The Neonatal Donor – Supporting the Family through Research and Medical Education

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Introduction

In September, 2012, IIAM was presented with a 36 week gestation anencephalic for donation for medical research and education. The donor family spent months contacting hospitals and facilities they hoped would assist with their desire for donation and were met with opposition. They finally reached out to their local Organ Procurement Organization and, through them, were introduced to IIAM. IIAM was to facilitate the placement of multiple organs and tissues within the timeframes of a birth plan.

Challenges

- Inability to secure baby's birth weight which played a factor in successful placement with certain researchers
- Assessing ischemic damage, a major limiting criteria for researchers, due to inability to predict birth to death timeframe
- Orchestrating family bonding time with their baby without impacting the recovery plan
- Coordinating limited flight transport that met researcher's target Cold Ischemic Time

Neonatal Lung Researcher -

"To improve our care of the premature infant, to encourage their lungs to develop along a normal pathway, it is important to understand what that normal pathway is. For the lung, that means understanding what cells develop where and when.

We have will continue to take care of this precious gift; we are so grateful."

Donor Family -

"We could not be more proud of our son. For us, donation was able to add an extra layer of meaning to his short 37 weeks in utero and 1 hour and 20 minutes alive in our arms.

It has also brought us unexplainable peace, joy, and healing."

Discussion

The parents stated their desire for organ donation upon the delivery and inevitable death of their newborn. Once transplantation was ruled out due to size, weight and gestational age, the OPO contacted IIAM for assistance in donation for medical research and education.

The parents had a very detailed birth plan and were strong advocates for organ, tissue and whole body donation. While identifying their emotional needs, they were willing to commit to necessary steps to support the opportunity for research donation. This included releasing their baby immediately after his death, a brief 1 hour and 20 minutes after his birth, for organ recovery, enabling them to proceed uninterrupted with personal ceremonies as planned upon completion.

The OPO's administrative staff was committed to this donation. Many discussions took place between the OPO, donor family, labor and delivery, surgical staff and IIAM so that all parties involved would be apprised with the most current information. Partnering with the OPO became a vital part of the success of organ and tissue recovery from this donor. Without their ongoing communication with the hospital, as well as their continued emotional care of the donor family, this donation would not have been possible.

IIAM worked with researchers and presented all possible scenarios pertaining to donor weight and identifying warm ischemic outcomes and impacts. The date of inducement was known up front and made organ placements more probable. All recovery protocols were presented to the OPO to support the preparation of the surgical team. Preliminary flights were laid out to ensure the researchers could receive the organs within the required time-frames.

"Surrender"
Created by Maria Elkins
In memory of Amalya Nathaniel Conkel

IIAM Neonatal Donor Program Summary YTD

IIAM NEO DONOR1	IIAM NEO DONOR2	IIAM NEO DONOR3	IIAM NEO DONOR4
DOB: 9/10/2012	DOB: 6/17/2013	DOB: 6/26/2013	DOB: 6/21/2013
DOD: 9/10/2012	DOD: 6/22/2013	DOD: 6/26/2013	DOD: 7/02/2013
COD: Anoxia 2° ICH; Anencephalic	COD: Anoxia 2° Cardiovascular; Anencephalic	COD: Natural Causes; Anencephalic	COD: Anoxia 2° Cardiovascular; Traumatic birth
Weight: 4 lb 9 oz	Weight: 6 lb 8 oz	Weight: 4 lb 10 oz	Weight: 9 lb 14 oz
Donation Outcome: PA, LI, Whole Body Donation – all for medical research	Donation Outcome: PA, LI, En Bloc Lungs – all for medical research	Donation Outcome: PA, En Bloc lungs – all for medical research	Donation Outcome: En Bloc Kidneys – transplant; En Bloc PA/LI, En Bloc Lungs – medical research
WIT: 2 hr 20 min	WIT: 5 hrs 10 min	WIT: Approx 6 hrs	WIT: 0

Summary/Conclusion

With a proactive donor family, support of OPO administration and hospital staff, IIAM was successful in placing the donor's liver and pancreas as well as coordinating whole body donation; all research supported childhood disorders.

Postscript

Since the donation of organs and tissue from this baby in September, 2012, IIAM has assisted 3 additional families with their desire for organ donation for their baby. Two of the donors were diagnosed with anencephaly; one donor suffered trauma during the birth process. IIAM was successful in placing multiple organs for medical research from each of these donors (Table). It is important to recognize the potential for donation from neonates and the impact their organs and tissues can have for the parents and families, as well as the groundbreaking research being done to study childhood and general diseases.

In Memory
OURANIA B. BRENNAN

6/22/2013

God saw she was getting tired
and the cure was not to be.
So He put his arms around her
and whispered, "Come with Me."
With tearful hearts
we watched her fade away.
Although we loved her dearly,
we could not make her stay.
A golden heart stopped beating,
hard working hands laid to rest.
God broke our hearts to prove to us,
He only takes the best.