and is viewed by the next of kin as the highest form of charity (Norris & House, 1991).

# Helpful Interventions for the Nurse

The process of organ donation can be difficult for nurses, particularly because the focus of care shifts as the patient's condition changes. For nurses who have been caring for the patient and family in efforts to promote health and life in that patient and family, the adjustment to organ donation and the end of life can be difficult.

In a study by Pelletier-Hibbert (1998), nurses utilized several coping strategies in caring for organ donors and their families, including exercising control over their emotions, distancing themselves, and taking time out at various stages of the organ donation process.

Tartaglia and colleagues (2002) found that the use of a standardized protocol relative to organ donation helped to reduce stress among critical care nurses. The consistent use of a multidisciplinary "best practice" protocol had the benefit of reducing role ambiguity (unclear professional responsibilities), role conflict (competing professional responsibilities), and role overload (too many professional responsibilities) among nurses. Nurses in this study reported that when there was a clear clinical trigger, they experienced no conflicts about when to initiate contact with the OPO. Role conflict was reduced after the staff from the OPO arrived and the nurses were less stressed by having to attend to both the patient and the family. With the multidisciplinary protocol, nurses perceived that the emotional, spiritual and informational needs of the family were being met and they could focus on the needs of the patient.

### Helpful Interventions for Family Members

According to Iserson (1999), more than 75% of family members and other survivors found the following to be helpful after a loved one's death:

- A separate room was provided for survivors.
- Survivors were told of the death in clear language.
- Survivors were given information about their loved one's care, they were allowed to view the body, and they were made to feel comfortable expressing their grief.

# Between 66-74% found the following to be helpful:

- A follow-up name and phone number were provided.
- Nurses showed care and concern.
- They were assisted in the completion of forms.
- They were given the opportunity to grieve.
- They were told when it was okay to leave.
- They received a follow-up phone call.

# Between 50 - 65% found the following to be helpful:

- They were given the opportunity to call their religious leader.
- They were allowed to see their loved one before death.
- They were given the opportunity to ask questions.
- They were told in advance that their loved one might die.
- They were given the opportunity to call other family members.
- They were told what to expect before viewing the body.

# **Required Request**

The concept of "required request," developed in the late 1980s, mandates hospitals to develop policies to ensure that families will be asked about donating their deceased loved one's organs. Hospitals have to document that such a policy is in place in order to receive Medicare reimbursement and hospital accreditation from the Joint Commission. A key provision of the Medicare regulations of the Center for Medicare and Medicaid on Hospital Conditions of Participation, as well as many state laws, is that only professionals who have specific training are permitted to request authorization from the deceased person's family. These trained personnel are known as "designated requesters."

OPO staff members are legally authorized to request authorization for donation from patients' family members. There are several reasons why these trained professionals should request authorization: they have experience in this very specific process; training; the time to spend with families; and, perhaps most important, a true belief that the process helps donor families. Unfortunately, many healthcare professionals view the request for donation as a negative experience for the donor's family that could cause emotional distress. This attitude makes the healthcare provider less comfortable with making the request, which can lead to an insensitive, task-oriented approach.

Like hospital staff, OPO staff members are saddened by the tragic events that confront the family of a potential donor. However, unlike hospital staff, OPO staff members bring knowledge, experience, and a confidence in their ability to handle all aspects of the donation process and know first-hand the benefits that the process offers donors' families (Viejo et al., 1999). Numerous studies have shown that when procurement coordinators are involved in the approach for donation, donation rates increase. Medicare regulations specifically state that families must be approached in a sensitive and caring fashion by OPO staff members or by designated requesters who complete OPO training requirements.

In a study funded by the Agency for Healthcare Quality and Research (2001), researchers at Case Western Reserve University and the University of Pittsburgh found that:

- Families who knew about the patient's wishes were seven times more likely to donate organs.
- Families who were kept updated about their loved one's condition and got timely and detailed information on organ donation were five times more likely to donate.
- Families who met with organ donation professionals about the donation process were more than three times as likely to donate in spite of other negating factors such as socio-demographic background or preconceived attitudes.
- Families who first met with the healthcare provider and then with an organ donation professional were almost three times as likely to provide authorization to donate organs.

The process for making a request to family members when there is no indication of the patient's wishes involves the entire healthcare team. One of the most critical issues is ensuring that the family understands the patient's condition and all their questions about their loved one's death have been addressed. The timing of the request is one of the most critical elements of the family request protocol. First and foremost, the request for donation must be decoupled from other end-of-life decisions if at all possible.

The premise behind *decoupling* is that the family must first acknowledge that death has occurred before the subject of donation is introduced. Families are making an unfamiliar journey when a loved one dies. Nurses should be attuned to signs that the family is finding it difficult to cope with the death of its loved one. Such signs might be denial of the seriousness of the illness or injury, disagreements between family members, or pressure for treatment at all costs (Viejo et al., 1999).

When families comment that their loved one "never wanted to be kept alive on machines," "this is no kind of life," "he's not there," or "he never wanted to live like this," they may be beginning to understand the

grave prognosis. Nurses should use these comments as opportunities to ask questions in order to better understand what family members know and what they want to know. In addition, family discussion of donot-resuscitate orders may indicate that the family is beginning to understand that death is imminent (Viejo et al., 1999b). However, these comments should not be used as an indication that the family is ready to talk about donation.

The following is an overview of the process after a patient has been determined to be eligible to be a candidate for organ and tissue donation (Chabalewski, 1996):

- OPO and hospital staff hold a collaborative family conference.
- Staff (clergy, social work, etc.) offer support services to family.
- Brain death protocol completed and documented according to hospital policy.
- Hospital generates death certificate/Medical Examiner (ME) form.
- Physician notifies family of death.
- OPO staff member offers the opportunity for organ and tissue donation.
- Authorized party provides authorization for donation.
- OPO staff member obtains witnessed authorization and medical and behavioral risk assessment from authorized party.
- Hospital staff notifies ME/Coroner (if applicable).
- ME/Coroner releases body for donation (if applicable the medical examiner may give restrictions or requests).
- If the family/ME/Coroner declines donation, hospital staff initiates post-mortem protocol and supports the family.

In the case of tissue or eye donation, the family may be contacted after they leave the hospital. The nurse will be asked to say to the family, "Our hospital works with (local OPO) for donation. Someone from there will be contacting you within the next few hours."

### **Authorization**

Authorization is a critical component of the request process. All recovery organizations have procedures to ensure that authorization for donation is informed and follow models developed specifically for organ and tissue donation.

In November 2000, the American Association of Tissue Banks, the Association of Organ Procurement Organizations, and the Eye Bank Association of America (2000) issued a joint statement outlining model elements of authorization for organ and tissue donation, which is provided below:

Human organ and tissue transplantation has become an important and growing part of modern medical practice. Advances in medical science have made it possible for millions of Americans to receive these life-saving and life-enhancing gifts. None of this would be possible, however, were it not for the tens of thousands of donors and donor families who give their organs and tissues to help their fellow men and women.

The decision to donate must, therefore, be an informed authorization, and it must be conducted under circumstances that are sensitive to the authorizing person's situation. Information concerning the donation should be presented in language and in terms that are easily understood by the authorizing person. The authorization should be obtained under circumstances that provide an opportunity to ask questions and receive informative responses. An offer should be made regarding the availability of a copy of the signed authorization form, and information should be provided regarding ways to reach the recovery organization following donation. Authorization should be obtained in accordance with federal, state and/or local laws and/or regulations. The person seeking the authorization should be

trained to appropriately answer any questions that the authorizing person may have. In addition, coercion should not be exerted in any manner, nor monetary inducement offered to obtain authorization for donation. The identification of who may be the appropriate person to authorize donation, and whether the authorization of any person in addition to the donor needs be obtained, should be evaluated in accordance with the applicable laws and organizational policy and is not addressed in this statement.

The following basic elements of authorization are intended to highlight the information that may be considered critical to informed decision making by a family member or other legally authorized person, who is being approached for authorization to organ and/or tissue donation. This listing, whether communicated verbally or included on authorization forms, is not intended to preempt any applicable federal, state, or local laws or regulations that may require more or less information to be disclosed for informed authorization to be legally effective.

In seeking informed authorization, the following information should be provided to the person(s) being approached for authorization:

- A confirmation/validation of the donor's identity and his or her clinical terminal condition.
- A general description of the purposes (benefits) of donation.
- Identification of specific organs and/or tissues (including cells) that are being requested for donation (with subsequent information provided on specific gifts recovered).
- An explanation that the retrieved organs/tissues may be used for transplantation, therapy, medical research, or educational purposes.
- A general description of the recovery process (including timing, relocation of donor if applicable, contact information, etc.).
- An explanation that laboratory tests and a medical/social history will be completed to determine
  the medical suitability of the donor, including an explanation that blood samples from the donor
  will be tested for certain transmissible diseases.
- An explanation that the spleen, lymph nodes, and blood may be removed and cultures may be
  performed, for the purpose of determining donor suitability and/or used to determine compatibility
  of donor and recipient.
- A statement granting access to the donor's medical records, and that the medical records may be released to other appropriate parties.
- An explanation that costs directly related to the evaluation, recovery, preservation, and placement of the organs and tissues will not be charged to the family.
- An explanation regarding the impact the donation process may have on burial arrangements and on appearance of the body.
- Any additional information required by federal, state and/or local laws and/or regulations.

# Additional Elements of Informed Authorization

In some situations, there may be additional information that should be known by the authorizing person(s), or that might be helpful for family decision making. At a minimum, if the donor family inquires about any of these additional matters, explanations should be provided.

The guiding principle for the use of these "Additional Elements of Informed Authorization" is to advance simplicity and reasonableness in seeking authorization (i.e., include these elements or additional comments if they are appropriate and might clarify any exigencies). For example, if there is the likelihood that the patient will become a Medical Examiner's case, then it should be appropriate to so inform the family. If it is unlikely that donated tissue is going to be used for aesthetic surgery, then it would not be reasonable to address this issue in the family approach.

One or more of the following elements of information may also be appropriate for communication to the person(s) being approached for authorization, depending upon the circumstances surrounding the donation and the potential gift(s):

- A description of any involvement by the Medical Examiner and/or Coroner, including an explanation that an autopsy may be performed.
- An explanation that transplantation may include reconstructive and aesthetic surgery.
- A reference to the possibility that the final gift may take a different form than originally recovered.
- An explanation that multiple organizations (nonprofit and /or for profit) may be involved in facilitating the gift(s).
- Reference to the possibility that tissue and/or organs may be transplanted abroad.

#### Donor Eligibility

The United Network of Organ Sharing (UNOS, 2015e) establishes the policies related to organ donor eligibility and procurement standards. These policies must be followed by the OPO and transplant centers. Currently, few medical contraindications to donation are absolute. This is an area that is under constant review as transplant technology and surgical techniques improve.

The following is an overview of the current UNOS policy related to evaluation of potential donors (UNOS, 2015f).

When available, the recovering OPO shall perform the following evaluations and provide this information to the OPO or transplant center. The transplant center will make the clinical decision whether to accept or reject the organ based on the available data or the need for additional information, including:

- Pronouncement of death according to applicable laws pertaining to organ donation.
- Conditions that may influence donor acceptance.
- The donor's history.
- The donor's medical chart.
- Physical examination of the donor.
- The donor's vital signs.
- Pertinent tests, including (for all potential donors):
  - o CBC
  - Electrolytes
  - ABO typing
  - Hepatitis screen; including HBsAg, HBcAb, and Anti-HCV
  - o VDRL or RPR
  - o FDA licensed Anti-HIV I/II
  - o EBV
  - o Anti-CMV
  - o Blood and urine cultures if the donor is hospitalized 72 hours or longer
  - Chest x-ray

Additional testing is required for each potential organ to be donated such as urinalysis, creatinine, bilirubin, ECG, and blood gases. The OPO staff will work with the hospital staff to obtain these vital tests.

The criteria for identifying a potential tissue donor are less restrictive than for solid organs. Tissues have a much longer viability after circulation ceases than highly metabolic vital organs. This allows tissues to be retrieved for a number of hours following circulatory death.

For eye donation, the only absolute contraindications recognized by most eye banks are HIV, AIDS, hepatitis, rabies, West Nile virus, and Creutzfeldt-Jakob disease. West Nile virus was recently added to the restriction list, which is why it is important for nurses to contact the OPO to determine donor eligibility.

The donation of most other tissues (such as skin, bone, heart valves) requires that the donor must, in addition to other criteria, be free of malignancy (other than non-metastasized, primary brain tumors), and have no unresolved infections at the time of death. A history of autoimmune or tissue-specific diseases, high-risk behaviors, or prolonged steroid use usually contraindicate donation (Norris & House, 1991). Donors generally are under 70 years of age, but there is no definitive maximum age limit in becoming a donor. Each organ and tissue procurement agency evaluates potential donors individually based on their medical suitability at the time of death.

The nurse's role in donor evaluation and eligibility is to work with the OPO to provide information and assist in obtaining the necessary testing to establish eligibility.

# **Donor Management**

Potential donors must be medically managed to sustain organ function while families are considering the option of organ donation. Donor management is critical to the viability of the organ for transplantation. Effective donor management requires a multidisciplinary approach involving, personnel from the OPO, the nursing, anesthesia, and surgery departments, and other ancillary departments of the hospital (Chabalewski, 1996).

## Nursing priorities are:

- Maintain patent airway.
- Maintain adequate organ perfusion.
- Maintain adequate tissue oxygenation.
- Maintain normothermia.
- Maintain adequate hydration.
- Prevent infection.
- Prevent complications.

An OPO staff member should be available onsite to assist healthcare providers in evaluating the patient. Medical management of the patient should begin as soon as possible after the determination of brain death (in the case of a brain dead patient) and acquisition of authorization from the patient's family. The OPO staff member, in conjunction with the OPO's medical director, assumes responsibility for the medical management and evaluation of the donor. A multidisciplinary approach is encouraged because it optimizes donor management and facilitates organ placement.

The OPO staff member is not an employee of the hospital and may not be aware of specific hospital policies, issues, and routines. He or she will depend greatly on assistance and guidance from hospital staff. Donor management begins with a consultation between the OPO staff member and the nurse to review the donor's clinical course and establish a plan of care. The OPO provides management guidelines to the nurse and ensures that the goals of donor management are achieved. The OPO staff member and the nurse must maintain an open line of communication about hemodynamic management and changes in the donor's status.

#### Management of Potential Organ Donors

The following general information describes typical clinical pathway management for the care of potential organ donors (UNOS, 2012). Please note that each recovery organization will provide *individual* clinical pathway management for each potential donor.

**Hypotension** (sustained systolic BP less than 90 mm Hg):

- Start Dopamine infusion and titrate to maintain Systolic Blood Pressure (SBP) between 90 and 110 mm Hg (max 20 mcg/kg/min).
- If Dopamine is at 15 mcg/kg/hr, Central Venous Pressure (CVP) greater than 6 and SBP remains less than 90 mm Hg or HR greater than 120, consider Neosynephrine infusion. Commence at 50 mcg/min and titrate to clinical effect (maximum 300 mcgs/min).
- Maintenance IV Fluid: D5 ½ NS with 20 mEq KCL at 150 cc/hr. (Saline may need to be adjusted for Na+ greater than 155).
- For CVP less than 7 and SBP less than 90, bolus with 500 cc Lactated Ringers solution.
- If brain death is believed to have occurred and declarations are initiated or pending, consider giving Solumedrol 15 mg/kg IVPB. Solumedrol will help to reduce the need for high pressures as well and reverse the inflammatory process associated with herniation. Please consider steroids when pressures are high.

- If Hematocrit (HCT) less than 25%, recommend 1 unit of Packed Red Blood Cells (PRBCs) over 1 hour, repeat as necessary to maintain HCT greater than 25%. If in Disseminating Intravascular Coagulation (DIC) please correct with Fresh Frozen Plasma (FFP), cryoprecipitate, and platelets.
- Monitor and replace calcium aggressively.

# Hypothermia (especially if patient is bleeding):

- Warming blanket to maintain core body temperature between 36.5° and 37.2°C.
- Ventilator Heating Circuit to 37°C.

# **Diabetes Insipidus:**

• For urinary output greater than 300 cc x 2 hours **and** specific gravity less than 1.005, recommend Desmopessin (DDAVP) at 0.1 mcg/kg in 50 cc normal saline (NS) over 20 minutes (may repeat at 0.2 mcg/kg after 2 hours if inadequate response).

# Hypoxemia:

- Titrate FiO<sub>2</sub> to maintain PaO<sub>2</sub> of 90-110, SaO<sub>2</sub> of greater than 97%.
- Tidal Volume at 10 to 15 cc/kg.
- Add Positive End Expiratory Pressure (PEEP) to 5 cm H<sub>2</sub>O, consider higher PEEP if oxygenation poor.
- Rate adjusted to maintain normal pH and pCO<sub>2</sub>.

#### **Electrolytes:**

- Monitor serum K+; if less than 3.5 give 20 mEq KCL IV over 2 hours.
- If tachycardic, consider checking Phosphorous and Magnesium, replace to hospital norms.

#### Labs:

• Suggest daily ABG, electrolytes, glucose, BUN and creatinine and CBC.

#### Management of Potential Eye Donors

- Instill sterile normal saline eye drops and elevate the head of the bed 30°;
- Lightly place tape over closed eyelids;
- Lift head so that it is gently placed on a soft pillow; and
- Place an ice pack over closed eyes.

These measures greatly assist in slowing the deterioration that might hamper optimal vision for the recipient. By using these simple interventions, the nurse greatly enhances the viability of the procured tissue.

#### Management of Potential Tissue Donors

The medical management of the tissue donor is minimal. Most tissues need to be retrieved within 6 to 24 hours, depending on whether the body is refrigerated. Whenever possible, refrigeration or cooling is arranged.

# **Recovery of Organs and Tissues**

The nurse's role in the recovery process will vary, depending on OPO and hospital policies. The following information applies to a typical recovery in the operating room (OR) setting, but each OPO, tissue or eye bank, and transplant team may have different policies. Nurses should become familiar with the policies within their own institutions.

Removal and successful transplantation of donated organs generally requires the surgical skill and effort of personnel from several transplant centers. Kidney recovery teams may include a local community surgeon or a transplant surgeon. Extrarenal recovery requires a team consisting primarily of individuals specially trained in transplantation and recovery techniques and may involve visiting recovery teams from other parts of the country.

Which organs or tissue will be recovered is determined prior to moving the donor to the operating room. Appropriate surgical teams will be assembled by the OPO. It is mandatory that an OR nurse review the medical record for appropriate documentation of the brain death declaration (in the case of a brain dead patient) and a properly executed authorization form. The nurse should also verify the presence of any other death paperwork required by hospital protocol. The OPO is responsible for verifying that all visiting surgeons are credentialed to perform the recovery procedure. The verification can be printed for the hospital record."

Continued hemodynamic stability in the OR is essential to ensure organ viability. The following should be available:

- Heating blanket
- Heated humidifier for oxygen administration
- Fluid warmers
- Transducers to monitor central venous pressure and arterial pressure, if lines are in place
- PEEP valve for ventilation
- Blood
- Heparin, mannitol, furosemide (Lasix)
- Vecuronium or pancuronium
- IV pumps

The room temperature should be increased to greater than 70°F to assist in donor temperature maintenance. Anesthesiology or respiratory therapy personnel must be available to assist with patient transfer from the critical care unit to the OR. Use of portable monitoring devices is recommended.

When the donor is brought into the OR, the body should be placed in the supine position on the operating table and reconnected to mechanical ventilation. EKG and pulse oximetry monitors, a noninvasive blood pressure monitor, and temperature probe should be connected. Transducers for CVP and arterial line monitoring should be connected and calibrated, if these lines are in place.

The anesthesiologist or nurse anesthetist will administer a muscle relaxant. Even after declaration of brain death, spinal reflexes may persist. The "Lazarus sign," which includes gooseflesh on arms and trunk, shivering extensor movement, flexion at the elbow, and movement of the hands toward the sternum, may be seen. This disconcerting activity is prevented with administration of a muscle relaxant.

Blood loss may be significant. Two to four units of blood should be available prior to beginning the organ recovery, as blood products may be needed to combat coagulopathy. The anesthesia team should monitor arterial blood gases, electrolytes, and hematocrit and manage any problems as indicated. Care should be taken with fluid management to prevent overload of the multi-organ donor. Engorgement of the liver, lungs, and heart may make those organs unsuitable for transplantation.

Every effort should be made to maintain an adequate systolic blood pressure. In addition to fluid replacement, Dopamine at less than 10 mcg/kg/min may be necessary if hypotension persists. Other resuscitative drugs should be available and administered as needed. Administration of a specific pharmacologic regimen, including diuretics and heparin, will be requested by the transplant or OPO team. The OPO or transplant coordinator should advise the anesthesia team of special management requirements. Once aortic cross-clamping has occurred and cooling of the organs begins, ventilatory support is discontinued.

Recovery teams will bring special instruments, solutions, and supplies that are not readily available in the donor hospital. The donor hospital OR generally provides the usual laparotomy and major surgical instruments, supplies, and personnel support, but this may vary according to the recovery organization involved.

Preservation of the organs is coordinated by the OPO. The OPO staff will provide special solutions and cannulas to the surgical recovery teams. Organ preservation is essential to ensure viability of the organs being recovered. Preservation time for organs is critical. Most organs are stored on ice after initial flushing with a cold hyperosmolar solution. All solutions should be applied at a reduced temperature, yielding a decrease in metabolic activity and requirements (Chabalewski, 1996).

Tissue recovery occurs in the OR, morgue, or other specifically designated area. Aseptic technique is maintained during the recovery process. Most tissue recovery teams function as self-contained units, bringing all personnel, supplies, and equipment needed for the recovery. A few bone teams may involve the OR staff in the recovery of bone and soft tissue, but they usually bring their own supplies.

If organ donation is to occur, tissue recovery will follow organ recovery. Corneas or eyes may be recovered on the nursing unit, OR, morgue, or funeral home, depending on where the death occurred and local practice. Generally, individuals who recover this tissue need no assistance or supplies (Chabalewski, 1996).

The OPO team will work with hospital staff to ensure that the donor is cared for in a professional and respectful manner. The donor is surgically reconstructed so that the donation does not interfere with funeral needs.

All procedures are performed to preserve the appearance of the donor. In skin donation, a layer of skin only 12 to 15 thousandths of an inch is removed. This is similar to mildly peeling sunburn. Skin is removed from areas such as the chest, back, buttocks, and thighs, which will be covered by clothing during the funeral. When the eyes are removed for corneal donation, they are replaced with prosthesis to maintain an unaltered appearance. Surgically removed bones are replaced with prosthetics before incisions are closed (Norris & House, 1991).

#### **Care After Donation**

Recovery organizations provide aftercare to both donor families and hospital staff. The donation and transplant community recognize the altruism of donors and their families, as well as the critical and often difficult role that nurses play in the process of organ and tissue donation. Nurses may be traumatized by the loss of a patient, saddened and empathetic with the grieving family, or affected by the recovery process in the operating room.

#### Aftercare for Donor Families

For donor families, OPOs and tissue and eye banks provide a range of services that may include thankyou letters, information about recipients, family recognition events and commemoratives, bereavement counseling services, and peer support groups staffed by grief and counseling specialists. They provide information on support groups, the grieving process, coping with holidays. They sponsor healing activities such as quilt making, annual recognition events, communication between donors and recipients, and volunteer opportunities.

The United Network of Organ Sharing (UNOS) has established a Donor Memorial at its headquarters in Richmond, VA, as a lasting tribute to donors and their families. This memorial also has a Web-based component at <a href="https://www.donormemorial.org">www.donormemorial.org</a>.

The recovery community has worked extensively with the National Donor Family Council (NDFC) of the National Kidney Foundation, the oldest and largest national voluntary organization dedicated exclusively to the needs of tissue, eye and organ donor families. With a Web site at <a href="www.donorfamily.org">www.donorfamily.org</a>, the mission of the NDFC is to enhance the sensitivity and effectiveness of the organ and tissue procurement process, to provide opportunities for families to grieve and grow, and to utilize the unique perspective and experiences of these families to increase organ and tissue donation. In addition to serving as an advocate and providing support for donor families, the council develops high-quality programs to meet the ongoing needs of families and those professionals involved in their care. Membership in the council is free.

Under the Gift of Life Donor Medal of Honor Program in New York State, donors and donor families are given medals by recovery organizations and transplant centers.

#### Aftercare for Healthcare Providers

The recovery organizations provide aftercare to hospital and nursing staff by making rounds shortly after the donation to discuss with the staff the outcomes of the donation. Thank-you letters are sent to unit head and the specific nurses involved in the donation process. Scheduled summaries are sent to executives of the hospitals. Many recovery organizations also give nursing staff the opportunity to participate in nursing advisory committees, include them in newsletter articles, and hold educational sessions and recognition ceremonies honoring the work of the nursing staff in donor hospitals.

# The Organ Donation Breakthrough Collaborative

There is increasing recognition on a national level of the importance of organ and tissue donation. Nurses are involved in these innovative strategies and are taking leadership roles to participate in addressing the widening gap between the supply and demand for organs and tissues.

The Organ Donation Breakthrough Collaborative was created by the U.S. Department of Health and Human Services (HHS) to generate significant, measurable increases in organ donation by helping OPOs and hospitals to quickly identify, learn, adapt, replicate, and celebrate "breakthrough" practices associated with higher donation rates.

The collaborative also is designed to enhance the understanding of existing knowledge and contribute new and vital information about increasing organ donation rates. The initial goals of the collaborative were to (USDHHS, 2003):

- Increase the average conversion rate of eligible donors from the current average of 43% to 75% in the nation's 300 largest hospitals;
- Increase donations by up to 1,900 donors per year;
- Increase the number of transplantations by 6,000 per year; and
- Help save the lives of thousands of people each year and prevent up to 17 deaths per day.

Fifty percent of the nation's eligible organ donors came from 200 hospitals. Fourteen of the largest hospitals in the United States have achieved organ donation rates of 75% or greater. Many other large hospitals, clustered in certain donation service areas, also have average donation rates that are well above the national average of 46% (USDHHS, 2003).

The high rates are no accident. The practices used by OPOs and large hospitals to generate these high rates can be replicated. Put simply, there is a gap between what we know generates these high rates and the performance of the current organ donation system (USDHHS, 2003).

In September 2003, the collaborative issued its *Best Practices Final Report*, outlining activities that appear to be associated with higher organ donation performance and are capable of being replicated in other OPOs and hospitals. A full copy of the report can be viewed here: <a href="http://www.lewin.com/~/media/lewin/site">http://www.lewin.com/~/media/lewin/site</a> sections/publications/organdonationbreakthroughcollaborative.p

Background information was gathered from six OPOs and sixteen affiliated hospitals to determine factors that contribute to organ donation. Data and observations were synthesized and analyzed to formulate overarching principles and best practices.

The best practices include:

- 1. Orient organizational mission and goals toward increasing organ donation.

  OPOs and hospitals demonstrate goal-focused leadership and management toward improving organ donation performance, including orienting operations toward measurable outcomes and making organ donation an expected, routine process of the organization.
- 2. **Do not be satisfied with the status quo; innovate and experiment continuously.**None of the OPOs and hospitals reported being satisfied with their current level of performance. In fact, some noted that maintaining the status quo is regressive. These entities regularly implement new, innovative strategies.

# 3. Strive to recruit and retain highly motivated and skilled staff.

Both OPOs and hospitals attributed their higher than average performance to their skilled, motivated, and tenured staff. Given high turnover in the industry, they are highly attentive to staff recruitment and retention.

#### 4. Appoint members to OPO board who can help achieve organ donation goals.

In most of the sites, OPOs organized their boards or advisory structures to advance all of the interests of the OPO, including donation, procurement, and placement of organs. Boards are comprised to promote collaboration and mitigate conflicts via professionally diverse composition and balanced representation of organ donation and transplantation interests.

# 5. Specialize roles to maximize performance.

Various key roles in organ donation are assumed by different actors. At least three critical roles are: family support, clinical coordination, and hospital relations. OPO and hospital staff are assigned particular roles according to their professional strengths, experience, and performance.

# 6. Tailor or adapt the organ donation process to complementary strengths of OPO and individual hospitals.

High performing OPOs and hospitals do not approach organ donation in the same way in all settings. With experience, and over time, they tailor their approaches based on their respective strengths, experience, performance, and the broader needs and context of their institutions and communities.

#### 7. Be there: integrate OPO staff into the fabric of high potential hospitals.

Among the sample of higher than average OPO and hospital performers, there is a high level of ongoing, routine interaction between OPO and hospital staff. OPO staff do not simply arrive on the scene at the time of a potential donation; they are well recognized in the settings of their affiliated hospitals.

8. Identify and support organ donation champions at various hospital levels; include leaders who are willing to be called upon to overcome barriers to organ donation in real time.

Hospital champions advocate organ donation, link the hospital to the OPO, facilitate the process of organ donation in hospitals, and break down institutional and other barriers to donation. OPOs endeavor to identify, support, and maintain relationships with these champions.

# 9. All aboard: secure and maintain buy-in at all levels of hospital staff and across departments/functions that affect organ donation.

OPO and hospital personnel do not rely on champions alone to achieve high levels of performance. They articulate the importance of "top-down, bottom-up and sideways buy-in," that is, identification with and commitment to organ donation. OPOs use diverse and creative strategies for securing and maintaining buy-in.

# 10. Educate constantly; tailor and accommodate to staff needs, requests, and constraints. Hospital staff in particular attributed higher than average performance, in part, to the repeated education they receive and provide to others in organ donation. Educational interactions address topics such as brain death criteria; donor identification, referral, authorization and recovery processes; mechanisms for matching organs to recipients; transplantation processes; recipient care; bereavement care; and criteria for donation after circulatory death.

# 11. Design, implement, and monitor public education and outreach efforts to achieve authorization and other donation goals.

OPO and hospital staff expressed differences of opinion on the impact of public education and outreach efforts on organ donation authorization and conversion rates. Hospital respondents tended to give greater weight to the role of public education campaigns; OPO leaders more often found little or no causal relationship between such efforts and organ donation performance. Most

hospital and OPO staff would concur that this type of education is a best practice when it has a specific purpose and continuing or improving it is linked to measurable outcomes.

## 12. Referral: anticipate, don't hesitate, call early even when in doubt.

One of the most important messages that OPOs convey in education sessions and via regular contacts with hospital staff is to call as early as possible to facilitate authorization and organ recovery. Among the hospitals visited, there is a common interest and willingness to make early referrals to the OPO and to consult its experts regarding potential donations. OPO personnel have cultivated this inclination by teaching the early signs of brain death and emphasizing the importance of not waiting until brain death declaration (in the case of brain dead patients) to place a call to the OPO.

13. Draw on respective OPO and hospital strengths to establish an integrated authorization process. One size does not fit all, but getting to an informed "yes" is paramount.

Obtaining authorization can be an intricate process that is highly dependent on the cooperation, skills, and responsiveness of OPO staff and hospital-based physicians, nurses, pastoral care staff, and social workers. The roles in the authorization process are largely consistent across high performing sites; however, they can be carried out by different combinations of OPO and hospital staff. Interacting with a potential donor family to achieve authorization to donate usually entails a sequence of time-sensitive events and carefully conveyed communications, all within a context of trust.

# 14. Use data to drive decision-making.

All of the OPOs and most of the hospitals cited the importance of data-driven decision-making to improve organ donation and focus their resources appropriately. Using data to inform and document decisions helps OPOs and hospitals to maximize referrals, authorizations, and donors and improve continuously. In particular, conducting regular death record reviews in all hospitals helps to determine those with the highest donor potential and ways to increase donations.

#### 15. Follow up in a timely and systematic manner. Don't let any issues fester.

OPO staff, physicians, and nurses affirmed that timely and systematic feedback is crucial to increasing awareness and improving organ donation processes at hospitals, thereby maximizing the number of early referrals and actual donors at hospitals. Immediate problem solving is another contributor to success. OPO and hospital staff emphasized that, when the organ donation process breaks down or when an aspect of the process has been poorly handled, it must be resolved as soon as possible so as not to adversely affect future events. OPOs conduct follow-up both formally and informally, using a variety of techniques.

Source: U.S. Department of Health and Human Services (2003). *The organ donation breakthrough collaborative: Best practices final report.* Washington, DC: Author.

The results from the Organ Donation Breakthrough Collaborative have been impressive. In 2004, the year following the launch of the collaborative, donation rates increased by 10.8%, reaching a new annual record of 27,033 transplant operations. In 2005, donation rates increased again by 5.9%. From 2004-2005, that average increased to 1,880 organs transplanted per month. In 2010, an all time high of almost 2,600 organs per month, 31,163 organs per year were transplanted (UNOS, 2011).

#### Conclusion

In today's healthcare environment, organ, eye and tissue donation has the potential to dramatically improve the lives of thousands of people. However, in order for organ, eye and tissue transplantation to be successful, donations must be increased. For the thousands who are waiting for an organ, donation is their only hope. Unfortunately many of those waiting for transplantation will die before a suitable organ is located.

There are many challenges to the process of organ donation, but there are also multiple efforts underway to improve and increase the process of organ and tissue donation. It is critical for nurses to take an active role in organ, eye and tissue donation so that the potential for an increase in available organs and tissues can translate to increased hope for the many thousands who are waiting for the opportunity for a healthy life.

#### Resources

# U.S. Department of Health and Human Services

www.organdonor.gov

The official U.S. Government Web site for organ and tissue donation and transplantation is maintained by the Health Resources and Services Administration (HRSA), Healthcare Systems Bureau (HSB), Division of Transplantation, an agency of the U.S. Department of Health and Human Services.

# **New York State Organ and Tissue Donor Registry**

New York State Department of Health Donate Life Registry 875 Central Avenue Albany, NY 12206

#### 866-NYDONOR

www.health.state.ny.us/nysdoh/donor/

The brochure, Be an organ, eye and tissue donor, Enroll in the New York State Donate Life Registry is available at the Web site or a copy can be obtained by writing the address above. This brochure is available in English, Chinese, French, Korean, Spanish, Russian, Italian, and Haitian Creole.

# New York Alliance for Donation, Inc.

www.alliancefordonation.org

The mission of the New York Alliance for Donation is to increase organ, eye and tissue donation in New York State through collaborative advocacy, education, promotion, and research. Our goal is to ensure a transplant for every New Yorker in need. The New York Alliance for donation is a 501(c)3 non-profit organization comprised of NYS-based recovery organizations as its corporate members, as well as donation advisory council members, and affiliate member organizations. All members are dedicated to developing strategies to increase public awareness, improve professional education, recognize donors and donor families, and improve donation and transplantation in New York. **Organ Procurement Organizations** 

In the U.S. and Puerto Rico, 58 organ procurement organizations (OPOs) coordinate organ procurement in designated service areas, evaluate potential donors, discuss donation with family members, and arrange for the surgical removal of donated organs; and preserve organs and arrange for their distribution according to national organ sharing policies.

A listing of OPOs is available at www.organdonor.gov.

There are four OPOs in New York State:

| Region             | Organization        | Phone Numbers | Web Site              |
|--------------------|---------------------|---------------|-----------------------|
| Albany             | Center for Donation | 518-262-5606  | www.cdtny.org         |
|                    | and Transplant      | 800-256-7811  |                       |
| Buffalo            | Unyts               | 716-853-6667  | www.unyts.org         |
|                    |                     | 800-227-4771  |                       |
| New York City      | LiveOnNY            | 646-291-4444  | www.liveonny.org      |
|                    |                     | 800-443-8469  |                       |
| Rochester/Syracuse | Finger Lakes Donor  | 585-272-4930  | www.donorrecovery.org |
|                    | Recovery Network    | 800-810-5494  |                       |

#### **Transplant Living**

www.transplantliving.org

Transplant Living is a project of the United Network for Organ Sharing (UNOS), a nonprofit organization that maintains the national Organ Procurement and Transplantation Network (OPTN) under contract with the Health Resources and Services Administration of the U.S. Department of Health and Human Services. The focus of this project is to advance living donation as an alternative to organs from deceased donors.

## **United Network for Organ Sharing**

www.unos.org

The United Network for Organ Sharing (UNOS) is a nonprofit scientific and educational organization that administers the nation's only Organ Procurement and Transplantation Network (OPTN), established by the U.S. Congress in 1984. Through the OPTN, UNOS:

- Collects and manages data about every transplant event occurring in the United States;
- Facilitates the organ matching and placement process;
- Brings together medical professionals, transplant recipients and donor families to develop organ transplantation policy.

## The Organ Procurement and Transplantation Network

http://optn.transplant.hrsa.gov/

The Organ Procurement and Transplantation Network (OPTN) is the unified transplant network established by Congress under the National Organ Transplant Act (NOTA) of 1984. OPTN is a unique public-private partnership that links all of the professionals involved in the donation and transplantation system. Its primary goals are to:

- Increase the effectiveness and efficiency of organ sharing and equity in the national system of organ allocation; and to
- Increase the supply of donated organs available for transplantation.

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# Think, Care, Act: The Role of the Nurse in Organ and Tissue Donation Course Exam

After studying the downloaded course and completing the course exam, you need to enter your answers online. **Answers cannot be graded from this downloadable version of the course.** To enter your answers online, go to e-leaRN's Web site, <a href="www.elearnonline.net">www.elearnonline.net</a> and click on the Login/My Account button. As a returning student, login using the username and password you created, click on the "Go to Course" link, and proceed to the course exam.

1. An average of 21 people die each day while waiting for a suitable organ to be donated.

2. The percentage of New Yorkers who die and become organ donors exceeds the national average

Note: Contact hours/CEUs will be awarded for this online course until April 9, 2018.

a. Trueb. False

|    | Of 76%.   |
|----|---|
|    | a. True<br>b. False   |
| 3. | One deceased donor can potentially provide: 1 heart or 2 heart valves, 2 lungs, 2 kidneys, 1 liver or multiple liver segments, 1 pancreas, 1 intestine, 2 corneas, bones, including whole joints, connective tissues, skin, and blood vessels.                        |
|    | a. True<br>b. False   |
| 4. | Donation is consistent with the life-preserving traditions of major religions.  |
|    | a. True<br>b. False   |
| 5. | The most frequently transplanted organ, both nationally and in New York state is:   |
|    | <ul><li>a. Liver</li><li>b. Heart</li><li>c. Intestines</li><li>d. Kidney</li></ul>   |
| 6. | The Uniform Anatomical Gift Act was created in 1968 in order to establish consistency in laws regarding organ and tissue donations throughout the US, ensuring that anatomical gifts can cross state lines and that there is compliance with the wishes of the donor. |
|    | a. True<br>b. False   |
|    |   |

- 7. The Healthcare Information Portability and Accountability Act (HIPAA) prohibits the disclosure of personal health information to Organ Procurement Organizations and other entities that engage in the procurement, banking or transplantation of cadaveric organs, eyes, or tissue for the purpose of facilitating organ, eye or tissue donation and transplantation.
  - a. True
  - b. False
- 8. A patient's ranking on the Organ Procurement and Transplantation Network (OPTN) database is based on:
  - a. Severity of medical condition
  - b. Tissue match and blood type
  - c. Immune status
  - d. All of the above
- 9. There is a misperception among some in the general population that healthcare providers are less likely to try to save one's life if it is known that the person has agreed to be an organ donor.
  - a. True
  - b. False
- 10. African Americans donate organs in proportion to their share of the population, that is, African Americans make up about 13% of the population and they comprise 17% of donors. They also comprise about 37% of those with end-stage renal disease who are waiting for a kidney.
  - a. True
  - b. False
- 11. The lower rate of African American organ donations has been attributed to:
  - a. Lack of awareness about transplantation and religious beliefs
  - b. Distrust of healthcare providers due to the disparities related to access and treatment
  - c. "Institutional racism" (unconscious bias)
  - d. All of the above.
- 12. The Hospital Conditions of Participation for Medicare and Medicaid (HCFA, now CMS, 1998) requires all hospitals in the US to:
  - Adopt a routine notification policy so that every death can be evaluated for potential donation.
  - b. Recognize that it is the Organ Procurement Organization's responsibility to request organ and tissue donation from the family of the patient.
  - c. Notify their federally designated organ procurement organizations of all deaths and all imminent deaths.
  - d. All of the above.

- 13. Early referrals to the Organ Procurement Organization are important because:
  - a. The patient's family is given time to be educated about donation, discuss the opportunity and makes an informed decision.
  - b. The patient's stability is maintained so that donation is medically possible if the family gives authorization.
  - c. Both A and B
  - d. Neither A nor B
- 14. Frequently, patients who become organ donors are those that have been declared brain dead and are connected to a ventilator. Current standards for making a diagnosis of brain death require the:
  - a. Identification of the suspected cause of the coma.
  - b. Determination that the coma is irreversible.
  - c. Performance of a clinical examination and/or interpretation of appropriate neurodiagnostic and laboratory tests.
  - d. All of the above.
- 15. Living donors add substantially to the possible number of transplantations. Living donors can donate all of the following **EXCEPT**:
  - a. A single kidney.
  - b. A single lung.
  - c. A portion of the pancreas and a portion of the intestines.
  - d. A portion of the intestines.
- 16. Nurses hold the following roles in the process of organ and tissue donation:
  - a. Advocates
  - b. Educators
  - c. Counselors and supporters
  - d. All of the above
- 17. Two simple steps that nurses can take to significantly improve the number of organs available are:
  - a. Pronouncement of death of a donor and talking to the family about donation of organs and tissues.
  - b. Identifying the patient as a potential donor and initiating discussion about donation with the physician.
  - c. Identifying the patient as a potential donor and contacting the local organ procurement organization, according to hospital policy.
  - d. Nurses cannot be helpful in improving the number of available organs.
- 18. A critical issue when there is no documentation of anatomical gifts is the issue of "decoupling." Decoupling is defined as the separation of the acknowledgement of the death as separate from the request for organ or tissue donation.
  - a. True
  - b. False

- 19. The timing of the donation request is one of the most critical elements of the family request protocol. A critical component is to ensure that the donor family understands the patient's condition and all of their questions about their loved one's death have been addressed.
  - a. True
  - b. False
- 20. Authorization is needed in order to donate organs and tissue. Elements of authorization for organ, eye and tissue donation include all of the following **EXCEPT**:
  - Information must be presented in language and terms that are easily understood by the authorizing person, with opportunities to ask questions and receive informative responses.
  - b. The process of authorization can only be undertaken by a licensed physician.
  - c. A copy of the signed authorization form should be offered to the authorizing person.
  - d. Authorization should be obtained in accordance with federal, state and/or local laws and regulations.
- 21. The United Network of Organ Sharing (UNOS) establishes the policies related to donor eligibility and procurement standards as it relates to organ donation. These policies must be followed by the OPO and transplant centers. The nurse's role in donor evaluation and eligibility focuses on working with the recovery organization to provide information and assist in obtaining the necessary testing in order for eligibility to be established.
  - a. True
  - b. False
- 22. The nursing priorities related to donor management include all of the following EXCEPT:
  - a. Maintaining a patent airway to insure adequate tissue oxygenation and organ perfusion.
  - b. Maintenance of normothermia and adequate hydration.
  - c. Cardiac and/or cerebral rehabilitation.
  - d. Prevention of infection and other complications.
- 23. The nurse's role in recovery varies based on the hospital and OPO policies. However, it is mandatory that the operating room nurse:
  - a. Review the medical record for appropriate documentation of the brain death declaration (in the case of a brain dead patient) and verification of the presence of any other death paperwork required by hospital protocol.
  - b. Review the medical record for a properly executed authorization form.
  - c. Both A and B.
  - d. Neither A or B.
- 24. Nurses are often in a difficult role in the process of organ and tissue donation. They can be traumatized by the loss of a patient; saddened and empathetic with the grieving family, or affected by the recovery process in the operating room. In order to address these and other aftercare issues, recovery organizations provide aftercare, including follow-up and support to both the hospital staff and the donor families.
  - a. True
  - b. False