Transplant Donation
Global Leadership Symposium
Family Authorization & Donor Registry Models

Howard M. Nathan, President and CEO, Gift of Life Donor Program
Gift of Life Donor Program
Best Demonstrated Practices

- **OPO Referral Trigger**: ‘Refer all vent-dependent patients with a non-recoverable neurological injury’
- **OPO Commitment**: Immediate on-site response to evaluate every organ donor referral
- **Hospital - OPO team approach**: to clinical management & family centered care
- **Strong OPO emphasis** on
  - Consistency in clinical practice
  - ‘Timely referral’
  - ‘Effective requestors’
  - Family empowerment
- **Routine open dialogue** w/care team; reinforcing environment of joint accountability for outcomes
Compassionate End of Life Care and Organ Donation should not be viewed as a Conflict of Interest…

…but rather a Confluence of Interests along the Care Continuum
Sustaining Hospital Relationships

Hospital Development Messages Promote Collaboration

TRUST

Experience with OPO in Clinical Setting
Interactive Training Models to Discuss Brain Death and Introduce OPO Coordinator For Residents and Physicians
Training Goals

Provide tools and resources to effectively communicate with grieving families in a concise and clear manner that:

– Conveys compassion
– Demonstrates your expertise
– Promotes family understanding of grave prognosis and/or brain death
– Guides the family in their decision making
Methods

Didactic

Surgical Resident Participant

Simulations

Training Conducted At OPO or Simlab

Tool

Ten Components of Explaining Brain Death

1. Assess Staff/Family/Situation Dynamics & Design Appropriate Communication Plan
2. Provide small amounts of ‘up-to-date’ information
3. Minimize the number of staff who talk to families about brain death
4. Choose words carefully
5. Simple language vs. clinical language
6. Use the word “dead”
7. Provide the “date/time of death”
8. Use visual aids (CT, x-rays etc.)
9. Provide family w/opportunity to observe neuro exam and give them time to ask questions
10. Check for family understanding

Don’t talk to patient once death is declared
Use “active listening”, parroting and paraphrasing
Recognize their understanding may require repeat and multiple explanations
<table>
<thead>
<tr>
<th>Item #</th>
<th>YES</th>
<th>NO</th>
<th>Score Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>O</td>
<td>O</td>
<td>Avoids suggestions of “hope” for recovery and possibility of “miracle”.</td>
</tr>
<tr>
<td>2.</td>
<td>O</td>
<td>O</td>
<td>Encourages family to ask questions.</td>
</tr>
<tr>
<td>3.</td>
<td>O</td>
<td>O</td>
<td>Provides the date and/or time of death.</td>
</tr>
<tr>
<td>4.</td>
<td>O</td>
<td>O</td>
<td>Uses simple words and phrases to explain clinical terms.</td>
</tr>
<tr>
<td>5.</td>
<td>O</td>
<td>O</td>
<td>Uses the word “dead”.</td>
</tr>
<tr>
<td>6.</td>
<td>O</td>
<td>O</td>
<td>Uses visual aids (CT, x-rays, CBF) appropriately.</td>
</tr>
<tr>
<td>7.</td>
<td>O</td>
<td>O</td>
<td>Explains findings and/or components of brain death protocol, neurological exams, apnea test or confirmatory tests for brain death.</td>
</tr>
<tr>
<td>8.</td>
<td>O</td>
<td>O</td>
<td>Checks for comprehension of information by family member(s).</td>
</tr>
<tr>
<td>10.</td>
<td>O</td>
<td>O</td>
<td>Uses repeated and/or multiple explanations to achieve comprehension by family member(s).</td>
</tr>
<tr>
<td>11.</td>
<td>O</td>
<td>O</td>
<td>If appropriate, offers observation of neurologic examination.</td>
</tr>
<tr>
<td>12.</td>
<td>O</td>
<td>O</td>
<td>Explains next decision-making steps without mention of organ donation.</td>
</tr>
</tbody>
</table>
TEMPEL UNIVERSITY HOSPITAL
Potential Organ Donor Outcomes
By Unit
2007*

* Medical record review complete through 04/30/2007.

Number of Potential Donors

<table>
<thead>
<tr>
<th>Unit</th>
<th>% of POTENTIAL</th>
<th>Donors</th>
<th>Referral Rate</th>
<th>Consent Rate</th>
<th>Conversion Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSICU</td>
<td>9%</td>
<td>2</td>
<td>100%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>NICU</td>
<td>24%</td>
<td>5</td>
<td>80%</td>
<td>75%</td>
<td>n/a%</td>
</tr>
<tr>
<td>SICU</td>
<td>31%</td>
<td>8</td>
<td>100%</td>
<td>87%</td>
<td>87%</td>
</tr>
<tr>
<td>CICU</td>
<td>14%</td>
<td>3</td>
<td>66%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>MRICU</td>
<td>9%</td>
<td>2</td>
<td>100%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Burn-ICU</td>
<td>0%</td>
<td>1</td>
<td>n/a%</td>
<td>n/a%</td>
<td>n/a%</td>
</tr>
<tr>
<td>ER</td>
<td>4%</td>
<td>1</td>
<td>100%</td>
<td>0%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Donor Distribution:
- NSICU: 2 Donors, 1 Family Declined
- NICU: 5 Donors, 2 Family Declined
- SICU: 8 Donors, 1 Family Declined, 2 Family Not Asked
- CICU: 3 Donors, 1 Family Declined
- MRICU: 2 Donors, 2 Family Declined
- Burn-ICU: 1 Other: Referred, Not Asked
- ER: 1 Donor, 1 Other: Referred, Not Asked
Is brain death synonymous with death?

Pre-Assessment
(n=140)

Post-Assessment
(n=128)

Source: Based on data through October 13, 2011.
I am confident about my ability to speak with families about brain death.

Source: Based on data through October 13, 2011.
It is, or should be, a standard protocol to make a referral to Gift of Life of a neurologically injured patient before brain death testing.

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree (5)</th>
<th>Agree (4)</th>
<th>Neither Agree Nor Disagree (3)</th>
<th>Disagree (2)</th>
<th>Strongly Disagree (1)</th>
<th>Mean Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pre-Assessment</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3.50</td>
</tr>
<tr>
<td>(n=140)</td>
<td>14.3%</td>
<td><strong>40.0%</strong></td>
<td>28.6%</td>
<td>15.7%</td>
<td>1.4%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(n=20)</td>
<td>(n=56)</td>
<td>(n=40)</td>
<td>(n=22)</td>
<td>(n=2)</td>
<td></td>
</tr>
<tr>
<td><strong>Post-Assessment</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4.29</td>
</tr>
<tr>
<td>(n=128)</td>
<td><strong>41.4%</strong></td>
<td><strong>49.2%</strong></td>
<td>7.0%</td>
<td>1.6%</td>
<td>0.8%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(n=53)</td>
<td>(n=63)</td>
<td>(n=9)</td>
<td>(n=2)</td>
<td>(n=1)</td>
<td></td>
</tr>
</tbody>
</table>

*Source:* Based on data through October 13, 2011.
Local Training Initiative

- Temple University Hospital Surgical Residents; (10 sessions/N = 72)

- FOUR Additional Participating Centers:
  - Albert Einstein Medical Center
  - Thomas Jefferson University Hospital
  - Hahnemann University Hospital
  - Christiana Hospital

- 12 sessions/ N = 102 residents trained
Organ and Tissue Donation: Effective Requesting Training

Geisinger Medical Center - Danville
December 8, 2011
Setting the Table: Family Communication and Support

Gift of Life Donor Program
“The family are not just visitors to the ICU; they are an extension of our patient and therefore experience the process of care along with their loved ones.”

Alvarez, GF; Kirby, AS. The perspective of families of the critically ill patient: their needs [Ethical, legal and organizational issues in the intensive care unit]. Current Opinion in Critical Care; Volume 12(6), December 2006, p 614–618
Family-Centered Conversation: “Setting the Table” for Next Steps

• Be a calming presence
• Listen without judging
• Families will look to you for guidance, and to answers questions like:
  – What’s happening?
  – What should they do now?
  – What’s next?
“This is ‘Coordinator’s First & Last Name.’

He is a member of our team who specializes in working with families like yours who lost someone they love.”
Approaching the Family
About Organ and Tissue Donation

The Fundamental Challenge of Organ Donation

It is at the beginning of a family’s grief when their own hope has been taken away that we ask them to invest in the lives of strangers through the life-saving gift of organ donation and that we ask them to make an investment in their own later stages of grief – stages they likely cannot imagine ever reaching.
Alternate Paths
You May Encounter
Introducing Donation Opportunity To Families:

- Brain Death Pronounced; Explained to the Family; Family Understands.
- Decision To Limit, Decelerate or Withdraw Life-Sustaining Therapies
- Pulmonary or Hemodynamic Instability
- Family Mentions Donation
- Donation Mentioned To Family Without Gift of Life Present

Gift of Life and Healthcare Team huddle; determine a plan to discuss donation with the family together
Donation Champion Seminars for Nurses

- First Donation Champion Session held in 2005
- Large donor potential hospitals were initially targeted, with approximately 10-20 attendees
- Now in our 8th year!
- Sessions open to all hospitals in our region; attendance typically 80 - 110 critical care nurses and RRTs
- 6.5 contact hours
- FIFTY-NINE sessions with more than 3,800 participants
Organ and Tissue Donation

Donation Champion Learning Session

Supporting Families and Sharing Best Practices

Wednesday, October 1, 2008

Agenda

8:00 – 8:30  Registration & Continental Breakfast

8:30 – 8:45  Welcome & Opening Remarks
Howard Nathan

8:45 – 9:30  Collaborative Overview: The Donation Champion’s Impact on Hospital Outcomes & Intention and Goals
Linda Herzog

9:30 – 10:15 Panel Discussion: Patient and Family Perspectives
Moderator: Jen Hutton
Panelists: Kay Pittman-Govito, Brock Barber, Lara Moretti

10:15 – 10:30 Break

10:30 - 11:15 Communicating Best-Demonstrated Practices: The Optimal Process
Jacki Giuffrida

11:15 - 12:00 Determination of and Communication Surrounding Brain Death
Dr. Leonard Berkowitz, Crozer Chester Medical Center

12:00 - 12:45 Lunch

12:45 - 1:30 Intensive Organ Donor Management: Saving Eight Lives Simultaneously
Tim Snyder

1:30 – 3:00 Effective Approaches to Optimizing Donation Opportunities
➢ Family Communication: A Step-Wise Approach
➢ Advanced Clinical Management of the Potential Organ Donor
➢ Donation after Cardiac Death

3:00-3:45 Panel Discussion: Ask the Expert - Essentials of Clinical Decision-Making Related to Organ Donation and Transplantation
Moderator: Veronica McCall
Panelists: Dr. Thacker, Txp. Surgeon, Temple; Linda Klein, RT, JHN; Cheryl Rottmayer, ICU Nurse Manager, St. Mary’s; John McCumber, TC, GLDP

3:45-4:00 Closing Remarks, Offers, Requests & Declarations

4:00-4:30 Tour of Gift of Life Clinical Facilities
A Session Goal: Provide Context For Clinical Practice

**OPO Interests**

- SOPs For Patient Referral And Family Communication Surrounding Death and Donation

**Hospital Staff Perception**

- Why are they here prior to brain death?
- Why can’t we initiate donation discussion?

**How We Achieved This:**

- Developed curriculum to ensure hospital staff gained insight and appreciation for hardwiring an optimal donation process into their hospital’s system
- Interactive sessions afforded opportunity to address questions and concerns in a non-threatening environment
- Peer influence – hearing perspectives from staff members across all types of hospitals (trauma/transplant centers and community hospitals)
- Utilized a panel discussion format representative of families and experts in donation and transplantation
“The donor family and recipient speakers were very powerful. They make you focus on the ultimate goal of serving our patients and families to the furthest extent.”

“Sessions were individualized, so we could ask questions. I left with doable action steps and take home messages.”

“Very interactive. We were given a great deal of information, but it was presented well. Thought panel of speakers were wonderful.”
U.S. Overview

- OPO’s have variation in roles, responsibilities and process

Specialized Requestors (family focus with minimal if any clinical responsibility) vs. Full Case Responsibilities (referral through the OR)

Approach for Authorization (non-designated donors) vs. Approach for Disclosure (designated donors)
All 50 States have Drivers’ License Registries

45.1% in PA (4,359,681)

NJ started July 2004
30.6% (2,159,679)

43.6% of drivers/ID holders in DE
(305,482)

Data as of March 1, 2011
Donor Designation and Disclosure:

• 24-hour access to Department of Motor Vehicles (in PA)
• Information shared with hospital staff
• Presenting this information to a family:
  – Explain that loved one made a very important decision
  – Questions / misconceptions are addressed
  – Understanding is verified
  – Most families are relieved
• Medical unsuitability precludes accepting the gift
• If family opposition
  – Decision to proceed will be made jointly
Authorization/Consent Philosophy and Interactive Training Model

• Process oriented (focus on clinical and recovery details)

• Script-like family conversations – Designated Requestor
  – Death Centered to help the grieving family
  – Requestor saw self as Donor Family Advocate

• Inconsistencies in the way staff conducted conversations (individual vs. organizational practice)

• Minimal orientation training (often preceptor driven)

• No continuing education training on consent
Optimal Family Approach Process

1. Identify brain death or imminent brain death
2. Referral to Gift of Life for patient evaluation
3. No premature mention of donation
4. Approach family collaboratively with Gift of Life and hospital staff
5. Ensure family understands brain death as death
6. Request donation in appropriate setting
7. Ensure informed decision; Support family decision
Goal: Inspire the family to donate by helping them understand the power of their decision.
What is Dual Advocacy?

With *Dual Advocacy* the donation professional’s responsibility is to advocate for both the waiting recipients and the potential donor family.

Donation Professionals (*Family Communicators*) see themselves as:

- Proactive specialists
- Members of the family care team
- Responsible to empower families to save and improve the lives of others through transplantation
Dual Advocacy-Philosophical Framework 
Based on Three Underlying Beliefs 
Held by Donation Professionals

<table>
<thead>
<tr>
<th>Belief</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most people given an opportunity to save a life, or help someone, will do it.</td>
</tr>
<tr>
<td>Organ / Tissue donation feels like the right thing to do.</td>
</tr>
<tr>
<td>The key role of the donation professional is that of a “Dual Advocate.”</td>
</tr>
</tbody>
</table>
Transplant Coordinator
Introduction to Family by Healthcare Team

“This is ‘Coordinator’s First & Last Name.’

He is a member of our team who specializes in working with families like yours who lost someone they love.”
At The Heart Of Dual Advocacy Lies A Simple Question:

"Yes"

Did we empower the family and give them something to say yes to?
Ten Components of the Family Approach and Donation Discussion

1. Assess Dynamics & Design Communication Plan
2. Collaborative Plan With Hospital Staff
3. Introduction to the Family
4. Express Condolences
5. Assess & Assure Family’s Understanding of Brain Death
6. Engage Family in Conversation about Loved One
7. Transition to Donation Discussion
8. Donation Discussion Principle Valued Explanation of Process
9. The “Ask”
10. Acknowledgement of Gift & Possible Reapproach
Leadership Models the Way

Organizational Commitment:

- Consistent messages
- Learning/Teaching culture
- Every opportunity matters
- Extensive training
- “Dual Advocacy” is both an organizational and individual responsibility
- 24/7 mentoring, coaching and guidance
Staff Development & Training

Orientation (4 Months)
- Classroom didactic (7 - 8 weeks)
- Preceptors
- Field experience
- Independent-Study Learning Modules

Family Communication Classes
- Active Listening
- Consent Module I: Introduction to Family Communication and the Donation Discussion: GLDP’s Dual Advocacy Philosophy
- Consent Module II: Developing Effective Family Communication Skills and Conversational Strategies: GLDP’s Family Communication Practice and Policies
- Consent Module III: Family Communication: Learning the Art of Averting and Overcoming Challenges and Obstacles
- Foundation for Understanding the Basics of Grief
- Legal Aspects of Consent

Didactic Classes = 33
Internet based skills practice
Variety of consent scenarios
Experienced mentor providing real-time feedback
Organ Donation Goal Setting

Monthly and Annual Performance Dashboards
## Musculoskeletal Goal Setting
Performance Dashboards

### TIC Musculoskeletal Donation Metrics
12/1/2010 to 12/31/2010

<table>
<thead>
<tr>
<th>Metric</th>
<th>Monthly Target</th>
<th>My Performance (Adjusted To Date)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Above Goal</td>
</tr>
<tr>
<td>Approaches</td>
<td>16</td>
<td>(&gt; 16) 19</td>
</tr>
<tr>
<td>% 1st Calls w/in 90 Minutes</td>
<td>50%</td>
<td>(&gt; 50%) 63%</td>
</tr>
<tr>
<td>Consent Rate</td>
<td>48%</td>
<td>(&gt; 48%) 79%</td>
</tr>
<tr>
<td>Conversion Rate</td>
<td>37%</td>
<td>(&gt; 37%) 74%</td>
</tr>
<tr>
<td>Bone Donors</td>
<td>6</td>
<td>(7+) 14</td>
</tr>
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</table>

Based on DARTS data as of Thu, 3/17/2011 at 15:20:19
# Gift of Life Donor Program

## Organ Donation Consent Rates 2000 - 2010

<table>
<thead>
<tr>
<th></th>
<th>Pre-Training</th>
<th>Training Implementation 2/1/2005</th>
<th>Post-Training</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Year</strong></td>
<td>2000</td>
<td>2005</td>
<td>2010</td>
</tr>
<tr>
<td><strong>Consent Rate</strong></td>
<td>51%</td>
<td>57%</td>
<td>67%</td>
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</table>
Gift of Life Donor Program
Organ Donor Experience
1974 – 2011

*Source: Based on GLDP data through December 31, 2011.
Bone Donors
Cornea Donors

*Based upon GLDP data through December 31, 2011.
Focus on Family Centered Care
It Really Is All About the 1’s……..

1 Donor at a Time
1 Donor Family at a Time
1 Transplant Candidate at a Time…..
Gift of Life Institute Celebrates Its 7th Year in Operation

• Over 250 workshops with 51 OPOs and tissue banks participating

• More than 3,500 donation professionals trained in the U.S. and Canada, Trainees from Australia, Netherlands, China, Japan, Germany, Canada, Philippines, Singapore and Spain

• National training curriculum with customized workshops at OPOs in Consent, Hospital Development, DCDs, Call center; also consulting services including OPO evaluation, focus groups, staff development, customized hospital assessment and strategic planning

http://www.giftoflifeinstitute.org