

Arkansas Regional Organ Recovery Agency

Designated Requestor Training **Self-Study Packet** **2006**

Introduction and Background

The purpose of this material is to train and re-certify Designated Requestors. The primary objective of this re-certification is to review and update the procedures for organ and tissue referrals and requesting for tissue donations.

Federal Regulations

Across the nation, there are over 90,000 people waiting for an organ transplant. Every 13 minutes another name is added to the national waiting list at the United Network for Organ Sharing (UNOS). And every day, 17 people die because they do not receive the organs they need to save their lives.

Last year there were approximately 25,000 people who died under circumstances that would have allowed them to be organ donors. Of those 25,000, only about 6,500 became donors. The need is critical.

In 1998, in an effort to improve the donation rates across the United States, the Center for Medicare and Medicaid Services (CMS) mandated legislation to hospitals receiving Medicare funding. This regulation is called “**The Conditions of Participation**” (COP’s), and it mandates the following:

1. Hospitals must notify the Organ Procurement Organization (OPO) of all deaths and imminent deaths;
2. Hospitals must have agreements with the OPO, as well as tissue and eye banks;
3. The OPO determines medical suitability for organ donation; it also determines suitability for tissue and eye donation, using the protocol developed by the tissue and eye banks;
4. Hospitals must ensure all families are offered the appropriate option for donation;
5. Donation options must be given to the family by requestors from the OPO or designated requestors trained by the OPO;
6. Hospital must work cooperatively with the OPO in medical record reviews and maintaining donors until recovery.

The goals of the COP’s are to increase consent to donation, maximize donation opportunities and learn about what works to increase donation and improve transplantation through research. Even with Federal legislation in place, there was not a significant rise in organ donors. In April 2003, Secretary of Health Tommy Thompson organized the National Breakthrough Collaborative on Organ Donation to address the severe shortage of organs available for transplantation. The goal was to bring the hospitals with the largest donor potential together with their OPO’s to spread the best known practices of referrals, requesting, donor management and to increase the rate of organ

recovery per donor. The number of donors has risen every month since the introduction of the Collaborative in August of 2003.

As a result of this federal call to action, the Joint Commission on Accreditation of Hospitals and Healthcare Organization (JCAHO) issued new Standards of Practice in July 2005. JCAHO surveyors monitor the following statistics in accredited hospitals:

1. Routine referral compliance
2. Timely referral rate
3. Consent rate
4. Conversion rate
5. APR rate

Definitions:

OPO stands for Organ Procurement Organization. ARORA is one of 58 OPOs in the US. The federal government decides the OPOs designated service area.

UNOS is the United Network for Organ Sharing. It is located in Richmond, VA and is responsible for maintaining the waiting lists at all transplant hospitals around the country in a fair and ethical manner.

Cardiac death is defined as cardiac standstill with interrupted circulation.

Brain death is defined by the following, "A person is legally dead when the brain has irreversibly ceased to function and there is an absence of spontaneous breath. The diagnosis of death shall be made using ordinary standards of medical practice" Act 99 of 1979, State of Arkansas, Sections 1 and 2.

Imminent death is defined as a severely brain injured, ventilator dependent patient with either clinical finding consistent with Glasgow Coma Score (GCS) of ≤ 5 or a plan to discontinue mechanical/pharmacological support.

Timely Notification or Referral

CMS requires a "timely" referral. With regard to cardiac deaths, ARORA has not established a specific time frame for those calls to be made. ARORA asks that the referral be made as soon as possible. Due to the nature of the recovery process and travel time for procurement coordinators, calling soon after the death is essential. Because screen criteria continuously change, every death should be considered a potential referral for donation and reported to ARORA for screening.

Early referral

When organ donation is a possibility, a call to ARORA prior to the first brain death exam is required. A neurologically injured patient on the ventilator with a GSC ≤ 5 is the clinical trigger for making an early referral. The earlier the phone calls are made, the more efficient the process becomes for everyone and the more likely the outcome will honor the family's wishes. In addition, a call to ARORA should be made before discussing a "Do Not Resuscitate" status with the family and before withdrawing ventilator support.

Two Types of Donation – Organ and Tissue

There is an Organ / Tissue dichotomy. The referral/reporting procedures, the circumstances of death, the criteria for donation, the organs and tissue for transplant and the person approaching the family to explain the opportunity of donation are different for organ donation and tissue donation.

1. Organ Donation requires the patient to be pronounced brain dead. These types of donations are characterized as life saving donations. The organs that can be used in transplantation are:

- Heart
- Liver
- Lungs (2)
- Pancreas
- Intestine
- Kidneys (2)

Organs are recovered in the operating room while the body is maintained on a ventilator.

2. Tissue Donation

Patients who are pronounced cardiac dead are potential tissue donors. The recovery team has 15 hours to recover tissue from a “warm” donor and 24 hours from a “cool” donor. Eyes should be recovered within 6 hours of the donor’s death. Recovery of tissue often occurs in the operating room, but single tissue donors (eyes) can be recovered in the patient’s room or other clean location. ARORA also maintains an off-site recovery suite that may be used. The tissues used in transplantation are:

Bone – Bone from the upper and lower extremities is used to replace or strengthen bone damaged by trauma or diseases such as cancer or diabetes.

Connective tissues – Tendons and ligaments are used for replacement of injured or diseased tendons and ligaments.

Skin – Most often used as temporary dressings for burn patients at AR Children’s Hospital to reduce fluid loss and reduce the risk of infection.

Heart Valves – Aortic and Pulmonary Valves are used to replace diseased or defective valves. Heart valves expand as pediatric patients grow and reduce the need for as many surgeries throughout their lifetime. Also, the use of donor valves does not require the patient to take blood thinners the rest of their lives, as the use of mechanical valves does.

Veins – Vascular grafts are used in coronary artery bypass surgery or similar vascular procedures.

Eyes for Corneas – Corneas can be transplanted to restore sight.

Tissue transplants are often characterized as life enhancing. The criteria used to screen tissue donors is subject to change periodically and tends to be stricter than the screening for organ donation.

Role Definitions

1. *The Role of the Family Services Counselors (FSCs)*

This is a position ARORA created in 2002 to provide early intervention to families of potential organ donors. The academic and professional background of the FSCs includes family therapy, chaplaincy, social work, psychology, and nursing. The FSCs at ARORA have been trained in bereavement counseling, crisis intervention, and discussing end of

life options with family members. Early introduction of the FSC with the family helps in many ways:

1. The family's physical and emotional needs are the initial focus as the FSC develops an empathetic and caring relationship with the family.
2. The role of the FSC is to ensure the family makes end of life decisions based on accurate information articulated in a clear, compassionate manner.
3. In order to be sensitive to the family's needs, the FSC is trained to assess the appropriate timing and setting to inform the family regarding donation.
4. The primary objective of the FSC is to ensure the family understands brain death and to fully inform the family of options, including organ donation.
5. The early involvement of the FSC working in partnership with the hospital medical staff has been shown to increase consent rates.
6. Should the family consent to donation, the FSC will complete the proper consent and medical/social history forms with the family and will continue providing care to the family while they remain at the hospital.
7. Should the family decline donation or should the patient not progress to brain death, the FSC is available to help the family with respect to other end of life decisions and may remain with the family offering support.

ARORA recognizes hospitals that have the supportive resources (chaplaincy and social work) available for their families may feel it is not necessary to involve ARORA's FSCs so early. However, it is "**best practice**" to introduce the FSC to the family prior to pronouncing brain death. Evidence shows when the OPO staff person spends half hour to more with the family before donation discussions take place, the consent rate rises 15% - 20%. Building rapport with the family is not very effective when the FSC meets the family for the first time when informing them of organ donation opportunities. It is also helpful for the FSC to be present during the discussion of brain death. Again, evidence shows when an FSC is present with the physicians during brain death conversations, the consent rates nearly double (63% vs. 34%). [Shafer, Teresa. In- House Coordinator Program Training Manual. (2003)]

In addition, the presence of the FSC during the brain death discussion with the family gives the FSC the opportunity to assess the family's acceptance of the brain death, which in turn aids in determining the timing for discussing donation.

An early referral to ARORA is always required to determine donor suitability as well as lay the groundwork for collaboration on the referral and eventual interaction with the family.

2. The Role of the Designated Requestor

A Designated Requestor (DR) is defined as an individual who has completed a course offered or approved by the OPO in this area – ARORA – in the methodology for informing families about tissue and eye donation. This individual needs to have a strong conviction that organ and tissue donation are loving and caring decision families make, the ability to support a family regardless of their decision and the understanding that all eligible families be allowed to make an informed decision. In other words, we hope a DR is not a person from the hospital informing families of donation opportunities because this duty has been forced on them.

The Designated Requestor's role is to ensure the integrity of the process with regard to potential tissue cases. This includes ensuring the family is **not** approached about

donation prior to a referral to ARORA. It also involves making sure the family is **not** approached about donation prior to declaration of death (cardiac death or brain death). Approaches prior to referral (APR) and approaches prior to declaration of death can jeopardize consent, may add undue stress to the family and are monitored and counted against the hospital during JCAHO or CMS audits.

The DR is trained for offering tissue donation opportunities to eligible families.

Discretion and sensitivity with respect to family dynamics, values, and beliefs of families of potential donors should be exercised at all times. Cultural issues should be explored and techniques adjusted prior to discussing donation options with a family whose cultural beliefs are different from those of the DR.

Whenever a potential ORGAN donor is identified, the DR is welcome to collaborate with ARORA personnel. OPO's around the country show collaborative approaches increase consent rates. In addition, this partnership creates a climate of complete care for the family. The primary caregiver (physician or nurse) is the best resource to answer specific questions about the care of the patient, and the FSC can provide detailed information regarding consent, organ donation and organ recovery. Collaboration between hospital and ARORA staff can improve quality of care and enhance communication with families, two important elements for increasing consent. When families are given time to understand and accept their relatives' death and are approached in a private setting by both an POP staff person and a member of the hospital staff, donation rates are 47% higher than when none of the elements are present. [Dejong, W. et.al., American Journal of Critical Care (1998)]

3. The Role of the Organ Procurement Coordinators

ARORA's Organ Procurement Coordinators are registered nurses who have professional experience in critical care or emergency/trauma nursing. The role of the Organ Procurement Coordinator is as follows:

1. Prior to written consent being obtained, the Organ Procurement Coordinators serve as a resource to the FSC, bedside nurse and physician as the focus of care changes from patient recovery to preserving organ viability.
2. After consent is obtained, two (2) Organ Procurement Coordinators arrive on site to manage the donor concerning organ perfusion and donor stability.
3. Organ Procurement Coordinators evaluate the suitability of the organs to which the family consented. Through UNOS, the Organ Procurement Coordinators begin placing those organs with transplant centers.
4. The Organ Procurement Coordinators schedule and facilitate OR times and then accompany the donor to the OR where they assist the arriving transplant teams in the recovery of the organs.

4. The Role of the Tissue Procurement Coordinators

ARORA's Tissue Procurement Coordinators are trained specialists certified in the recovery of tissue and bone. The role of the Tissue Procurement Coordinator is as follows:

1. The Tissue Procurement Coordinator is the primary contact person when the DR or hospital staff makes a tissue referral.
2. The Tissue Procurement Coordinator will determine donor suitability.
3. If the DR is unable to approach the family regarding donation, the Tissue Procurement Coordinator will approach the family for consent by telephone.

4. The Tissue Procurement Coordinator will complete the medical/social history with the family.
5. After consent is obtained, the Tissue Procurement Coordinators will arrive on site.
6. The recovery of tissues can take place in the hospital OR, a “clean” but not sterile location (for eye recovery only) or at ARORA’s off-site location.
7. The Tissue Procurement Coordinators recover all tissues for which the family has consented.

In the event the donor is an organ AND tissue donor, following the completion of the organ recovery, the Tissue Procurement Coordinators will recover the appropriate tissue for which the family specified consent.

Pre-Screening

Pre-screening patients for donation reduces the number of inappropriate approaches to families, which will help prevent the family from forming false hopes for donation when donation is not an option.

Determining the medical suitability of the patient to donate organs and tissues, in accordance with CMS regulations is the responsibility of ARORA. Being prepared with the correct information makes it easier to inform the family and offer the options for donation. This is significant because in Arkansas approximately 74% of the population is ruled out due to medical/social reasons. For this reason, it is extremely important to verify medical suitability of the potential donor as well as which tissues are suitable for donation **before** discussion donation with the family.

Pre-screening also provides information on Donor Registry status.

Once pre-screening has taken place and a potential tissue donor is identified, the DR will offer the option of donation for the appropriate tissues. The DR will be the person to discuss tissue donation with the family and relay the family’s wishes to ARORA.

Remember, if the DR is not available or unable to approach a family, ARORA is always available to offer the family tissue donation and secure consent over the telephone.

Information Needed When Reporting a Death to ARORA

ARORA’s call center, Acadian in Louisiana, will screen the initial call. The phone number is **800-727-6726**. They will request some basic information. The call will go much more quickly if the following information is ready:

Hospital phone number

Hospital name

Unit where the patient’s death occurred and name of the person reporting the death

Admission date

Patient’s name, age, sex, race, date of birth, height and weight

Brief history of this admission

Any fluids or blood products given and the amount

Was patient previously on a ventilator? For how long?

Date and time of death

If the primary caregiver is not making the initial call, it may be important for that person to be nearby for further clinical evaluation if necessary.

It is extremely important the hospital does not release the body to the funeral home while the patient is being evaluated for donation. It is preferred a call to the funeral home is made AFTER donation evaluation is complete. If the patient is a candidate for donation and the family consents, ARORA will call the funeral home and inform them of the donation and provide time frames. If the funeral home calls inquiring into the release of the body, please inform them donation evaluation is taking place and a call will be returned to them once a decision has been made. After embalming has taken place, donation is not possible and the family loses the right to follow through on their decision or carrying out their loved one's decision to donate.

Training and Re-certification

Informing the Family of their Opportunity to Donate

As a Designated Requestor, you will NOT be approaching families about **organ** donation. As stated earlier, this type of approach is always to be done in collaboration with an ARORA staff member (FSC). However, it is common for families to initiate conversation regarding organ donation. When this happens, it is best to explain to the family you will contact ARORA to come give them information and answer their questions about donation.

If the patient is neurologically injured, on the ventilator and the family initiates discussion about organ donation, the FSC will arrive on site to get an assessment from the medical staff regarding the patient's prognosis. Following this, the FSC and the hospital staff may then talk with the family about the potential for organ /tissue donation and answer any questions the family may have about donation.

As a DR, you will be in a position to inform families regarding tissue and eye donation. The following information will be helpful as you prepare to talk with families.

It may seem insensitive to discuss donation with families at such a difficult time. However, many donor families have stated if donation is offered in a caring and sensitive manner, they are often relieved someone has reminded them of their opportunity. Donor families also state there is nothing worse than the loved one's death: therefore discussing tissue donation does not add to their distress nor does it complicate their grief. Actually, offering the option of donation is giving some control back to the family. Since admission to the hospital, the medical staff has determined many decisions about their loved-one's care. Making a decision about donation often empowers the family.

In addition, if the family is not given accurate and complete information regarding donation options and if they are not fully informed of the donation and recovery process, then their decision is not an informed one.

Designated Requestor Training Objectives

The goals of the DR training are as follows:

1. Understand the elements in establishing successful donation conversations.
2. Understand the structure and steps of a "typical" donation conversation.
3. Identifying core concerns and responding to family's decisions.

4. Relaying the information to ARORA for adequate consent.
5. Role Playing

1. The Elements of the conversation

The elements in establishing successful donation conversations include determining the legal next-of-kin, offering hospitality, allowing for decoupling, selecting an appropriate location to present donation information to the family, the DR's posture and body language and picking up discomfort cues from the family.

Legal Next-of-Kin

The Legal Next-of-Kin hierarchy, as determined by the Uniform Anatomical Gift Act of 1968 is as follows:

1. Spouse
2. Adult Child
3. Parent
4. Adult Siblings
5. Grandparent
6. Legal Guardian

The legal next-of-kin must give final consent for donation. The Donor Registry in Arkansas is very successful and approximately 80% of licensed drivers have indicated their desire to be an organ or tissue donor. However, the law is written in Arkansas to require the consent of the legal next of kin. In some cases it is difficult to determine the legal-next-of-kin. They may not be at the hospital or even in the state. No one other than the legal next-of-kin can authorize donation. If the legal next-of-kin is not at the hospital, the DR needs to get a phone number to reach them. A phone approach and consent must be recorded and will need to be completed by ARORA staff.

Hospitality

Caregivers and DR must anticipate the family's needs and offer the family hospitality, such as a beverage, a tissue, a blanket, a cell phone, etc. Many times the family doesn't know what to do next or what to ask for. Asking about family photographs that may be in the patient's room, requesting to see a photograph or inviting stories about the loved one is a way to connect with the family and build some rapport with them. The goal is the family feels cared for by hospital staff.

Decoupling

After the physician has informed the family their loved one has died, it is important to allow for time to pass prior to informing the family of donation opportunities. This process is called **decoupling**. The length of time to allow for decoupling varies by family and by situation. Decoupling usually happens quicker in the cardiac death patients than it does with brain dead patients.

Location

Selecting an appropriate location to present donation information to the family is very important. Privacy increases consent rates and allows families the opportunity to ask questions to make an informed decision. A conference room or private office near the patient's room is the first choice of location. An empty patient room, ICU or ER workroom will also provide privacy. Because the chapel and cafeteria are public places, they are not to be used if it can be avoided. Crowded waiting rooms and hallways are to be avoided. The worst location to discuss tissue donation with the family is at the

patient's bedside. This is an emotionally charged area and may not allow the family the opportunity to think clearly.

Posture

The DR's body language and posture are very important when speaking with families about donation. Information is communicated by words (7 – 10%), by tone of voice (23%) and by body language (70%). Being aware of body language assures unintended or mixed messages are not being given to the family. Also, observing the family member's body language may provide additional information. The DR's body language needs to convey this message, "I am completely comfortable here talking with you and I have all the time in the world for you to make your decision".

- Offer a handshake if that is what is comfortable for you. Then, refrain from touching family members unless it is invited. Mirror their cues.
- Relaxed muscles in the face, shoulders and arms. Arms down at your sides with palms slightly turned out when standing. Avoid covering your chest with paperwork or folders.
- Slow movements. The family can't process information at a normal rate. They are grieving or may be in shock. Their time is altered. Walk slower, speak slower, movements should be slower, smaller and closer to the body. When seated, do not cross arms or legs, don't clasp hands or put them in your pockets.
- Same plane positioning. Sit when they sit, stand when they stand. Mirror their cues.
- Slight tilt back when seated. Leaning forward in the chair increases the feeling of threat or persuasion. As they become comfortable with the conversation, they may lean forward when asking questions. Again, mirror their cues.
- Reduce direct eye contact. Look up and down, using intermittent eye contact. A hard, continuous focus may feel threatening and aggressive.
- Avoid over focusing on the men in the room, the tallest man in the room and those who agree with donation. The legal-next-of-kin will make the final decision. Be sure the conversation is inclusive of the legal-next-of-kin and the "decision maker" of the family. [Verbal, Worth & Verbal (2001)]

Discomfort Cues

Observe the family's body language and look for discomfort cues from the family when the donation discussion is not going well or as expected.

- Folded arms across the chest may or may not be a discomfort cue. It may be the person is cold, it may be a habit or they are trying to contain their grief. Folding arms across the chest becomes meaningful if it happens during the donation conversation.
- "Flanking" is turning away from the speaker. Flanking can be done when standing or seated.
- Eye or eyebrow rubbing may indicate the person is a visual thinker and has just made a mental picture of the donation offer. Rubbing the eyes may mean the person is trying to erase the mental picture.

- Nose rubbing, when not associated with crying, may be a sign the person has doubt or doesn't believe what is being said about donation.
- Picking lint off clothes or picking nails usually indicates the person is seriously listening and considering what is being said and offered but has made a decision they are comfortable with at this time. [Verbal, Worth & Verbal (2002)]

2. Steps and Structure of a “Typical “donation conversation

Discussing the options of tissue donation is one aspect in the process of caring for the family. There is no single blueprint that works for all families. The ability to care for a family and inform them of their donation options requires you, as a Designated Requestor, are comfortable in your role to assess when the family should be approached, as well as being capable of introducing donation and articulating clearly how the process works and the benefits to recipients. Thoughtfully letting the family know which tissues are suitable for donation and the positive effects of donation, will give the family the information they need in order to make an informed decision.

Bridge to Donation conversation

Once the family has started to discuss funeral plans or there is evidence in their conversation that they have begun the decoupling process, it may be time to bridge the conversation to donation. A good bridge or lead-in is as follows:

Mrs. Smith, another decision you will need to make is what you want to do about donation for transplantation.”

Script for Donation (Donor not listed in the Registry)

“Due to the circumstances of your son’s death, you have the opportunity to donate corneas and other tissues for transplant or research. I would like to share some information about what tissue can be donated and how it helps other people. There is no cost to your family for this gift you are sharing. It shouldn’t affect your funeral plans. You don’t have to decide right now, but I want you to have all the information you need to make a decision.”

Script for Donation (Donor IS listed in the Registry)

“Due to the circumstances of your son’s death and because he was in the donor registry, we would like to help you carry out your son’s wishes to donate tissue for transplant or research. I would like to share some information the tissues that can be donated and how it helps other people. There is no cost to your family for this gift you are sharing. It shouldn’t affect your funeral plans.”

To be certain the family is making an informed decision, look for a strong consent or a strong refusal of donation. If their refusal is weak, they may have some concerns or questions they have not verbalized. Ask the legal NOK or the family spokesperson a clarifying question such as:

“Are you saying you object to donation in general or are you saying you aren’t interested in donating the eyes specifically?”

If their refusal is strong, validate their decision with a statement such as:
“Donation is not the right decision for every family. I think you have made the right decision for your family.”

3. Identifying core concerns and responding to family’s decisions

It is important to understand when to continue to give the family information and when to ask questions.

Ask the family questions when:

- They express a concern
- You are checking for understanding
- You don’t know what else to do
- You are losing control of the conversation
- They are mad
- They start to repeat themselves

Provide information when:

- You explain the cause of death
- After you introduce donation
- After you have understood their concern
- You explain the continuation of the consent process with ARORA staff

4. Relaying the information to ARORA for adequate consent

When the DR obtains verbal consent for tissue donation, the ARORA staff needs to be contacted to complete the consent process and obtain the medical/social history. ARORA will review the disclosures and clarify any questions or address any concerns.

The DR will explain confidentiality of the donation. All information concerning organ and tissue donation is kept confidential. The donor family will receive a letter after donation providing general information about tissues recovered. Information about transplanted tissue is not always available. Families seeking more specific information about transplanted tissue will need to contact ARORA staff.

Tissue recovery will take place at the ARORA off-site facility if the death occurs within a 125 mile radius of Little Rock, unless the family objects to moving the donor or time constraints exist. Donors in hospitals outside the 125 mile radius will be recovered in the hospital where the death occurs.

There is no cost to the family for tissue donation. All costs incurred by donation are paid for by ARORA. Funeral expenses are still the responsibility of the family, as with any other death.

5. Role Playing

- Approach the parents of a teenage boy killed in a car accident who is listed in the donor registry.
- Approach the husband of a woman who died of a heart attack who is not listed in the donor registry.
- Approach the wife of a man who died in an accident at his job who is not listed in the donor registry.

- Approach the daughter of a woman who died of metastasis cancer who is in the donor registry.