



## *Addison Kelly*

CHILDHOOD ILD

*By Mary Kelly, Addison's mother*

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When I was 26 weeks pregnant with my second child, Addison, my husband and I were told our baby had a mediastinal teratoma and was in severe fetal hydrops. She (and I) underwent fetal surgery at the Children’s Hospital of Philadelphia Center for Fetal Diagnosis and Treatment. The tumor was removed, but Addison was born at 27 weeks and intubated. She spent nine months in the NICU, received treatment for kidney failure, sepsis, and necrotizing enterocolitis, to name a few. She also went through surgeries such as bilateral diaphragm plication, tracheostomy, and gtube placement. One of her doctors told us she was the sickest baby in the NICU.

Addison’s physician remained positive and realistic, and all of the doctors treated my husband and me as part of the team. They included us when talking about their plan and helped us appreciate the small gains Addison made—one hour, day, and month at a time.

When Addison was four months old, failed extubation and further testing revealed both sides of her diaphragm were paralyzed. One phrenic nerve was severed and the other was damaged by scar tissue. I will never forget the day I was told that my daughter needed a tracheostomy for long-term ventilatory support. I cried. How was Addison going to play with her brother, friends, or simply just be a little kid? The CHOP nurses shared other families’ similar experiences, which helped to guide me in this non-typical life.

With a miniature NICU in your home, your world becomes very small. As supportive as my community was, I still felt isolated and lonely with a technology dependent child at home. Simple tasks like a trip to the grocery store became overly

## CHILDHOOD INTERSTITIAL LUNG DISEASE (chILD)

The word “interstitial” refers to the tissues that surround the air sacs (alveoli) in the lung and airways (breathing tubes). Interstitial diseases can make lung function and oxygen levels low. Childhood Interstitial Lung Disease (chILD) is a group of rare lung diseases found in infants, children and teens. Adults can have ILD too, but their diseases differ from children’s.

Types of chILD have included:

- Bronchiolitis Obliterans
- Chronic Bronchiolitis
- Connective tissue associated lung disease
- Cryptogenic Organizing Pneumonia (COP)
- Alveolar Capillary Dysplasia
- Hypersensitivity Pneumonitis
- Lung growth abnormalities
- Neuroendocrine Hyperplasia of Infancy (NEHI) or Persistent Tachypnea of Infancy
- Pulmonary Interstitial Glycogenosis (PIG)
- Surfactant dysfunction mutations

*Learn more: ATS Patient Education Series. “What is Interstitial Lung Disease in Children?” New York, NY. 2010. patients.thoracic.org*

burdensome. And then there was trying to maintain some sort of normalcy for our son, who was two when Addison came home from the hospital. We did not want him to be afraid of his sister, but we needed him to understand that he could not pull on her trach, gtube, or vent tubing. We had an accidental decannulation at one point, when he used her vent tubing as a leash! But I loved the fact that they were laughing and playing together just like any other siblings would. We were being “normal.”

When Addison was learning to walk, my husband built a stand for the ventilator on wheels. Eventually, Addison started pushing it herself, which gave her freedom and independence. Also, we hired a physical therapist who helped start a ballet class for children with special needs, a speech therapist who was one of very few to also offer feeding therapy, and an occupational therapist. All were key in her development.

When Addison was nearly two years old, we slowly started weaning her from the ventilator, and she got to the point when she only needed support at night. Our life has simplified, as we are now down to the Bipap machine and pulse ox. Thank you to all of the teams who gave us the confidence to establish our own “normal,” which has helped us raise an energetic, smart, and thriving 6-year-old girl!

*Mary Kelly spoke at ATS 2013 International Conference in Philadelphia.*