Caitlyn & Elizabeth Hilton

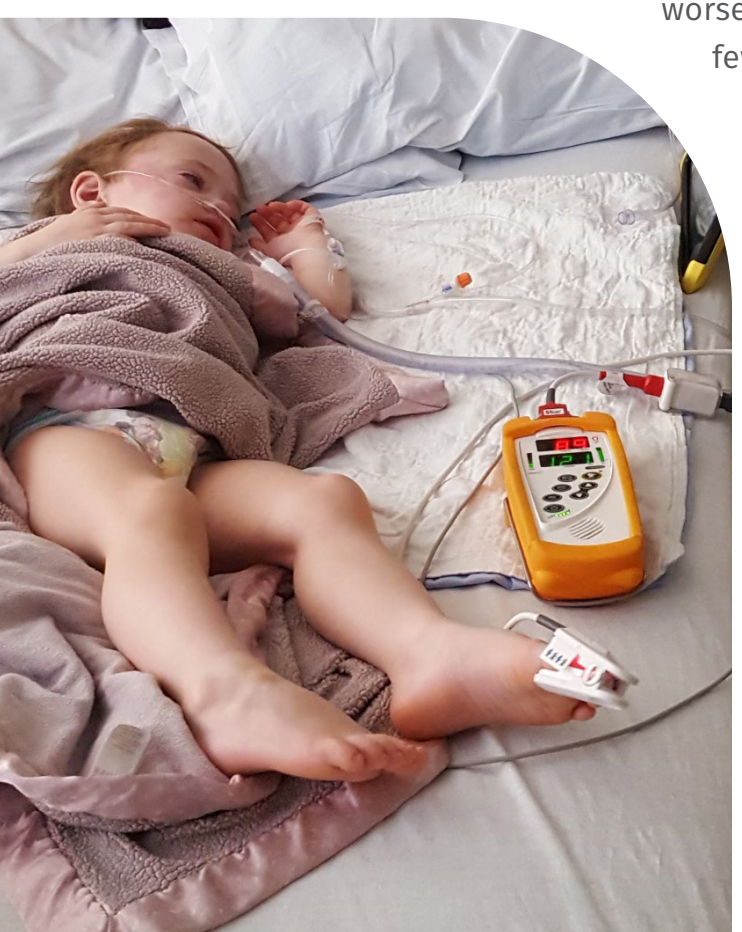
Children's Interstitial Lung Disease

Caitlyn was born at 36 weeks and 3 days, weighing a healthy 5 pounds. About 15 minutes after birth, Caitlyn was blue, floppy and having trouble breathing as she was rushed to the NICU, where she would spend the next 10 days on oxygen, struggling with feeds. As a seasoned mom I could not shake the feeling something was wrong, and I begged the doctors to do an ultrasound to see why Caitlyn would scream every time I sat her up. They agreed, and found a mass in her abdomen, which we were told was likely cancer.

The next day, Caitlyn went into surgery. It was not cancer but a torsed ovary and necrotic fallopian tube, both of which were removed. During the recovery period, Caitlyn experienced what would be the first of several respiratory arrests, which was attributed to her premature birth and small size.

After two weeks, Caitlyn came home. She caught one respiratory virus after another and would land in the PICU requiring oxygen. The first year of her life I remember thinking that she was frequently sick. I discussed my concerns with her doctors and was told it was because she was a preemie.

At 13 months, Caitlyn shut her finger in a door, resulting in a cut that became infected. She was treated with antibiotics, and it healed. Two weeks later, Caitlyn developed a targetoid rash, and was treated for ring worm. She was placed on topical steroids which made the lesions worse. They would heal but reappear every few days. With these lesions, her eyes would swell, and she would scream for hours each day, vomit, refuse to eat, and often had blood in her urine.



We were referred to a dermatologist, who found small vessel vasculitis. We were sent to a number of specialists who didn't know what to do and after a series of repeat respiratory infections, respiratory failures, and PICU admissions, we sought care out of state at the top children's hospital.

We were desperate for answers. I will never forget the day we met the rheumatologist who said “I believe you. There is absolutely something very wrong, and I promise you we will help.” I felt like I could breathe again! We saw this physician a few times, and she referred us to a pulmonologist.

While we were waiting to see the pulmonologist, then two-year-old Caitlyn got another respiratory infection. I took her to our local hospital, and again, she needed oxygen. I was assured that she was ok, and it was just a case of preemie lungs and a cold. She was admitted and despite me repeatedly bringing up that Caitlyn was seeming to struggle to breathe and her O2 saturations were 89-90 per-cent despite oxygen support, I was told it was fine.

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By the third day I was very concerned. She was no longer able to stay awake and had a high fever. Again, I was told she was fine. A few hours later, she was not fine - they couldn't get her oxygen levels to come past 70 percent despite the 15 liters of oxygen. They called for an ambulance for emergency transport to a children's hospital with a PICU.

This PICU took away all her medication, despite me begging them not to. Within 12 hours, Caitlyn declined even more, and I was told she may not survive. She was on the maximum respiratory support, still struggling to breathe, and had a 108.4-degree fever. She went into respiratory arrest.

Somehow, she pulled through. The day she was discharged I called the pulmonologist and begged them to get her in right away. They got her in the very next day! We walked in and met this amazing physician who asked me how Caitlyn slept, how often she needed oxygen, and a series of other questions. We went in for a chest x-ray, CT scan, bronchoscopy, and sleep study.

Her chest CT showed interstitial lung disease, but unfortunately her first lung biopsies have not provided us with what type of ILD she has.

Caitlyn's symptoms continue to worsen. She has been put on BiPAP at night, has developed metabolic respiratory lactic acidosis, renal tubular acidosis, and has had a G-tube placed due to failure to gain weight and grow. She has been evaluated for a lung transplant but ultimately was denied. Genetic testing shows nlrp12 and spinocerebellar ataxia 13, but this still has not led to a confirmed diagnosis or treatment plan. Caitlyn's lung disease continues to progress, she is now on five liters of O2 and has frequent illnesses. I am heartbroken that no one can help my little girl and am terrified that I am going to lose her.

Children's Interstitial Lung Disease

Children's Interstitial and Diffuse Lung Disease (chILD) is a group of rare lung diseases found in infants, children and teens. There are many types of chILD:

- Some types of chILD are genetic and passed through families. Some types are caused by an environmental or infectious trigger. Some have an unknown cause. More and more genetic causes for chILD are discovered as we learn more about genes.
- ChILD symptoms start at different ages. Some types affect babies while others affect older children. Some types of chILD run in families.
- Interstitial lung disease can be hard to detect and even harder to diagnose. Because of this, if your child has symptoms of interstitial lung disease, they should be seen by a pediatric lung specialist doctor (pulmonologist). There is no single test to diagnose chILD, since each type of chILD is different. The lung specialist will choose which tests to order based on your child's symptoms.

Learn more

ATS Patient Education Series