

## Parent's Grand Rounds Speech on Neonatal Intensive Care Unit Experience

**Nancy Montalvo**  
**Brian P. Vila**

About two and a half years ago, Nancy and I were expecting our first child. One night Nancy came home from her job as an art therapist, feeling extremely exhausted. She was admitted to the hospital, and it was discovered that she was in preterm labor. Attempts to stop her labor failed. She was in the 23rd week of pregnancy.

Nancy's regular obstetrician was on vacation, and the substitute obstetrician was in a rush to go out for the evening. All he told us during our brief interview was that there was a 50% chance the baby would not make it and that a cesarean delivery would improve the chances by causing less trauma to the baby's head. He mentioned that we were on the "cutting edge" of medical technology, a situation that seemed to excite him, but had no meaning for us as nonmedical people with no previous experience.

He did not elaborate. He did not mention the overwhelming possibility of severe short- and long-term morbidity, the astronomical medical bills, the prolonged hospitalization, or the incredible suffering that awaited us and our baby. The only choice we were given was between a vaginal delivery and a cesarean section. Totally uninformed and wanting to do what we thought was the right thing for our baby, we chose a cesarean section.

I was not permitted to be with Nancy during the delivery as we had planned. She was put under general anesthesia, and the baby was delivered by a "classic" cut. We were not consulted about this at the time, but were later told that this type of incision meant Nancy would never be able to give birth normally again.

Our son, Emanuel, was born at 23 weeks' gestation (although the ultrasounds showed 23 weeks, the doctors called it 24 weeks), weighing 615 gm. Nancy was not allowed to go to the neonatal intensive care unit (NICU) to see him because of her postsurgical condition. She was only told by nurses that he was "very sick." Neither one of us was given the opportunity to speak to a neonatologist until a week after our son's birth.

I, however, was able to go to the NICU and see our son. I was amazed at the technology and the skill of the medical professionals. My initial relationships with everyone I met in the unit were

positive. They sensed my interest in their work and responded well to me. I was curious about the techniques they used, and they were happy to talk to me about them.

However, when Nancy was finally well enough to visit the unit, she was treated as if she were ignorant and inconsequential. The staff would never directly answer her questions, saying that we both had to be there before they would talk to her. This was not always possible because I was working. Finally, Nancy simply stopped asking questions. It is not very hard to cause a mother who already feels like a failure to withdraw and become passive.

Eventually, despite my initial good relationship with the staff, even my questions began to make them uncomfortable. I wanted information on statistics and outcomes, and this made them nervous and evasive. At one point, a nurse referred me to the hospital's medical library, and it was there that I discovered that our son's chances for major neurologic damage were close to 50% and this did not include the almost certain risk of so-called "minor" disabilities, such as cognitive and behavioral disorders. Although some refer to these problems as minor, we have since learned that these so-called minor problems prevent many preemies from ever being able to lead independent lives.

As we scanned the medical and developmental literature, Nancy and I began for the first time to develop a realistic picture of what our son's future would be like. We were understandably angry that no one had told us any of this. We began to distrust the doctors who had misled us and failed to inform us. Through our outside reading and contacts with other parents on the Internet, we discovered that we were far from alone in having been manipulated and misinformed.

From that point on, we questioned everything that was done to Emanuel. This led to many hours of discussions with the staff, who came to see us as "difficult parents." When we learned (on our own) that an ethics committee existed at our hospital, we asked for a meeting. We were told that the person in charge of these things was on vacation, and it took nearly a month to arrange an ethics committee meeting. We were given highly contradictory information about our ethical options from the different neonatologists we spoke with. One told us that it was too bad they didn't know our thoughts on resuscitation at the time of delivery, because they would have honored them. Another told us that our wishes would not have mattered, because they always resuscitate and treat any baby that weighs >600 gm and is >23 weeks of age, no matter what the parents say.

When the ethics meeting was finally held, it was a farce, a mere formality to rubber stamp the course of action the neonatologists were

*Milwaukee, WI.*

*Address correspondence and reprint requests to Brian Vila, 2533 North Oakland Avenue #318, Milwaukee, WI 53211.*

*Journal of Perinatology* (1999) 19(7) 525–527  
© 1999 Stockton Press. All rights reserved. 0743–8346/99 \$12

<http://www.stockton-press.co.uk>



already determined to take. The neonatologist present at the ethics meeting claimed that Emanuel faced only a 20% risk of major sequelae, when their own diagnoses as well as the recent literature in their library put the risk at more than twice that figure. When we pointed this out to them, our relationship with the staff became so acrimonious that one of the neonatologists would actually break out in tremors at the sight of us.

The neonatologists not only dismissed our opinions but they punished us for expressing them. When we started to question their actions, the hospital social worker started hanging around like an inquisitor, whereas before she was noticeably elusive. False and twisted accusations about us were entered into our son's medical records. About a week before Emanuel was to be discharged from the unit, we heard a loud banging at our apartment door. The people at our door were investigators from Child Protective Services. They were there to accuse us of child abuse, despite the fact that our child was still in the NICU!

It was like a scene from an undercover drug bust, or a visit from the KGB. They interrogated our neighbors in a search for any incriminating information they could use against us. We managed to rid ourselves of their presence only through the help of an attorney. We have learned through our contacts with other parents on the Internet that such retaliations against dissenting parents in the NICU are common.

All this happened simply because we had expressed our belief that we should have had the right to genuinely informed consent about the treatment of our extremely premature infant. This belief has been shown in polls<sup>1</sup> to be shared by over three quarters of the general public; it has been repeatedly upheld in court cases, and it is explicitly recognized in the neonatal guidelines drawn up by the states of Colorado<sup>2</sup> and Wisconsin.<sup>3</sup>

We feel that we have been subjected to a medical assault, an assault that has devastated our lives. Like so many other parents of preemies, we have had to deal with the overwhelming practical and psychological repercussions of a preterm birth. Our son is severely handicapped and will have incredible medical and caregiving needs for the rest of his life. Our dreams of a decent and normal family life are gone. They have been replaced by unimaginable medical expenses and profound grief and suffering. We know that these conditions will be with us for the rest of our lives. Emanuel's compromised survival has also drastically altered our relationships with our former friends and family members. We have found that few people can bear to face the realities that we must live with, and so they relate to us in the same manner as the NICU staff: with denial, evasion, and platitudes.

We think that neonatologists who bring these burdens into another life without permission should be held accountable for their actions. We are joining with other parents, some of whom are medical and neonatal professionals themselves, in mounting legal challenges against the sorts of arrogant injustices that were practiced on us. We are devoting our lives to making sure that all parents enter the NICU with a genuine understanding of the realities of neonatal care, of the poor outcomes and horrendous costs, and of the options that are

legally available to them. We hope to give parents an understanding of the financial and professional motives that are driving neonatology. We hope to give them an understanding of the misery and suffering, broken marriages, and broken lives that neonatal technology has left in its wake.

Through the Internet and other forums, we hope to make available the facts about neonatal outcomes at various gestational ages. We want parents to understand the risks of treatments and procedures that neonatologists discuss freely with one another at medical conferences but rarely share with parents. How often do you tell parents the real risks of drugs such as postnatal dexamethasone,<sup>4,5</sup> or the results of studies on high-frequency ventilation?<sup>6-8</sup> Do you tell them about the toxic levels of aluminum in hyperalimentation fluid?<sup>9</sup> Do you leave them with the false reassurance that unless their baby suffers a major intraventricular hemorrhage (IVH) or periventricular leukomalacia (PVL), all will be well?

How often do you tell parents that there are guidelines in this state (Wisconsin) that allow them to decide about the resuscitation and treatment of babies of <26 weeks' gestation?<sup>3</sup> How often do you tell parents that the choices and options offered at one hospital in this city may be entirely different from those offered at a similar nearby hospital? How often do you tell them that whether their baby is resuscitated and treated depends on such chance factors as the personal philosophy and motives of the physician who happens to be on duty when their baby is born?

Parents need such information from unbiased sources, and they need it during pregnancy, before the baby is born, or, in the case of emergencies, as soon as possible. They need to know beforehand about their options and about the philosophies of doctors and hospitals to whom they entrust their lives and future well-being. We are working with other parents and enlightened neonatal caregivers to make this information widely available through printed fact sheets, on Internet web sites, and through books and videos.

Once parents are in the NICU, we feel that constant communication with caregivers should be encouraged and augmented with audio recordings of all important discussions parents have with the medical team. Parents would keep these recordings to document their interactions with staff and to study at their leisure. Parents should also have free access to the medical literature and to other parents who have been through similar ordeals.

We hope to encourage nurses, who often feel closer to the suffering of babies and their families, to speak out against overtreatment by physicians. We want to encourage them to inform parents accurately and to act as advocates for parental rights.

People try to have children hoping to continue the family line; to experience the joys of family life; to see a child take his first steps, throw his first baseball, graduate from school, and eventually fly the nest to become independent in the real world. We and our son will never experience many of these things. Instead, we will experience the desolation of watching from the sidelines as our neighbors' children attain these milestones, knowing they will be permanently out of our reach. We cannot help but know the difference between what is and



what should have been. And what future lies ahead for our severely disabled son when we pass away or cannot cope any longer? Most likely it will be the brutality of an institutionalized existence.

When people are faced with such tragedies they often try to find comfort by speaking of “miracle babies” and “God’s will.” However, back when God played God, babies such as our son died quickly and mercifully at birth. It seems to us to be a violation of the natural order of things to try to save marginally viable infants, babies who only a few years ago would have been considered miscarriages. The “miracles” that occur in salvaging these unfortunate fetuses do not seem to us to be divinely inspired, but more the product of an all-too-human and highly imperfect and experimental technology.

This technology and the physicians who use it all too often merely prolong the dying process or save severely blighted infants for a future of pain and disability. Why, Nancy and I wonder, did doctors feel compelled to “torture to life” an infant who will never have a chance at a normal life? Is it for their research and professional advancement? To produce good survival statistics for their unit? Is it misplaced legal paranoia? Is it the need to fill beds in children’s hospitals at a time when other populations of patients are declining? All we know is, it was *not* done because it was in our son’s best interests or in ours.

No parent should have to come into a high-risk delivery as uninformed as we were. No parents should have to stand by helplessly as their baby is treated against their wishes. Parents must have the right to truly informed consent even if there are no choices to be made, simply because it is the only ethical thing to do.

## References

1. Abrams FR, Cargo RA, Foss LL, Mashaw R. Colorado Speaks Out on Health: The Final Report of a Two Year Educational Program and Study of Public Opinion on Critical Care Issues; a multi-medical study done in Colorado; 1988:1–9.
2. Guidelines for the Management of Low Birth Weight/Early Gestational Age Newborns (23–26 weeks, 400–7650 grams). Denver, CO: The Colorado Collective for Medical Decisions; 1997.
3. Guidelines for the Responsible Utilization of Neonatal Intensive Care. Madison, WI: Wisconsin Association for Perinatal Care, PS7. Publication 10/97/2500.
4. Hack M, Friedman HG, Minich NM, Fanaroff AA. Antenatal steroids have not improved the outcomes of surviving extremely low birth weight (ELBW) infants (<770 g). *Pediatr Res* 1998;43:216A:1264.
5. Soll R. Clinical trials in perinatal neonatal medicine platform: early postnatal dexamethasone therapy for the prevention of chronic lung disease. *Pediatr Res* 1999;45:266A:1328.
6. Morriette G, Walti H, Chognot D, et al. Prospective randomized multicenter comparison of high frequency oscillatory ventilation (HPOV) and conventional ventilation (CV) in preterm infants < 30 weeks gestational age (GA) with RDS. *Pediatr Res* 1999;45:212A:1247.
7. The HIFI Study Group. High frequency oscillatory ventilation compared with conventional mechanical ventilation in the treatment of respiratory failure in preterm infants. *N Engl J Med* 1989;320:88–93.
8. Han HK, Shakelford GD, Hamvos A. Infants undergoing long-term high frequency ventilation develop hydrocephalus. *Pediatr Res* 1999;45:200A:1173.
9. Bishop NJ. Aluminum toxicity in preterm infants receiving intravenous-feeding solutions. *N Engl J Med* 1997;336:1557–61.