

Choosing Hospice and Donation After Cardiac Death (DCD): Collaborating With a Pediatric Family to Honor Their Decision to Provide Hospice Care to Their Eight Year Old While Simultaneously Planning to Pursue the Possibility of Organ Donation

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NATCO 35th Annual Meeting

Gift of Life Donor Program
Philadelphia, PA

Gift of Life Donor Program Philadelphia, Pennsylvania USA



- Non-Profit OPO/Tissue Recovery/Eye Bank
- Established in 1974
- Federally designated OPO (by Medicare) for eastern PA, Southern NJ & Delaware
 - 138 Acute Care Hospitals
 - 15 Transplant Centers, 43 Programs
 - 10.2 Million Population
- **439 organ donors in 2009; highest volume in US history & 43 Donors/MM; 1,026 bone recoveries and 2,366 eye recoveries**
- **Over 29,000 organs for transplantation and over 250,000 tissue allografts**
- Accredited by: Association of Organ Procurement Organizations (AOPO), American Assoc. of Tissue Banks (AATB) & Eye Bank Assoc. of America (EBAA), UNOS/OPTN member OPO



Discussing Donation With Families: Five Scenarios That Trigger A Conversation

- If patient has been pronounced brain dead *and* this has been explained to the family *and* the family demonstrates an understanding that death has occurred
- If the family mentions donation *or* expresses an interest in talking about it
- If the family indicates that they want to limit or decelerate therapy or withdraw support; this could compromise their donation opportunity
- If the patient suffers pulmonary or hemodynamic instability; this could also compromise their donation opportunity
- If any hospital staff mentions donation or initiates a donation discussion (*NOT OPTIMAL PROCESS*)

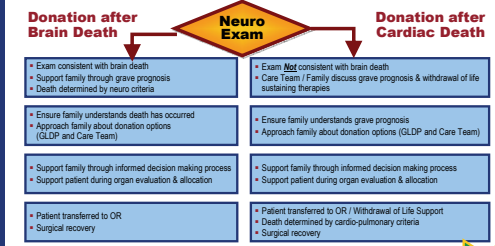
Gift of Life and hospital staff huddle; then approach the family together

“The Hospice and Palliative Nurses Association (HPNA) supports appropriate education and interventions to help patients and families donate organs & tissues. Furthermore, HPNA supports palliative care for the DCD donor before and during the withdrawal of mechanical ventilation.”

HPNA Position Paper
Journal of Hospice & Palliative Care Nursing
Vol 11, No 2, Mar/Apr 2009



Potential Organ Donor All Vent-Dependent Patients With A Non-Recoverable Neurological Injury



107,972 Total Waiting in U.S.

Pediatric Organ Transplant Waiting List June 2010*

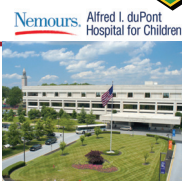
6,281 Total Waiting In Our Region
1% Waiting Are Children

62 Children Waiting In Our Region

24	Kidney
23	Liver
8	Heart
4	Lung
3	Heart/Lung

*Source: Based on OPTN data as of June 25, 2010. Count = candidates. A patient who is waiting at more than one center, or for multiple organs, is counted as only one candidate. Totals may not add due to patients included in multiple categories.

Hospital Profile



- 280-bed teaching hospital which provides more than 30 specialties including organ transplantation
- Level II Pediatric Trauma and Emergency Department plus Fast Track Urgent Care
- Delaware's *only* children's hospital and *only* transplant center
- Transplant Programs
 - Heart, Kidney & Liver



Referral and Initial Family Contact

- 1/05/2010 @1442
- Initial referral to Gift of Life Donor Program by Oncologist at the family's request
 - Patient remains on outpatient service
 - OPO met with Oncologist to obtain HPI and to discuss current neuro status
 - Emphasis on need of this being a family driven process
 - Initial contact to parents by telephone and future meeting scheduled

Patient Profile

- 8 year old Caucasian Male
- Ht: 47 inches Wt: 23 kg
- **Blood Group:** O negative
- **Diagnosis:**
 - Diffuse Pontine Glioma (DPG) (non-metastatic)
 - Diagnosed December 2008
 - Treatment included: chemotherapy, radiation and angiogenesis inhibitor administration (Avastin)
 - Surgical biopsy and resection were not indicated
 - Death imminent within weeks
 - Palliative Care & Hospice Involved



A Family Driven Process

- OPO met with family in their home (1/15/2010)
 - **GOAL:** Support family through decision making
 - Explanation of Brain Death vs. DCD donation pathways
 - Necessity of making advance plans
 - Importance of partnering in hospice care provider, first responders, and hospital personnel
 - The need for airway stabilization and the necessity for an elective intubation
 - The OPO ensured the family understood all possible outcomes and the unpredictable nature of the patient's clinical course
 - Supported all family requests for continued education through meetings and telephone support
- Family elected to continue with in-home hospice care while reflecting upon decision, ultimately making the decision to pursue donation opportunity.

Admission Course: 10 days post family meeting

- Patient developed severe headache and respiratory distress and admitted to PICU
- Referral called to OPO at request of parents
 - Coordinator onsite for evaluation
- Parents requested intubation with goal of supporting patient through event and secondary goal of preserving donation opportunity
- Irreversible neurological decline
- Two (2) days post admission, decision to w/d support and proceed with DCD donation

In The Face of the Uncommon or Challenging Nature of Case Presentation:

- Awareness of opportunities in non-traditional settings is crucial
 - Effective and meaningful communication to family and health care team is essential
 - Empowering family to make a fully informed decision
- “OPO's are charged to be both advocates and stewards for donation”*



OUTCOMES

- **Right & Left Kidneys:** Transplanted in 53 y/o married father. On the list for 1,764 days (4.8 years)
- **Liver:** Placed for Research
- **Corneas:** Transplanted
- **Glioma:** Placed for DPG Research Study

