

February 11, 2020  
Testimony of Robin Pierucci, MD, MA  
Born Alive Protection Act  
Before the Senate

Dear Mr. Chairman and Senators

I am here today because as a neonatologist my job is to care for babies. Neonatologists are physicians who, after completing their pediatric training, continue to specialize in the care of babies who are critically ill. Some of the babies we care for are born at term but are too sick to remain under their primary physician's care, some of the babies are healthy but premature, and some are both premature and ill. While completing my training in neonatology, I also completed a master's degree in bioethics. Since then, I've been in practice for approximately 20 years in a busy 50 bed neonatal intensive care unit (NICU). With this background and bedside experience, I have been asked to describe today's medical standard of care for babies who are born alive.

Without hesitation, if born alive, all babies should be assessed and then receive the appropriate degree of intervention as outlined by the Neonatal Resuscitation Program (NRP).<sup>1</sup> This guideline is based on the evidence compiled by the American Academy of Pediatrics (AAP) and the American Heart Association Guidelines for Cardiopulmonary Resuscitation and Emergency Cardiovascular Care of the Neonate. This program was devised to help medical personnel "learn the cognitive, technical, and teamwork skills...to resuscitate and stabilize newborns"<sup>2</sup>. All babies, even if born at term, are at risk for having problems transitioning from the intra-uterine to the extra-uterine environment; this is why the NRP program exists. Clearly, the more premature a baby is at birth, the more at risk they are for requiring significant help making this transition. However, the NRP's algorithms are specifically designed to guide neonatal teams' assessment and intervention for even our sickest and smallest babies. NRP is the culmination of the latest scientific evidence shown to be the most beneficial for resuscitating newborns. It defines the medical standard of care that all live-born newborns are to receive; it defines the standard of care that the medical staff are responsible for providing.

Because the neonatal intensive care unit (NICU) that I work in is the regional referral center for our area, we have a transport team that is deployed whenever we are called about a baby who is too ill for the services available where he or she has been born. Studies have demonstrated that extremely premature babies have better outcomes when born in a hospital that routinely cares for their unique needs. We and other NICUs with transport programs throughout this country successfully transport babies into our units every day. Emergencies happen, that's just one reason why we in the NICU and all critical care responders exist. No one guarantees the outcome; all of us guarantee that we will show up when called. This is the medical standard of care for all physicians and we promise to apply it consistently to every human being. There is no ethical reason why this medical standard of care should be abandoned for a subgroup of people because they might be less "wanted" than others; wantedness does not determine humanness. Put

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<sup>1</sup>Weiner, Gary M., Jeanette Zaichkin, and John Kattwinkel. *Textbook of Neonatal Resuscitation*. Elk Grove Village, IL: American Academy of Pediatrics, 2016.

<sup>2</sup> Ibid, pg 3

another way, it would be an abandonment of my medical and ethical duty if I only respond to the needs of some babies and not to others.

While it is always my duty to care for every baby, this is not equivalent to aggressively resuscitating every baby. Exactly like patients seen by doctors in almost every other medical discipline, there are patients that are beyond our ability to heal. The NRP guidelines acknowledges these situations stating:

“The birth of extremely premature babies and those with significant chromosomal abnormalities or congenital malformations frequently raises difficult questions about the initiation of resuscitation. Although general recommendations can guide practice, each situation is unique, and decision making should be individualized”<sup>3</sup>

Of note, medical “viability” is consistent with the legal definition, which is commonly defined as “the state of fetal development when, in the judgment of the physician based on the particular facts of the case before him or her and in light of the most advanced medical technology and information available to him or her, there is a reasonable likelihood of sustained survival of the unborn human being outside the womb, with or without artificial support.” The point is, a living baby is a real patient, and just like every other patient newborns need to both skillfully and compassionately evaluated. Just like every other living patient, we err on the side of life, with a simultaneous awareness that there are times when keeping our patients safe and free from unnecessary pain or procedures that offer minimal benefit, is the better “medicine”.

Over the years, there have been a handful of times when it became clear that despite doing everything we knew to do for the baby, we were not going to be successful. And not only were we not going to be successful, for a variety of reasons, a baby was going to die without a parent present to hold him or her in those final moments. It is at those times that I have had the privilege of taking those impossibly tiny hands into my own and simply holding the little one for the duration of his or her life. Mother Teresa stunned the entire world by picking up dying, disregarded people from the gutters of Calcutta and tending to them whether or not they could be cured. We too should never allow a baby, especially a baby, to die anywhere but in the warmth of our arms, nestled securely against our hearts.

In cases where our technology is insufficient to help, it is appropriate to provide palliative care. The goal of this kind of care is to help the baby and their family live well with what we do not have the ability to “fix”. In such cases, we avoid uncomfortable tests and procedures that will neither solve a problem or will only prolong suffering. We also strive to minimize things such as IV tubing and monitors that may interfere with a family’s ability to simply hold their little one.

The concern about avoiding, minimizing, or directly treating procedural pain in NICU patients is also today’s medical standard of care, as noted by the AAP’s 2016 updated policy statement and multiple additional studies. As a neonatologist, my medical standard of care is to keep my patients free from unnecessary noxious stimulation because there are both immediate and long-

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<sup>3</sup> Weiner, Gary M., Jeanette Zaichkin, and John Kattwinkel. *Textbook of Neonatal Resuscitation*. Elk Grove Village, IL: American Academy of Pediatrics, 2016, pg 269.

term side effects. It is important to remember that, when determining what procedures should be done, it is equally important to evaluate which interventions should not be initiated or should be stopped due to a lack of response or being more burdensome than helpful.

**Conclusion:**

A newborn's first and primary diagnosis is, it's a baby. All other diagnoses (prematurity, respiratory distress, sepsis, etc) are secondary and never negate the first one. Because of their preeminent diagnosis, (human baby), we are always obligated to care, whether or not we have the ability to heal. This means that all human babies who are born alive are our patients and as such, medical personnel should be ready to either directly provide the medical standard of care or be prepared to stabilize the baby until a team with more advanced training arrives. I offer this testimony in the hope that by consistently caring for all babies, we will simultaneously also better care for their mothers, which will extend to an entire family tree of affected loved ones.