

## Healing Through Giving

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## Midwest Transplant Network Services

- Organ and Tissue Procurement Organization



☆ Headquarters  
☆ Satellite Offices

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## The Critical Organ Shortage

The tragic truth is, despite continuing advances in medicine and technology, the demand for organs drastically outstrips the number of organ donors.  
(www.UNOS.org)



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## Why is donation important?

- Every 16 minutes another name is added to the national waiting list
- Eighteen people will die waiting for an organ transplant every 24 hours
- 750,000 people could benefit from a tissue transplant each year



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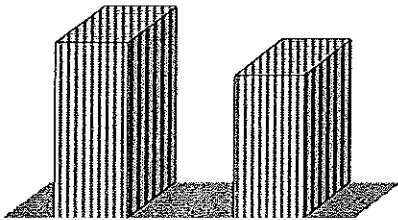
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## Americans support organ donation



\*The Gallup Organization 1993

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## Never Say Never...

80 y/o donor liver!



- 10 65+ y/o donor lungs transplanted in 2007
- Youngest heart transplant recipient?
- 96 y/o liver donor (NYODN)
- 1 65+ y/o donor heart transplanted in 2007
- 103 y/o cornea donor
- Longest kidney waitlist time (uninterrupted)?

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### Huh?

- 54 y/o woman
- Liver transplant for autoimmune hepatitis
- Intracranial hemorrhage post-transplant
- R/O for liver and kidney donation



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### Common Injuries of Potential Organ Donors

- Acute Neurological Trauma
- Intracranial Hemorrhage
- Drug Overdose
- Primary Brain Tumor
- Asphyxiation; Hanging; Drowning
- Cardiovascular event
- SIDS
- Shaken baby syndrome

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### When Donation Occurs

- Two types of death = two types of organ donation

Cardiac Death

Brain Death

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### Donation After Brain Death

- Severe neuro insult occurs
- Pt progresses to brain death
- Brain death testing
- Pronouncement of brain death by physician
- MD discusses brain death with family
- INITIAL discussion of the opportunity for donation
- Pt transported to the OR w/ circulation intact due to artificial support
- Circulation stops in the OR

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### Donation After Cardiac Death (DCD)

- Severe neuro insult occurs
- All life-saving measures exhausted
- Grave prognosis shared with family
- Family decision to remove artificial support
- MTN evaluation for suitability
- INITIAL discussion of the opportunity for donation
- Artificial support removed with family present
- Declaration of cardiac death by physician
- Pt transported to OR in full cardiac arrest

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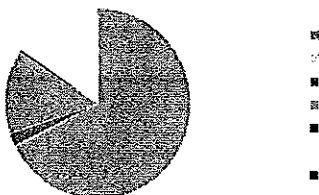
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### 2007 Deceased Donors By Ethnicity



www.unos.org, 2007 data

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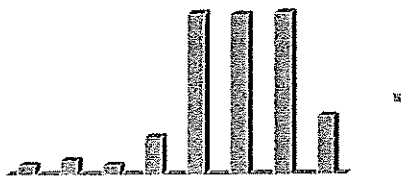
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### 2007 Deceased Donors By Age



www.UCOP.org, 2007 data

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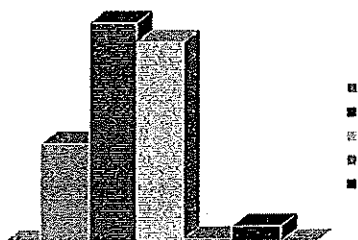
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### 2007 Deceased Donors by COD



www.UCOP.org, 2007 data

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### Why Do Families Donate?

- Siminoff, et al, 2007: study of 420 donor families
  - Altruism (78%)
  - Knowledge of wishes (75%)
    - Signed donor card
    - Explicit conversation
    - Confidence that donation would be patient's preference
  - Family had positive attitude about donation (62%)
  - Coping strategy (32%)
  - Belief that the patient no longer needed his/her organs (22%)

*But only 10% gave one reason for donating!*

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### Why Do Families Decline?

• **Reasons cited**

- Belief that the patient would not have wanted to donate (51%)
- "Family stamina" (44%)
- Disfigurement concerns and/or belief that donation would prevent viewing at services (43%)
- Mistrust (25%)
- Incorrect determination by family/team that pt not medically eligible (19%)
- Family disagreement (14%)

Siminoff, et al, 2007

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### Frequent Family Concerns

- Will my loved-one feel pain?
- Will the donation cost anything?
- Will the donation effect or delay the funeral arrangements?
- What about my religion?
- Will I get to know about the recipients?

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### Automatic Rule-Outs

- HIV positive
- Hx of melanoma
- Most active cancers

*Never Say Never*

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### Organs That Can Be Donated

- Heart
- Lung
- Liver
- Kidneys
- Pancreas
- Small Intestines

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### Organ Allocation

- Blood type
- Height & weight
- Status
- HLA matching
  - Kidney
  - Pancreas
- Length of time on list
- Geography
  - Local
  - Regional
  - National
  - Canada
- Directed Donation

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### Optimal Preservation Times

- Heart 4-6 Hrs
- Lung 4-6 Hrs
- Pancreas 12 Hrs
- Liver 12-24 Hrs
- Kidney 24-48 Hrs
- Intestine 6-12 Hrs

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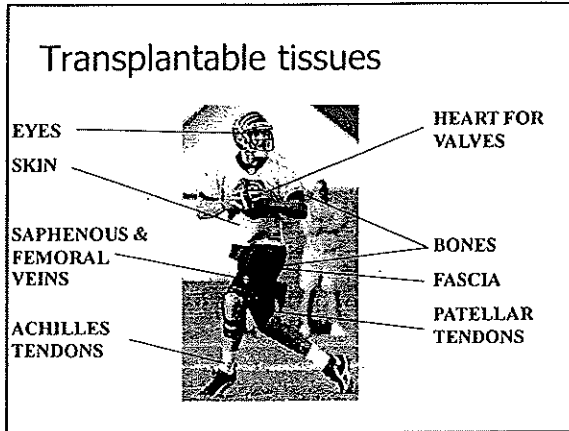
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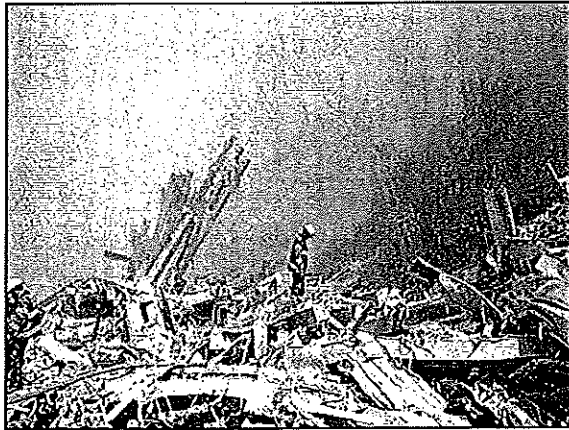
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**THE END IS THE BEGINNING**

*"What we call the beginning is often the end.  
And to make an end is to make a beginning.  
The end is where we start from."*

T.S. Elliot

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### Initial Outcome Follow-Up

- Within 15 working days
- Organ donors – age, sex, region, illness, outlook
- Tissue donors – what was recovered and how tissue is utilized
- Eye – age, sex and region if transplanted

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### Additional resources

- *"For Those Who Give & Grieve"* booklet
- *"To Remember Me"* poem
- *"Serenity"* newsletter
- MTN Aftercare Services
- Billing information

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### Aftercare Follow-up

- 3 month card
  - Thinking of you card from all staff
  - *The Next Place* to MTF families
- 6 month letter
  - Grief issues, meeting reminder
  - *"Writing to Transplant Recipients"* for organ families
- 12 month letter
  - Grief issues, meeting reminder
- 24 month letter
  - End of formal aftercare
  - Aftercare can continue at family's request

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**Follow-up Information Requests**

- When available – within 15 working days

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**Communication between donor family and recipients**

- Option for organ and eye families; in some cases tissue
- Work in partnership with other OPO's and transplant centers to facilitate communication

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**MTN Communication Policy**

- Anonymous communication for one year following donation
- Non-anonymous – donor families and recipients can exchange contact information when:
  - Each has written to the other at least one time anonymously
  - It has been at least one year post-donation
  - Both have signed release and consent forms

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### ***Serenity* Newsletter**

- Debuted in January 2007
- Quarterly publication
- Currently distributed to 2800 families
- Contents
  - Notification of upcoming events including support group meetings and special events
  - Feature stories

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### **Quarterly Support Group Meetings**

- Meetings are held throughout MTN service area
  - Kansas City
  - Wichita
  - Columbia
  - Joplin
  - Topeka
  - St. Joseph (new group in 2009)

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### **"Gift of Life" Services**

- Recognition of donors and their families
- Kansas City - December
- Wichita - April

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### MTN Donor Memorial Quilt

- Began in 2000
- Over 350 families have created a quilt square in memory of their loved one
- 8 completed quilts
- Quilt pinning
- Website
  - View by quilt or square
  - Search by name

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### Website

- Visit MTN website at [www.mwtn.org](http://www.mwtn.org)
- Enroll in state-wide donor registry

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### Donate Life Month Activities

- Hospital and community events
  - Tree plantings
  - Memorial ceremonies
  - Donor awareness activities
  - Mayoral/gubernatorial proclamation signings
  - Educational seminars
  - Donor registry booths
  - 10k Run for Life

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### Annual Summer Event

- Kansas City and Wichita
  - Royals
  - T-Bones
  - Wranglers



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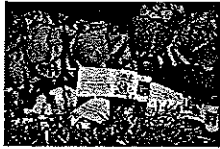
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### Tournament of Roses Parade



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### Donor Family Follow-up Surveys

- Began 9/07
- "Has MTN support been of value to the family?"
  - 95% positive response from donor families
- "Would you support donation for family & friends?"
  - 90% positive response from donor families
  - 6% "maybe" response from donor families

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