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## **Guidelines for Neonatal Organ Procurement And Donation (NOPD)**

The policy statement of the American Academy of Pediatrics (AAP)<sup>1</sup> on Pediatric Organ Donation and Transplantation states that “organ donation is an integral part of end-of-life care that provides families with a final decision to make concerning a loved one. Every family should be given the opportunity for organ donation if it is medically appropriate, and it should be the expectation that the family will be approached in a professional, compassionate manner. The decision to donate is one made by the family, not by physicians.”

### **Neonatal Organ Procurement And Donation (NOPD): Guidelines**

It is not necessary for each Hospital NICU to have their own trained and experienced NOPD coordinator. In fact, it is not feasible. But having at least one hospital in each big city with a total deliveries (entire city) exceeding 15,000 that will champion the cause will help at least 10 families per year achieve organ donation. The families that lost the babies will find some closure and will see a purpose of their babies' lives. From each donor, up to six to eight people can benefit.

Pediatric organ donation and organ transplantation can have a significant life-extending benefit to the young recipients of these organs and a high emotional impact on donor and recipient families.<sup>1</sup> To facilitate the process of organ donation and procurement, the following guidelines are recommended. Usually these donor infants tend to have prenatally diagnosed lethal conditions or have fatal disorders hitherto undiagnosed but were noted unexpectedly in the delivery room. They also frequently tend to be Neonatal ICU infants that gradually or suddenly developed irreversible organ damage, etc.

- Eligibility: Babies with no congenital infections or known or suspected major chromosomal anomalies with expected fetal / Neonatal weight of at least 5 pounds (2268 grams) are eligible donors.
- An umbrella protocol needs to be written for each institution based on Federal, State, local and institutional rules and regulations, with the understanding that an individualized care plan will be written for each infant and family.
- NOPD Coordinator should have the knowledge, people skills, time, commitment, innovative skills and patience to design, follow and carry out the plan.

Immediate consultation with the NOPD Coordinator (phone number or e-mail address of NOPD Coordinator needs to be easily available to OB and Nursery staff) is strongly recommended when a physician (to include Pediatrician, Neonatologist, Obstetrician, Perinatologist or even Cardiac team) encounters any potential organ donation scenario either during prenatal exams or consultations (like a fetus with anencephaly), or in a Neonatal ICU (like an infant with hypoxic ischemic encephalopathy with no survival potential).

- The coordinator will meet with the infant's family prior to the delivery (whenever possible) and as many times as needed and plan further steps.
- Also as soon as possible, the coordinator will meet with the Neonatology team (Neonatologist and NICU staff) and family together, and later coordinates meetings between the family and other physicians including Family Physician, Obstetrician and/or a Perinatologist and Surgeons.

**Checklist of steps for NOPD Coordinator include (can be modified based on regional practice):**

- a) Contact various team members, immediately.
- b) Make a list of key professionals with their phone numbers, e-mail addresses, etc. and distribute to all members of the team: Parents and family members, NOPD members, Labor and delivery nursing staff, Neonatal ICU/Delivery team nurses, Respiratory therapy staff, Neonatologist, Obstetrician, Perinatal nurse navigator, Pastoral care team, Children's Operating room staff and Transplant surgical team, receiving Surgical team, local lab supervisor and specialty labs (HLA, Blood Institute, Cytopathology), Neonatal transport team, etc.
- c) Coordinate initial meetings, in order to facilitate various team members meeting the parents and family. And, also, various teams may need to meet each other. Frequently, more than one meeting is needed to have all members meet the parents and the family.
- d) Explain to the parents and family about each professional's role in simple words. Later the family should be given a step by step picture of the care that will be provided to the mother starting when she enters the hospital on the day of delivery and, the father and the baby including delivery room care, care in mother and baby's room, etc.
- e) Clearly document the wishes of the parents and family, with a clear verbalized understanding that the parents and family can change their plans at any time without giving any explanation.
- f) Complete a separate sheet that explains that infant's individual Organ donation potential.

- g) Prepare algorithm-based care plans, including one for “Donation After Circulatory Death”.<sup>2</sup>
- h) Ensure the parents and family are given lots of time for questions, and that all questions are answered to their satisfaction.
- i) Initiate a few trial runs with an empty incubator between the delivery room and the mother and baby’s room and also from mother and baby’s room to the operating room.
- j) Actively communicate with all of the teams, starting with mother’s first referral day (day 1) until discharge.
- k) Involve the Palliative Care and Bereavement teams as soon as possible. Frequently, a lot of health care professionals are members of more than one committee. For example Pastoral care members frequently are members of the Palliative care team and Ethics committee.
- l) Involve the Ethics committee early also, to be comprehensive. Involving the Ethics committee to make sure the family does not feel pressure, feels fully informed, and knows they can change their decision at any time for any reason can provide reassurance to the family.
- m) Keep Hospital administration in the loop, such as NICU administrators in particular. This can be helpful in that administration can provide appropriate staffing for such a situation, and can also accommodate the family by easing any potentially restrictive visiting policies until organ donation is completed. Administrators can also provide guidance to the team.

**References:**

1. The American Academy of Pediatrics (AAP) Policy Statement—Pediatric Organ Donation and Transplantation, Pediatrics Vol. 125 No. 4 April 1, 2010 pp. 822 -828
2. Workman, JK, Myrick, CW, Meyers, RL, Bratton, SL, Nakagawa, TA, Pediatric Organ Donation and Transplantation, PEDIATRICS Volume 131, Number 6, June 2013 pp 1723- 1730

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