

**INSIGHTS**



# Family reflections: living with hope and heartbreak after NEC

Elaine Turk Nell<sup>1</sup>✉

© The Author(s), under exclusive licence to the International Pediatric Research Foundation, Inc 2022

*Pediatric Research* (2023) 93:1105–1106; <https://doi.org/10.1038/s41390-022-02388-y>

There are areas of our home that resemble a hospital or pharmacy. Medications and related supplies fill kitchen cabinets and counters. An intravenous (IV) pole with an attached feeding pump is in a bedroom. Various medical supplies are stuffed under beds and in closets. Medications and bottles of formula line refrigerator shelves. A large blue bowl sits on the kitchen counter, its contents waiting to be washed—bottles and caps, feeding tube extensions, G-tube venting devices, and countless color-coded medicine syringes. Once cleaned, they dry on racks surrounding the sink. Soon, the bowl refills.

according to her nutritional needs at the time. The formula composition, strength, volume, and feed rate are altered depending on what her gut tolerates. Lydia carries her feeding pump in a backpack during most waking hours. Any little cold or illness impacts her gut and her ability to tolerate feeds. This puts her at risk for dehydration, malabsorption, and developing an ileus. Dumping syndrome or slowed motility sometimes lasts for weeks or even months. Any of these may require hospitalization and almost always result in weight loss.



Every evening since Lydia came home from the neonatal intensive care unit (NICU) 11 years ago, we've mixed the next day's "recipe" of various elemental formulas, sometimes combined with liquid pectin, Microlipids, Pedialyte, or water

Lydia and her twin sister Carol were born at 27 weeks 3 days gestation by emergency C-section due to placental abruption. Lydia had intrauterine growth restriction and came into the world weighing a mere 1 lb. 9 oz. She was in the hospital for the first

<sup>1</sup>Clemmons, NC, USA. ✉email: [info@pedres.org](mailto:info@pedres.org)

Received: 21 October 2022 Accepted: 21 October 2022  
 Published online: 9 December 2022

304 days of her life. Carol weighed 2 lbs. 5 oz. and was hospitalized for 78 days.



One evening a few weeks after their birth, my husband and I returned from the lactation room to a swarm of nurses and respiratory therapists around Lydia's isolette. Blood was in her stool. A neonatologist showed us Lydia's abdominal X-rays and said the haunting words, "The diagnosis is necrotizing enterocolitis, and it is significant." Antibiotics were started, but Lydia's condition quickly deteriorated, and within a few hours, she was transferred to a Level IV NICU. Lydia's bowel perforated during transit, and emergency surgery was needed. That night, my husband and I knew nearly nothing about necrotizing enterocolitis (NEC). We soon learned why it is a leading cause of infant mortality and lifelong morbidity in the U.S.

At the children's hospital, my husband and I were taken to see Lydia in the NICU. We knew it was a chance to say "goodbye" because she might not survive the surgery. Lydia's skin was ash gray. She was too fragile to be moved to the operating room, so surgery was done at bedside. For the next several hours, we anxiously watched the door and prayed. A nurse eventually came out and said, "Lydia survived but didn't come out unscathed." When the surgeon later came to the waiting room, the first words I remember her saying were, "Lydia really rallied." However, extensive necrosis throughout the bowel required resection of 80% of her large intestine and 80% of her small intestine. NEC left our precious baby with a serious lifelong medical condition called short bowel syndrome (SBS).

A cascade of other health problems followed. Lydia battled infections and had countless medical procedures and blood transfusions as well as several more surgeries, including a serial transverse enteroplasty procedure (STEP). Prior to NEC, her head ultrasounds were clear, and retinopathy of prematurity (ROP) was stage 1. After NEC, however, she developed an intraventricular hemorrhage and then periventricular leukomalacia. Eventually, she was diagnosed with mild cerebral palsy. Her ROP rapidly progressed to stage 3 with plus disease and required immediate surgery to save her vision. We were told all of this was likely a result of trauma from NEC.

Liver failure is a leading cause of mortality for infants on long-term parenteral nutrition. Because Lydia was already suffering from total parenteral nutrition (TPN)-induced liver injury, her medical team obtained a fish oil-based lipid emulsion called

Omegaven to replace the intralipids in TPN, which was believed to harm the liver. They appealed to the Food and Drug Administration for it through an Individual Patient Expanded Access for Investigational New Drug application. We were elated when the request was approved. By the time the medicine arrived, Lydia had cholestasis and looked like she'd been sunbathing in the tropics. Her inflammation eventually reduced upon starting Omegaven and supplementing her formula with Microlipids and fish oil. A recent liver biopsy, now a decade later, shows no signs of liver disease.

The past 11 years have been a blur of complex parenting and intense medical care combined with countless appointments, therapies, hospitalizations, emergency room visits, labwork, tests and procedures, financial strain, and relentless advocacy for our daughters. Lydia is a kind, compassionate little girl who loves to read and play with her sister. However, her medical care is complex and time-consuming. She receives in-home services through our state's Medicaid waiver for medically fragile children. Without it, we couldn't keep Lydia at home because, like most employer-based health insurance policies in the U.S., ours doesn't cover services such as in-home nursing or respite care, home/vehicle modifications, or many of the formulas, medications, and therapies she needs.

Lydia lives with SBS, one of NEC's most serious long-term consequences. A host of physical conditions often co-exist with it, such as gastroesophageal reflux disease, vitamin/mineral deficiencies, small intestine bacterial overgrowth (SIBO), and the formation of intestinal strictures and pelvic adhesions. All too often, abdominal pain is an unwelcome daily companion for NEC survivors, especially those with SBS. Better ways to treat it may occur with the hope of regenerative medicine, refined intestinal imaging, and improved diagnosis and treatment of pelvic adhesions and SIBO. Additionally, a better understanding of the neuro-gut connection to pain, such as that occurs with visceral hyperalgesia, and more research on NEC's neurodevelopmental effects could improve quality of life.

The emotional impact of chronic illness or pain can be severe for anyone, including NEC survivors and their families. Improving access to mental health services as well as developing more pediatric community-based hospice and palliative care programs would give needed support and improved quality of life for this population. These holistic programs ideally include multi-disciplinary teams with specialists such as trauma-informed physicians, nurses, neuropsychologists, social workers, counselors, chaplains, child life specialists, and expressive art therapists trained in palliative care. They could partner with or even be incorporated into intestinal rehabilitation programs.

A physician once stated, "Lydia's done better than anyone imagined possible." Hers is indeed a medical success story. Other than having serious medical conditions and developmental delays, she's very much like most children and has grown into a sweet, smart, fun-loving little girl. We're grateful that she's still with us, that her disabilities are not more severe, and for the amazing medical care she's received. We look forward to further research and medical advances to improve her health and quality of life.

Our family's intense experience with NEC brought out the advocate within me. Since the girls were toddlers, I've volunteered with the NEC Society, a nonprofit 501(c)(3) that is working to build a world without NEC through research, advocacy, and education. You can learn more and join us by visiting [NECsociety.org](https://NECsociety.org).