

NEONATE DONATION

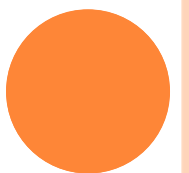
One Family's Journey

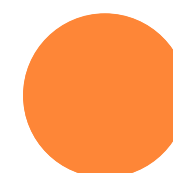
Kelli Liechty LCSW, CTBS

Candace Klitzke, CTBS



string of
Pearls

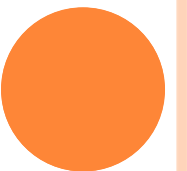




STRING OF PEARLS

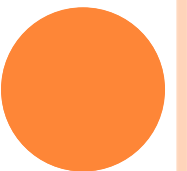
MISSION STATEMENT

- ❑ 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.**



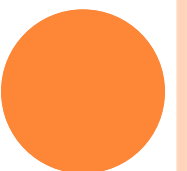
OBJECTIVES OF PERINATAL HOSPICE

- ❑ 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



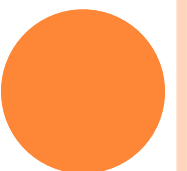
FAMILY DRIVEN PROCESS

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



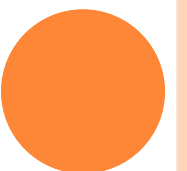
HEART FOR VALVES

- ❑ 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



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



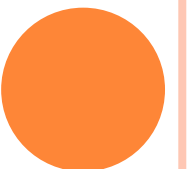
Urea Cycle Defect in Newborns and Children

- 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



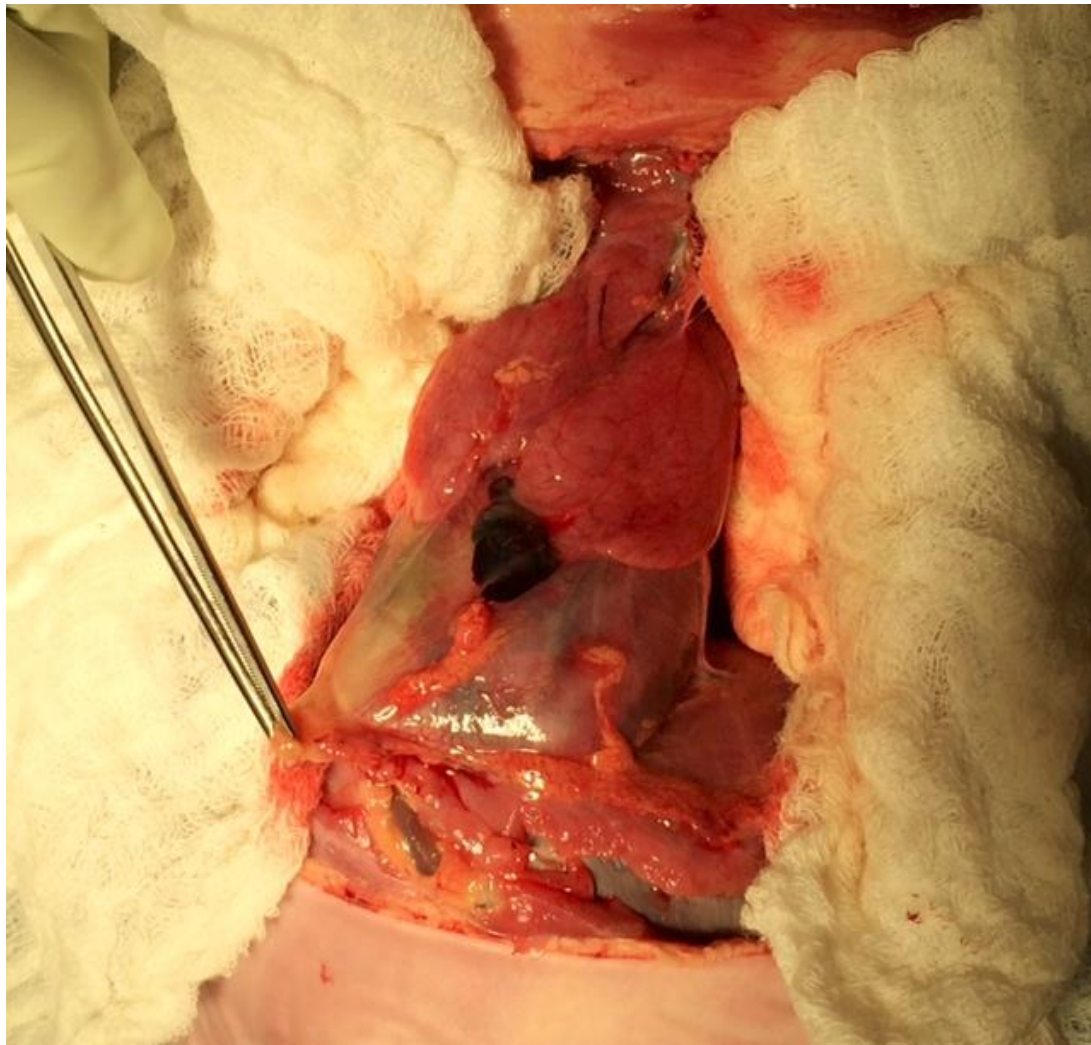
COORDINATION OF RECOVERY

- 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

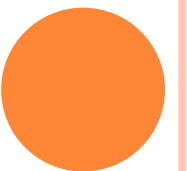
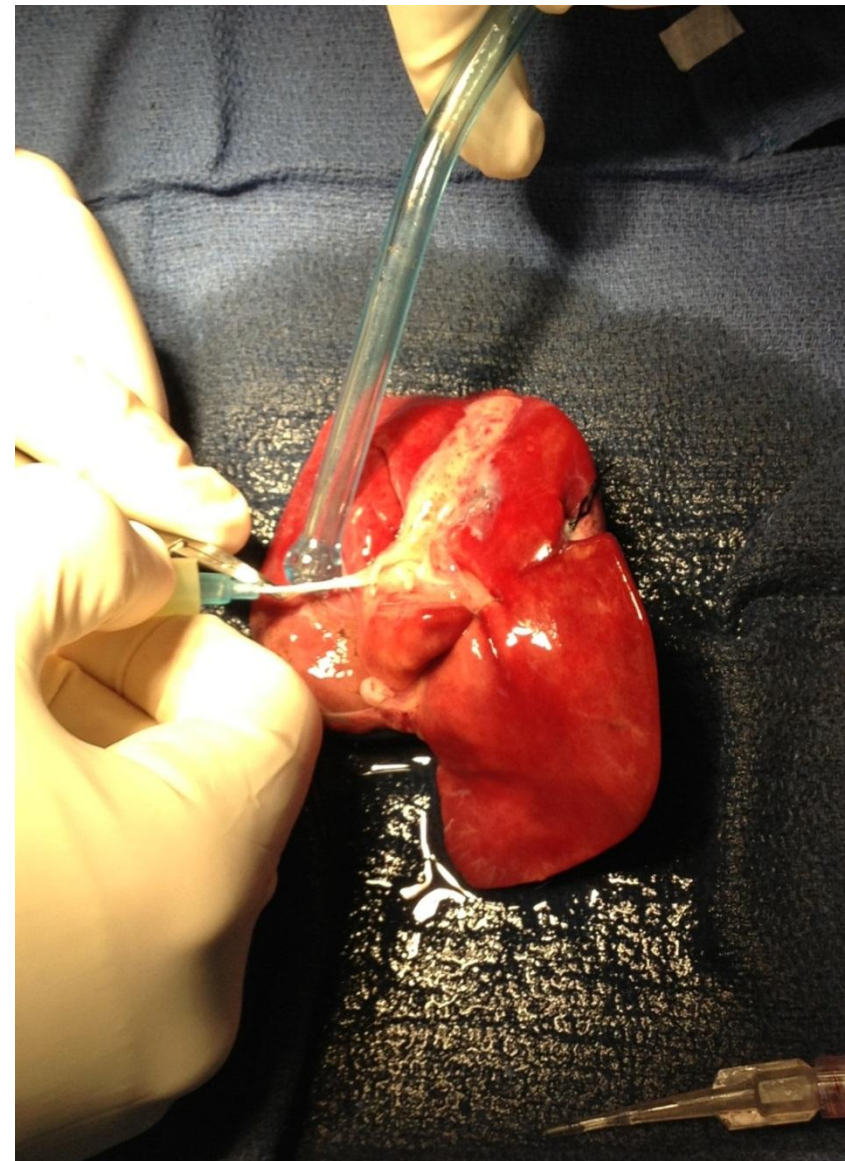


RECOVERY OPTIONS

Pediatric Heart for Valves

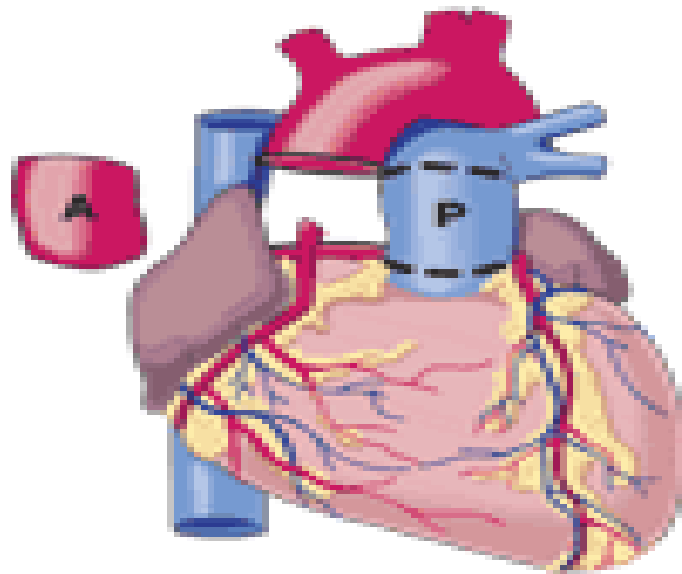


Hepatocytes from Liver

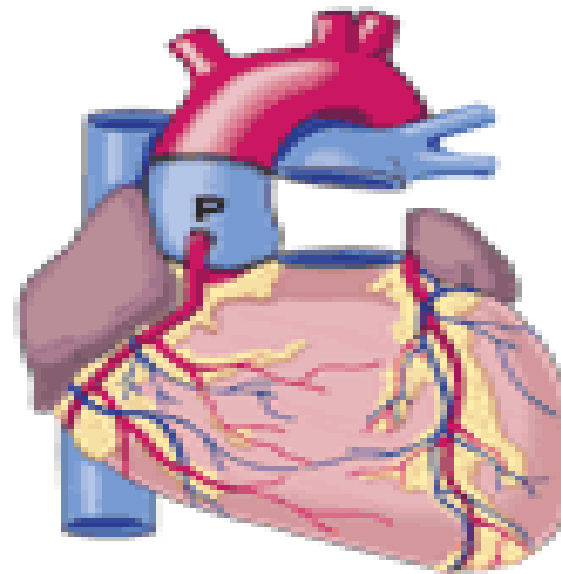


Ross Procedure

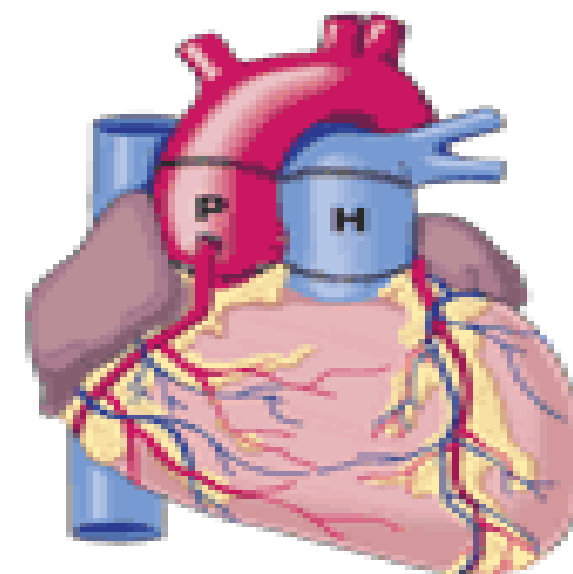
Ross Procedure



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).



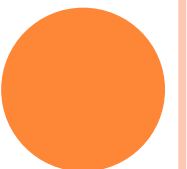
A homograft (allograft) pulmonary valve and portion of artery (H) are placed in the pulmonary position.

NEONATAL LIVER RECOVERY

In the OR recovering liver and heart for valves



The liver is removed and packaged



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

