Neonate Donation

One Family's Journey

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String of Pearls

String of Pearls Mission Statement

- String of Pearls was created to provide a nurturing and safe place for families as they navigate the path following a fatal prenatal diagnosis that will result in the death of their baby prior to, or shortly after birth. The path between grief and hope is a difficult place to walk; our desire is to provide guidance, compassion and practical suggestions as plans to honor the life of pre-born babies are crafted. Each life has a story worthy of telling and we are here for support as stories are lovingly written.

Objectives of Perinatal Hospice

- Provide unconditional support from point of diagnosis and up to 2 years following delivery
- Freedom from fear of abandonment
- Allow parents to fully experience the birth of their child and encourage bonding during the time of pregnancy and beyond
- Parents will know they treasured their baby's life, no matter how long or short

Family Driven Process

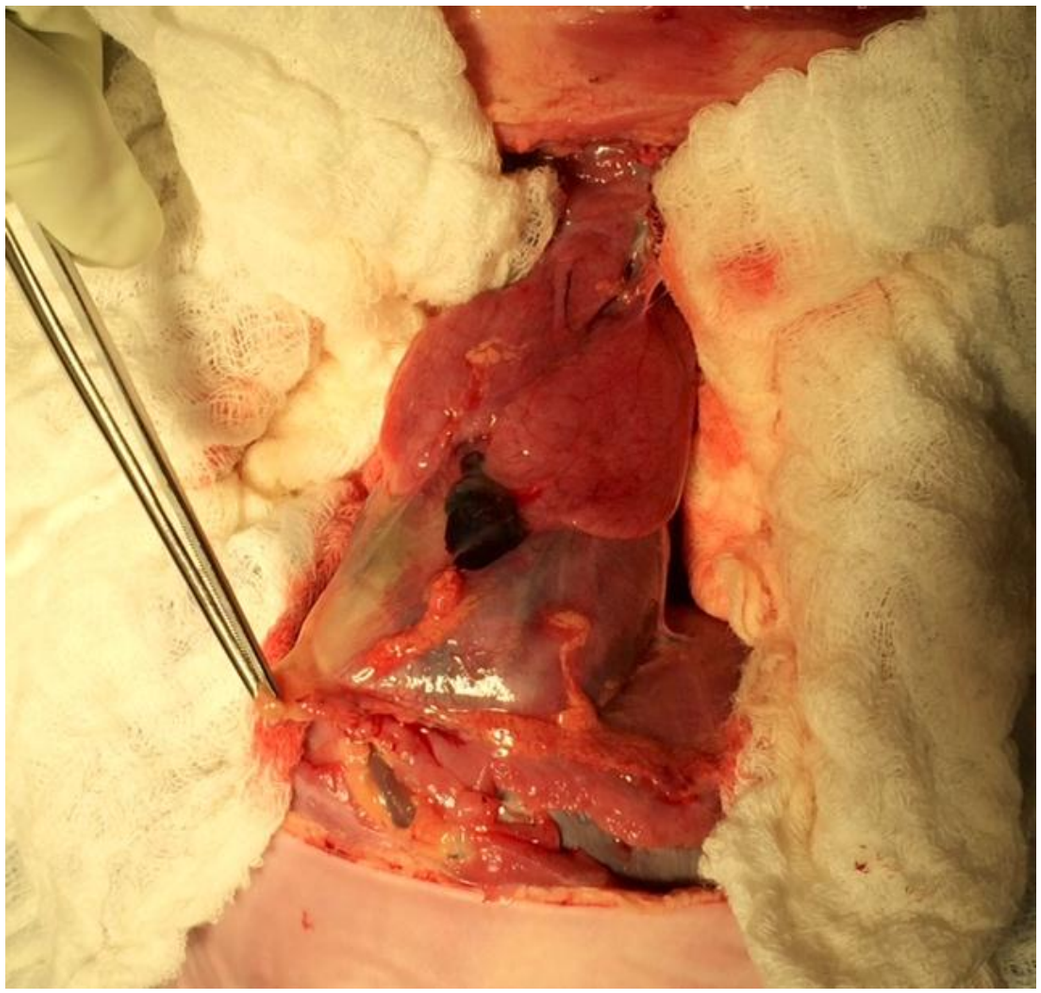
- Meet on families' terms
  - Paperwork, blood draws, etc completed at hospital after doctor appointments
- Education
  - Eligible tissues
  - Recovery process
  - Post recovery
- Support
  - Collaborate with String of Pearls

Coordination of Recovery

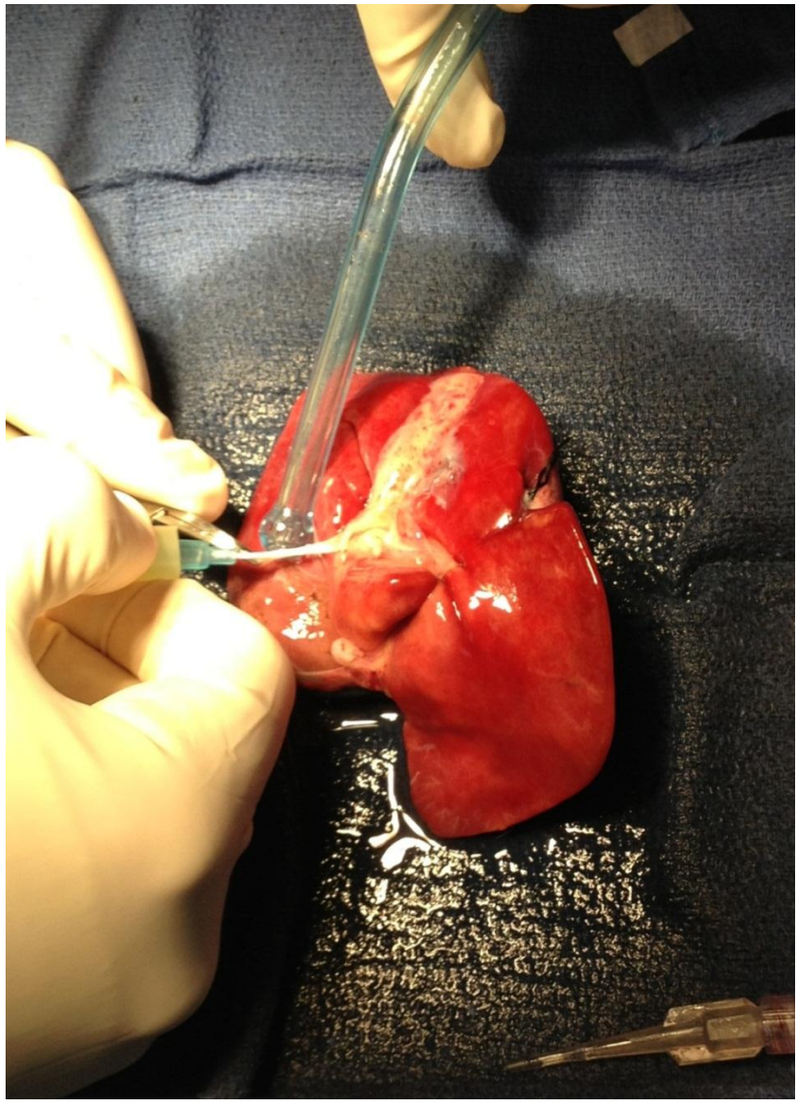
- Clear communication with Hospital Staff
  - Coordinate with OR team
    - Discuss recovery location and time frames
  - Coordinate with RNS and L&D
    - Arrange for family to bring baby to OR for recovery
- Team is “on-call” 24/7 through process
  - Regular updates of delivery and post delivery status
  - Recovery team is not on the unit in most cases

Recovery Options

Pediatric Heart for Valves



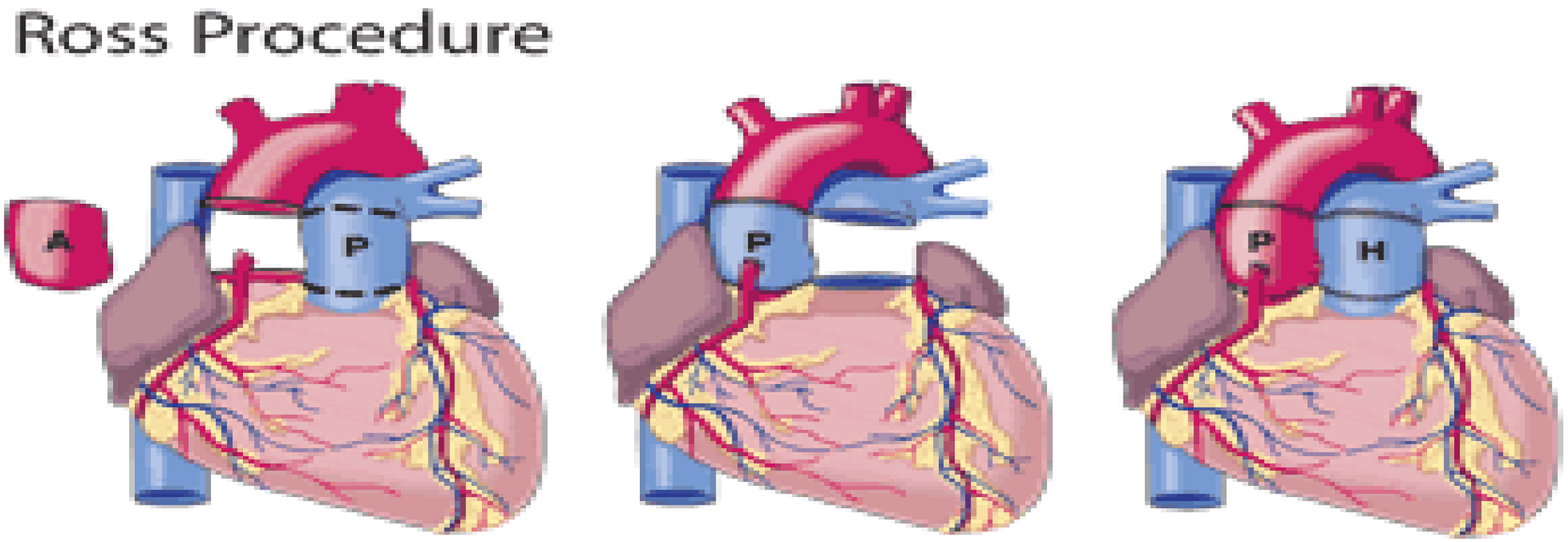
Hepatocytes from Liver



Heart for valves

- Pulmonary and Aortic Valve recovered
- Recovery Time Frame
  - 24 hrs after cardiac time of death/last known fetal movement
  - 2.76 kg wt requirement
  - 36 week gestation
- Transplant/treatment
  - Repair valve defects, using methods such as the Ross Procedure
  - Patch grafts which assist in reconstruction of heart defects
  - One donor can save up to 2 lives

Ross Procedure



The diseased aortic valve and a portion of the aortic artery (A) are removed.

The pulmonic valve and a portion of the pulmonic artery (P) are excised and placed in the aortic position. The left and right main coronary arteries are attached to the pulmonary artery (P).

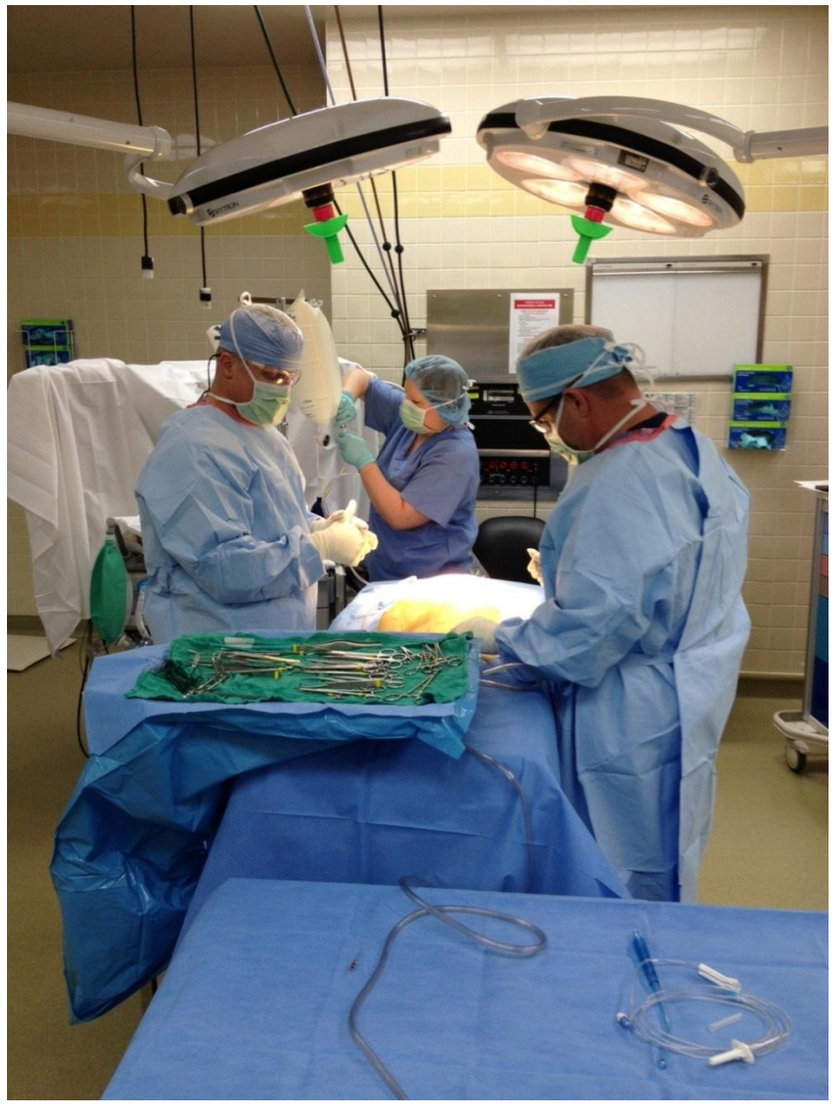
A homograft (allograft) pulmonary valve and portion of artery (H) are placed in the pulmonary position.

Liver for Hepatocytes

- Liver cell therapy
- Bridge to transplant
- Recovery challenges
  - Liver must be perfused within 3 hrs of asystole
  - Apgar of 1
  - 2.2 kg wt requirement
  - 32 week gestation – 28 days
  - “transplantable” quality
  - Trisomy 13 or 18, not acceptable
  - Anencephalic and congenital abnormalities, generally acceptable
- Transplant/treatment
  - Urea Cycle Disorders

Neonatal Liver Recovery

In the OR recovering liver and heart for valves



The liver is removed and packaged

Urea Cycle Defect in Newborns and Children

- UCDs represent a devastating class of inborn errors of metabolism
- Complete deficiency typically presents in neonatal period
- Even with best available medical treatment, very high morbidity and mortality
- Hyperammonia crises cause neurological damage
- Less than 20% of patients survive into teen years, most survivors suffer from developmental problems
- Approximately 1:50,000 neonates have full deficiency UCDs (USA)

- Mortality:
  - 30 - 50% within 1 years
  - 65 - 70% within 5 years
- Mean IQ of 47
- Mental Retardation: 79%
- Spastic Palsy: 46%
- Multiple Neurologic Deficits: 46%
- Organ transplantation in newborns is not possible

Family Needs

- Education
- Clear plan decided before CTOD
- Balance: cell viability and family's time with the baby
  - Family is included in the process from start to finish
  - Father (or other family member) has option to bring baby into OR
- Option to see baby post recovery
  - Full reconstruction with dressing placed over incisions
  - Baby's clothing and blanket placed in a warmer during recovery then dressed to be presented back to family