



## INSIGHTS

# Family Reflections: harnessing the power of families to improve NEC outcomes

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Despite doing everything “right,” my twins, Micah and Zachary, were born at 27-week gestation, each weighing just over 1100 g. I had never stepped foot into an intensive care unit, had never seen a breast pump, and was completely overwhelmed by feelings of guilt and anxiety. Gradually, my twins and I became more competent at our tasks at hand. By the time they were 6 weeks old, the twins had doubled their birth weight and were beginning to breastfeed. I could finally see the light at the end of the tunnel, and knew that they would both be home soon. Unfortunately, Micah developed necrotizing enterocolitis (NEC).

NEC is a devastating intestinal disease of severe inflammation that affects vulnerable infants in their first few weeks and months of life. I had never even heard of NEC until Micah was being diagnosed. I had no idea that my twins were at increased risk, and I was not informed about the potential risk or the protective factors that are associated with NEC. Micah’s outcome could have been different if I had the information I needed to serve as an informed and empowered member of my son’s care team. I saw the early warning signs of NEC, but I did not have the skills, awareness, or confidence to effectively voice my concerns. No one informed me that formula increases the risk of NEC, while human milk can serve as a potentially lifesaving intervention for babies like mine. I knew nothing about NEC prevention, the importance of swift intervention, or the options available to Micah, so I was unable to have meaningful discussions with his care team. At best, we can recognize these barriers as unhelpful.

NEC left Micah critically ill, yet somehow, he had the strength to survive. Micah suffered from acute kidney injury, and despite everyone’s hope, his kidneys never recovered. Micah became fully dependant on hemodialysis, as peritoneal dialysis was ineffective. Months later, our family’s dream finally came true when we brought Micah home. We had specific plans and knew how we would support Micah through his lung disease, his short-bowel syndrome, his liver disease, and even his end-stage renal disease. Tragically, we never got that opportunity. Micah passed away from these complications of NEC just before the twins’ first birthday.

Just a few weeks after Micah died, I returned to work at the Ecology Center, a nonprofit environmental organization. Despite my passion for environmental health, I was compelled to direct my

resources and skills to an organization that was working on NEC. Yet, not a single NEC nonprofit organization existed, so I created the NEC Society. The NEC Society is led by patient families working hand-in-hand with leading NEC clinician researchers. We represent thousands of families and clinicians from around the world who are dedicated to building a world without necrotizing enterocolitis. Together, we advance research, raise awareness, and improve care for vulnerable infants at risk of NEC.

Since Micah’s passing, I have learned that NEC is too often regarded as an unavoidable complication of prematurity. After decades of inadequate funding and research, there has been unsatisfactory progress in prevention and treatment options. For much of the last 40 years, there has been little collaboration and no sense of community. The NEC Society is working to change this by uniting diverse stakeholders around this complex, multifactorial rare pediatric disease.



To build a world without necrotizing enterocolitis, it is essential for us to understand how medical practices impact intestinal development as a foundation for disease prevention. We need to

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develop ways to diagnose the disease early and monitor progression, such as with biomarkers, and to develop treatments for NEC that minimize long-term intestinal dysfunction and the related life-threatening complications.



It is also imperative for the NEC community to elevate the voices of families who understand the urgency of this work. The NEC Society's families, who have held our own children as they suffer and die, have critical insight to contribute, and are eager to partner with scientists on advancing NEC research. Specifically, the NEC Society's families are frustrated by the variation in care and lack of universal high-quality care standards regarding the prevention and treatment of necrotizing enterocolitis. Specifically, we are eager for the NEC community to:

- Establish best practices that remain underutilized to better prevent NEC and implement high-quality care standards based on sound evidence to minimize variations in care.
- Increase equitable access to human milk for all vulnerable babies.
- Improve our understanding of how communication and language are used and interpreted in the NICU with patient families, for example, recognizing that the term "Human Milk Fortifier" often misleads families who do not realize that their baby is receiving a bovine-based product.
- Cultivate a process for studying and informing the routine use of probiotics to help prevent NEC, while engaging families in shared decision-making.
- Collaborate with NEC survivors to build our understanding of long-term outcomes, and how this disease continues to affect individuals into adulthood.



To effectively drive systematic change and prevent NEC, our community must engage the patient families who have been directly affected by this devastating disease. Together, we can raise the profile of NEC, secure adequate resources, and advance meaningful research. Patient families have compelling narratives that humanize the disease and demand action. These voices are essential to building a world without NEC.