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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Gift of Life Donor Program
Philadelphia, PA

"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
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A Family Driven Process

Family elected to continue with in-home hospice care while reflecting upon decision, ultimately making the decision to pursue donation opportunity.

OUTCOMES

Right & Left Kidneys: Transplanted in 33 yrs: married father.

OPO: Accredited by: Association of Organ Procurement Banks (AATB) & Eye Bank Assoc. of America (EBAA); UNOS/OPTN member OPO

Patient Profile

• 8 year old Caucasian Male
• Ht: 47 inches  Wt: 23 kg
• Diagnosis (non-metastatic)
  - Bilateral Pulmonary Gliomas (BPG)
  - Diagnosed December 2008
  - Treatment included: Chemotherapy, radiation, and embolizations (infusion
administration (Avastin)
  - Surgical biopsy and resection were not indicated
  - Death imminent within weeks
  - Palliative Care & Hospice Festival

Referral and Initial Family Contact

1/05/2010 @1442
• Initial referral to Gift of Life Donor Program by Oncologist at the family’s request
• Family remains on eligibility service
• OPO met with Oncologist to obtain HPI and to discuss current neuro status
• Initial contact to parents by telephone and future schedule

Patient Profile

+ 1/05/2010 @1442
- Hospitalized for several reasons
  - Illness course
  - Hospital course
  - Treatment included:

Admission Course:
10 days post family meeting

• 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.”

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