

# ARORA

Arkansas Regional Organ Recovery Agency

Presents:



Designated Requestor  
Workshop



# About ARORA

- Established in 1987 by Dr. Wagner a Pediatric Kidney Transplant/General Surgeon at Arkansas Children's Hospital in Little Rock
- Federally Funded Not For Profit Organization
- Located in:
  - Little Rock, Arkansas
  - Fayetteville, Arkansas



# Milestones

- Researchers began experimenting with organ transplantation on animals and humans in the 18<sup>th</sup> century. Over the years, scientists experienced many failures, by the mid-20<sup>th</sup> century, successful organ transplants had been performed.



# Milestones

- In the last 20 years, important medical breakthroughs such as tissue typing and immunosuppressant drugs, such as cyclosporine, have allowed for a larger number of organ transplants and a longer survival rate for transplant recipients.
- 1954 First successful kidney transplant in Boston, Massachusetts



# Critical Need throughout US

## January – October 2005

- 90,000+ patients on transplant waiting list
- 26,984 transplants performed in 2005
- 12,106 donors in 2005
  - Cadaveric – 6,338
  - Living – 5,768
- 74 people receive a life-saving transplant each day, while still another 17 die while waiting



# Critical Need – Arkansas 2005

- 11,806 Deaths in hospitals reported to ARORA
- 134 Eligible to be Organ Donors  
*(a little over 1% of all reported deaths)*
- 85 Families consent to donation  
*(almost 63% of all eligible)*
- 70 Recovered donors  
*(donated 242 organs)*



# 10 Year Trend

Year	Recovered Donors	Waiting List
1992	4,519	19,000
2002	6,184	68,000



## Alexa's story

- Monica Kersting, Alexa's mother, is speaking to the crowd at the National Breakthrough Collaborative for Organ Donation in Birmingham, AL in January, 2005.

# Federal Regulations Impacting Donation

- Legislative overview
- CMS Conditions of participation
- JCAHO standards





# Government Regulation of Donation and Transplantation

- Many legislative initiatives have taken place in an effort to facilitate organ and tissue donation and transplantation.
- The evolution of law and the development of legal precedent has followed the emergence of transplantation as an accepted therapy for end-stage organ failure. Replacement of missing or diseased bone, skin, and other tissues has also become standard, non-experimental therapy.



June 22, 1998

## Conditions of Participation

- Requires all hospitals participating in Medicare and Medicaid to:
  - Notify OPO in a timely manner of all deaths or imminent deaths.
  - Incorporate an agreement with at least one organ, tissue and eye bank.
  - The OPO will determine medical suitability for organ, tissue and eye donation .



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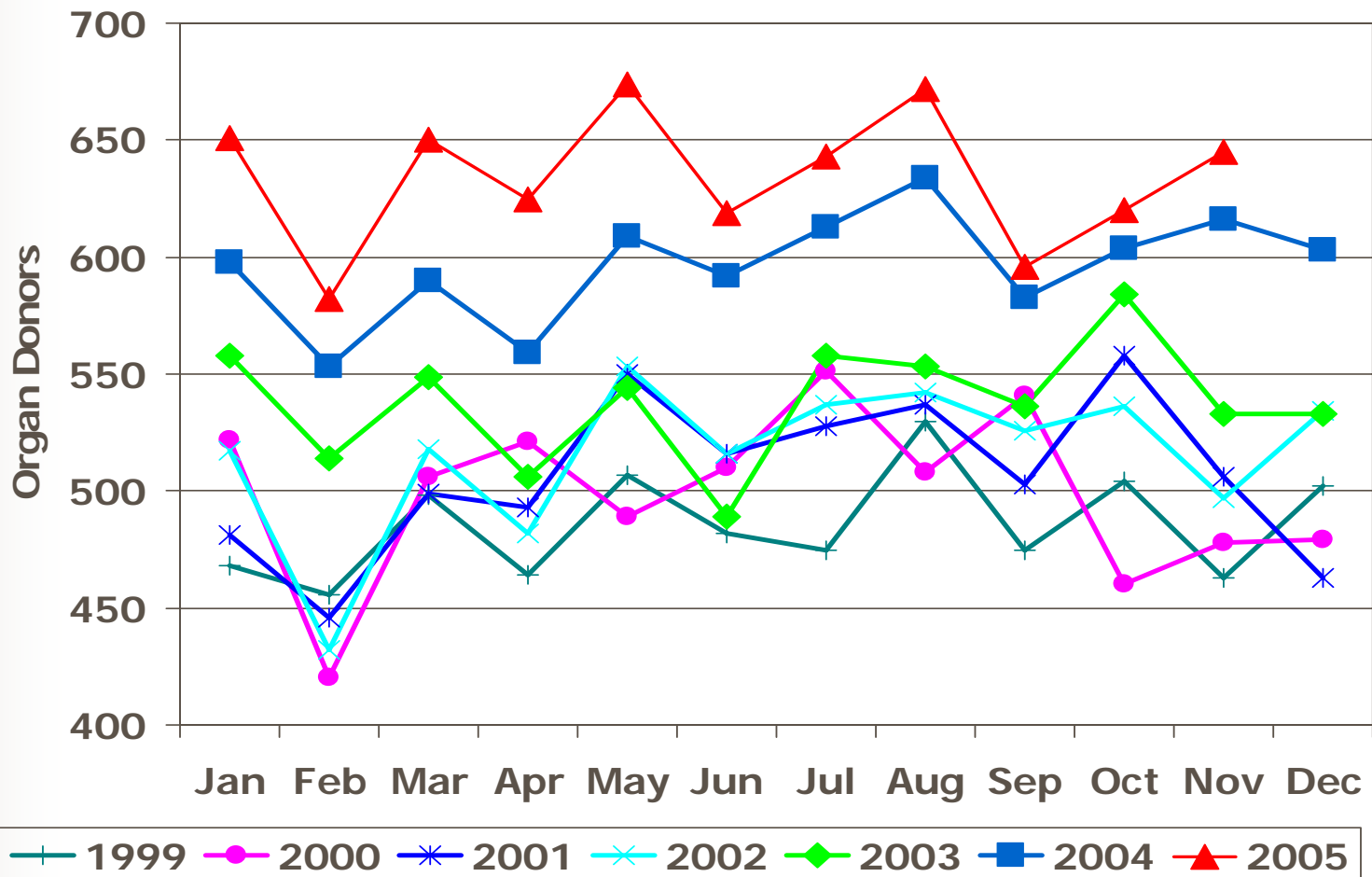
- Ensure that all *appropriate* families are offered the option of donation.
- Donation options must be given to the family by requestors from the OPO or designated requestors trained by the OPO.
- Hospitals works cooperatively with OPO, tissue, and eye bank to provide donation education, review death records, and maintain donors until organs are tested and placed.



# National Breakthrough Collaborative on Organ Donation

- Started in April of 2003 by Secretary Tommy Thompson to address the severe shortage of organs available for transplant.
- Focus National attention on donation as the biggest public health care crisis.
- 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.

# Unprecedented Month-by Month Increases in Number of Organ Donors





# JCAHO Standards July, 2005

- Hospitals will be responsible for reporting and maintaining the following data:
  - Routine referral compliance
  - Timely referral rate
  - Consent rate
  - Conversion rate
  - APR rate



# Administration of the Allocation Process

- United Network for Organ Sharing (UNOS)
  - Located in Richmond, VA.
  - Responsible for developing organ allocation resources and maintaining a national waiting list.
  - Assure listing occurs in a fair and ethical manner regardless of race, gender, religion, socioeconomic status, or personal behavior status.
  - Facilitates organ matching and allocation process.



## Allocation Process – Listing with UNOS

- The process begins with an in depth medical evaluation and interview process conducted by a physician affiliated with a transplant facility.
- This information is then relayed to UNOS and entered into the national data base.
- Listing is conducted on a points system. The more points you receive the higher up on the waiting list your name will appear.
- Patients can be listed on more than one transplant center waiting list at a time.



# Listing Criteria

- Based on points system:
  - Urgency status based on:
    - Medical status
    - Time waiting
    - Regional review boards
    - Pediatric consideration

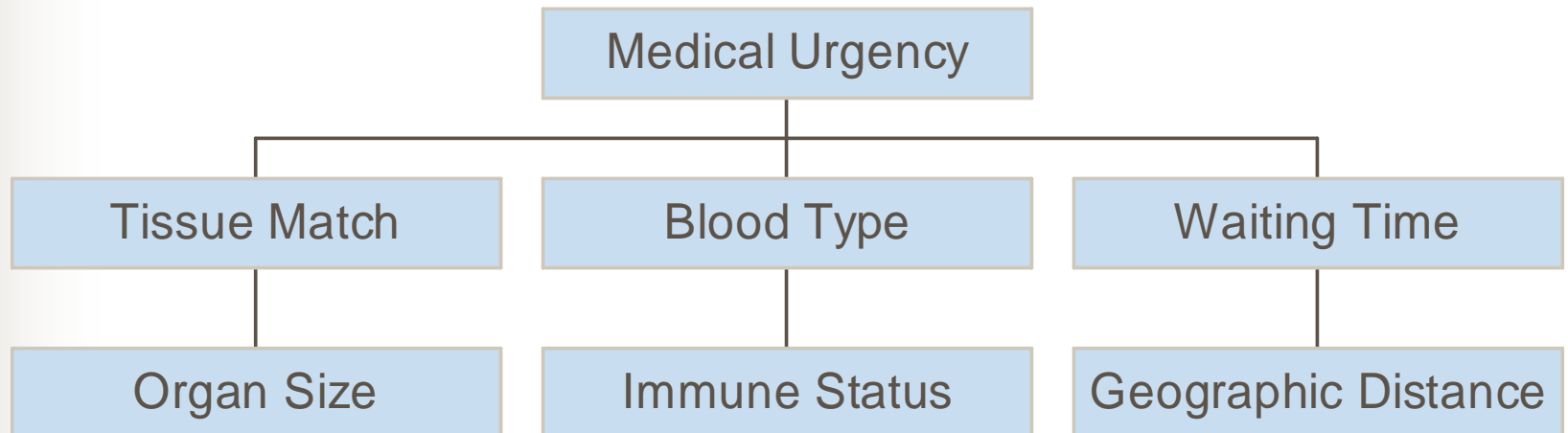
Urgency status for Heart: Status 1A, 1B, 2

Urgency status for Liver: Status 1, 2A, 2B, 3

Kidney and pancreas also considers tissue typing

# The Perfect Match

## Organ Matching Criteria



# Local vs. National



- Abdominal organs are allocated locally, regionally, and then nationally
- Thoracic organs are allocated
  - Locally
  - Transplant centers within 500 miles of the donor
  - 500-1000-mile zone
  - Hospitals greater than 1000 miles from the donor hospital.



# Two Types of Donation

The circumstances of a person's death determines the type of donation potential, organ or tissue.

Hospital Designated Requestors approach families regarding Tissue donation.



# The Organ / Tissue Dichotomy

- Imminent Death Referral
- Brain Death
- Organ Donor
- OPO requestor/Team request
- Post Death Reporting
- Cardiac Death
- Tissue Donor
- Hospital Designated Requestor / Phone request



# The Organ / Tissue Dichotomy

Imminent Death Referral  
(Early Referral)

vs.

Post Death Report

# Imminent Death Referrals....



- Call center is Acadian
- Determine donor suitability for potential organ donation
- Potential donor information relayed to ARORA
- FSC/IHC comes on site when appropriate



# Imminent Death Referrals.....

- Early referrals are necessary to ensure specific medical procedures are implemented to preserve organs for transplantation when a patient's life can not be saved.



# Imminent Death Referral..... For Potential Organ Donation

- Within one hour of patient meeting Clinical Triggers
  - Brain injury
  - Mechanical ventilator support
  - GCS (Glasgow Coma Score)  $\leq 5$

# Post Death Reporting....

- Call center is Acadian
- Determine donor suitability for potential tissue donation
- Potential donor information relayed to ARORA Tissue Coordinator
- Approach to families is made on the phone or by hospital Designated Requestor





# Referral Pre-Screening

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



# Referral Pre-screening

- Pre-screening and donor suitability are done by the OPO in accordance with CMS regulations.
- Pre-screening provides the requestor with accurate and timely information. Being prepared with the right information makes it easier to approach the family and offer the option of donation.
- Pre-screening provides information on donor registry status.



# The Organ / Tissue Dichotomy

Brain Death

VS.

Cardiac Death



# Brain Death

- 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.



# Brain Death

- Patient maintained on mechanical support with heart beating.
- Absence of brain stem reflexes:
  - No cough, gag, cornea, no oculocephalic reflexes (doll's eyes), no vestibulo-ocular (cold caloric)



# Confirmatory Testing for Brain Death

- EEG
- Cerebral Blood Flow Study
- Cerebral Angiography
- Apnea Exam
- \*Policy on Brain Death declaration varies by hospital



# Cardiac Death

- Total cessation of cardiac and respiratory function.



# The Organ / Tissue Dichotomy

Organ Donation

vs.

Tissue Donation



# Brain Death

- Potential Organ and Tissue Donors
  - Heart
  - Liver
  - Lungs
  - Pancreas
  - Intestine
  - Kidneys
  - Tissue



# Brain Death/Organ Donation

- FSC/Team obtains consent from family
- Organ Procurement Coordinators on site
- Donor Management phase & labs
- Organ allocation
- Transplant surgeons and teams arrive
- Donor transferred to OR on the vent for organ recovery



# Cardiac Death

- Potential Tissue Donors
  - Bone
  - Soft Tissue
  - Skin
  - Heart for Valves
  - Veins
  - Eyes for Corneas



# Cardiac Death/Tissue Donation

- Designated Requestor or Call center obtains consent from family
- Tissue Procurement Coordinators on site
- Corneal tissue recovered within 6 hours of death.
- Have up to 24 hours to recover other tissue if body has been refrigerated and 15 hours if the body has not been refrigerated.
- Recovery may occur in the OR, other designated area or ARORA off-site facility.



# The Organ / Tissue Dichotomy

OPO Requestor/Team request

vs.

Hospital Designated Requestor / Phone  
request



# OPO Request

## Role of Family Services Counselor (FSC)

- FSC provides early family intervention and support of potential organ donors.
- FSC does not mention donation until patient is declared brain dead - unless family mentions organ and tissue donation.
- Focus is family care and hospital staff support.



# OPO Requestor/Team request

- The FSC and the hospital staff (doctors, nurses, chaplains or social workers) may have a team huddle and approach the family about donation together. This approach is used most often at Arkansas Children's Hospital.



# Designated Requestor Approach for Tissue Donation



# Critical Need – Arkansas 2005

- 11,806 Deaths in hospitals reported to ARORA
- 1,552 Eligible to be Tissue Donors  
*(almost 8% of all reported deaths)*
- 185 Families consent to donation  
*(little over 8% of all eligible)*



# Thanks to requestors.....

- People receive bone grafts
- People have damaged heart valves replaced
- Athletes have sports injuries repaired
- Burn victims receive skin grafts
- Dialysis patients receive new access grafts
- People have their eyesight restored



# A Family Member's perception of the Designated Requestor

- A donor father commented:

“You are a visible representation of an invisible God who is present in the moment with the person experiencing the trauma.”

It is not possible to over-estimate the difference a caring, skilled professional can make at this time.



# A Recipient's perception of the Designated Requestor

- “Yours is the only voice I have.”
- “Approach the situation with the belief that donation will change my life.”
- “I expect you to be pro-donation, not neutral.”

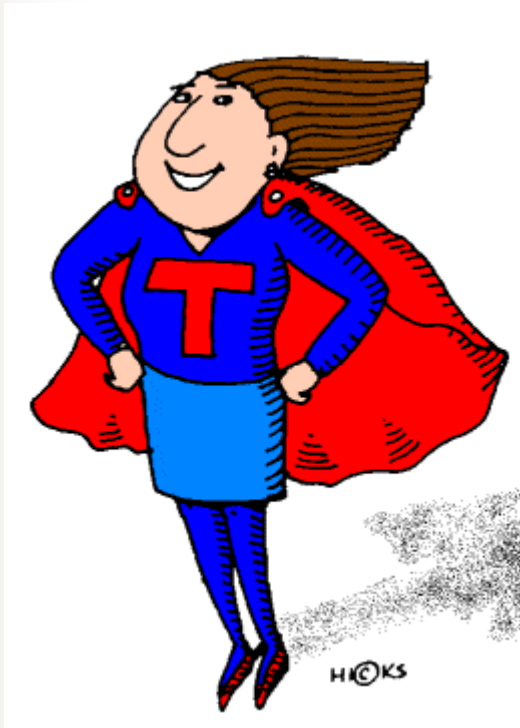
1,000,000 people are counting on YOU!

# Negative Image of Requesting



- Requesting for donation is  
” a bother to the family.
- Requestors “prey” on a family at a vulnerable time.
- The request for donation will upset the family.
- This is something I have to do.

# Positive Image of Requesting



- Donation empowers the family.
- Donation “gives” something to the family.
- Donation can add meaning to a tragedy.
- Donation saves lives!



# Objectives of DR Training

- Understand the elements in establishing successful donation conversations.
- Understand the structure and steps of a “typical” donation conversation and of responding to families decisions.
- Relay the information for adequate consent.
- Practice questioning techniques to identify core concerns and to provide reassurance and comfort.




# Elements of the conversation

- Determine Legal-Next-of-kin
- Hospitality
- Decoupling
- Location
- Posture
- Discomfort Cues



# Legal Next-of-kin as determined by the Uniform Anatomical Gift Act of 1968

- Spouse
- Adult child
- Parent
- Adult siblings
- Grandparent
- Legal Guardian



Legal Next-of-kin is the only person who can give consent. If the Legal Next-of-kin is not at the hospital, the DR can NOT offer the option of donation to the family.

The DR needs to get a good telephone number for the NOK and let the family know they will be contacted at home for some routine information.

Do not mention donation at this time.



# Hospitality

Make sure the families immediate needs are met. Do they need:

a tissue?

a blanket?

something to drink?

you to call someone?

Caregivers must anticipate needs. Families often don't know what to do or what to ask for.



# Decoupling

- The process families go through to accept the death of a loved one.
- Donation conversation should not take place until the family has had some time to begin the process of decoupling.
- Decoupling time varies by family and situation.



# Location

Privacy increases consent rates.

1<sup>st</sup> choice: Conference room or private office  
not far from the patient.

2<sup>nd</sup> choice: Empty patient room or secluded  
ICU or ER work area

3<sup>rd</sup> choice: Chapel or cafeteria nook

Avoid: Crowded waiting room and hallways

**WORST OPTION:** In room with the patient



# Posture

- Information is communicated by words, tone of voice and body language.
  - **23%** by tone of voice
  - **7 – 10%** by words
  - **70%** by **BODY LANGUAGE**



# Posture

- Handshake, refrain from other touching
- Relaxed muscles
- Arms down, palms out
- Slow movement
- Same plane positioning
- Slight back tilt
- Reduce direct eye contact



**AVOID** over-focusing on:

the men

the tallest man

those who agree with you



# Body Language Goal

“I am completely comfortable here talking with you and have all the time in the world for you to make your decision”




# Look for Discomfort Cues

- ⌘ Arms across the chest
- Flanking
- Eye or eyebrow rubbing
- Nose rubbing
- Lint picking
- Nail picking



# Structure and steps of a “typical” donation conversation



**Avoid questions that have a “yes or no” answer..... such as**

Would you like to talk to someone about donation?

Have you ever talked about donation?

Did he ever mention he wanted to be a donor?



Assess their understanding of the situation.

Do they understand their loved one is dead?

Do they have questions about what they have been told by the medical staff?

Are they in denial?

When they understand, **ASK ABOUT FUNERAL PLANS.**



# Bridge to approach

After funeral plans have been discussed.....

*“Mr. Estes, another decision you will need to make is what you want to do about donation for transplantation.”*



# Donation Script

## (Not in the Donor 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 effect your funeral plans. You don’t have to decide right now, but we want you to have all the information you need to make a decision.*”

Remember to speak slowly.

VWV 2005



# Donation Script (In the Donor 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 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 effect your funeral plans.*”

Remember to speak slowly.



# Eyes for Corneas

- Corneas must be recovered within 6 hours for death.
- The entire eye is removed and the cornea, the clear front covering of the eye, is recovered.
- Corneal blindness is like looking through frosted glass and can be completely debilitating.
- Corneal transplants are very successful.
- Prosthesis and eye cap are implanted and eye recovery is not usually detected at an open casket funeral.



# Heart for Valves

- While the complete heart can't be transplanted due to the circumstances of the death, the heart valves can be recovered and transplanted.
- Heart valve transplants in children grow with the child, requiring fewer surgeries as they grow to adulthood.
- Mechanical heart valves require the recipient to take blood thinners for the rest of his life.



# Skin

- Skin is recovered, processed and used at the burn unit at AR Children's Hospital.
- Temporary skin transplants can be life saving. The transplant helps keep the burn patient from losing too much fluid and helps fight life-threatening infections.
- Skin is recovered from the back of the body and the backs of the thighs.
- Skin recovery can not be detected during an open casket funeral.



# Bone, Veins and Connective Tissue

- Bone grafts are used in many orthopedic and spinal surgery procedures.
- Bone grafts can prevent amputations in people with bone cancer.
- Veins are recovered in men only.
- Veins are used in heart bypass & vascular surgery.
- Connective tissue is used in many surgical reconstruction procedures.



# Benefits of Research

Transplantation is the #1 priority in donation. Sometimes tissue is not medically suitable for transplantation, but is invaluable in research.

Research can help 100 or 1,000 or 10,000 people.



## MTF video

- Amazing video of a mother's situation and reaction following her son's fatal accident and the family's decision to donate tissue.



# Refusal Discussion

Look for a strong consent or a strong refusal.

- If refusal is weak, ask a clarifying question.

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

- If refusal is strong, validate their decision.

*“Donation is not the right decision for every family. I think you have made the right decision for your family.”*

VWV 2002



# Identify family's core concerns

Ask 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



# Identify family's core concerns

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



## Relay the information for adequate consent.

- Let them know someone from ARORA will be contacting them to complete the consent process.
- Let them know ARORA will need some medical history information.
- Explain confidentiality of the donation.
- Explain tissue recovery will take place at the hospital or designated location in LR.
- Remind them there is no cost to the family.



# Role play

- 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.