



Neonatal Donation

Guidelines and Communication

The International Institute for the Advancement of Medicine (IIAM) is a non-profit organization that works with researchers and medical education programs in the U.S. and abroad. We support families of babies with terminal diagnoses in contributing to medical advancement through organ donation. This program offers a unique service to researchers and to families whose babies will pass from natural causes shortly after birth.

Communication is paramount with the logistics of donor cases. These guidelines will drive all parties in regular communication “huddles”. Huddle timeframes will be discussed and determined based on communication needs. IIAM can organize, schedule and proctor the huddles via a teleconference line as needed and agreed upon.

Source of Referral

 Parents/Family  OPO/Tissue Bank  Hospital

Family

- Family dynamics
- Birth plan
- Expectations for donation
- Prognosis
- Family’s wishes for medical interventions
- Resources: a list of resources to offer as guidance to donor families is provided separately
- Identify local OPO

OPO

- Identify “OPO Champion”
- Consent/Authorization discussion
- Medical/Social history of mother
- Serology Panel
- Evaluation for transplant possibilities
- Ascertain who will correspond with the donor family after the donation: the OPO’s AfterCare program or IIAM’s AfterCare?

Clinical

- Baby diagnosis
- Baby due date
- Projected date of delivery
- Ultrasound results, follow up dates
- Estimated weight of baby
- Gestational maturity
- Type of delivery

OPO & Donor Hospital

- OPO liaisons work with hospital administration to garner support for organ recovery
- Determine location of delivery hospital vs. recovery suite
- Identify surgical teams
- Obtain necessary supplies

IIAM

- Follow case closely and participate in communication “huddles” with OPO and Donor Hospital (timelines TBD based on development of case)
- Contact researchers to evaluate and gauge interest as donor information becomes available
- Explore all medical rule outs up front (WIT, CIT, diagnosis, etc.) so we can prepare all parties with possible outcomes
- Plan logistics with shipping courier and establish target flights (to be done close to due date)
- Provide OPO and donor family with Neonatal FAQs
- Provide OPO and recovery teams with recovery protocols

(continued)

Frequently Asked Questions

How long can the mom/dad be with their baby before they need to release him/her for organ recovery?

The parents may desire to spend time with their baby immediately after birth. For families who choose this, it is an extremely important part of bonding with their baby. OPO and hospital staff need to maintain a keen awareness of the time constraints set forth by the researchers. Please remember that balancing this time is critical to accommodate both the parents' needs for bonding and the need to honor the gift of donation.

What bonding options are available to the mom/dad after organ recovery?

Private time with the baby, prearranged by the OPO and donor hospital, may be helpful to meet the family's need for additional bonding. Families should be informed that there will be a change in appearance and weight of their baby after donation and should be given the option to make arrangements with a funeral home if they do not request additional time.

Do we need a medical/social history and any testing from the mom as part of the screening process?

Yes. The medical/social interview is essential to the screening process for donation. Additionally, a standard infectious disease panel will need to be done, specifically for HIV and Hepatitis, and must be negative to proceed with donation.

What organs can potentially be recovered for medical education and research from neonatal donors?

All organs/tissue are evaluated at the time of referral. While every effort will be made to make donation for research happen, unforeseen events may occur to prevent this. If it is found that organ donation cannot take place for any reason, inform the family as soon as possible to allow them time to make arrangements, edit their birth plan, and be mentally and emotionally prepared.

What kind of perfusion and recovery is necessary for each organ?

Upon the acceptance of each referred organ, IIAM will provide a detailed Recovery Protocol that will include perfusion methods and other transport criteria as well as blood sample requirements from the mom and baby as necessary.

IIAM and the OPO will work closely together up to and after organ and tissue recovery to ensure all necessary details are provided. Throughout the process, please continue to be proactive asking questions and offering input whenever necessary.

Thank you for your support of these families and of medical advancement through donation for research.