

KID'S PROFILE



Taylor

PROFILE:

Born: 2010

Diagnosis: NEHI/Unknown ILD

Favorite color: Purple

Favorite animal: Zebra

Most prized possession: Her blanket, aka her "wubby"

What she wants to be when she grows up: Nurse

Favorite thing to do: Play softball

TAYLOR'S MEDICAL JOURNEY

My name is Nicole and this is my story about my daughter, Taylor. About two weeks after she was born, I was sitting in the living room with Taylor and our dog, when I heard what sounded like my dog panting. Then I realized it was Taylor that was breathing so loud and hard. Her pediatrician said it's normal for newborns to breathe fast and she will grow out of it. But at six months she was still breathing hard and our new pediatrician told that that it wasn't normal. She was admitted to the hospital for low oxygen saturations and possible whooping cough, then a chest X-ray indicated bronchiolitis and double pneumonia, so she was put on antibiotics. This was followed by weeks of additional doctor visits and hospital stays, but her oxygen saturation remain stubbornly low.

Eventually a CT scan indicated that she might have a type of children's interstitial lung disease called Neuroendocrine cell Hyperplasia of Infancy, (also known as chILD NEHI), so Taylor came home with oxygen and an NG feeding tube. She had a lung biopsy when she was 12 months old to confirm that she did in fact have NEHI. Since then, Taylor has had multiple other issues with different organs and has developed asthma, as well. Her most recent CT scan indicates that she may have Unknown ILD rather than NEHI; hopefully, future scans will provide a more definitive diagnosis. She has been in the hospital for more than 600 total days in her life, has had 12 surgeries, and is still on oxygen most of the day.

She went from being dependent on a feeding tube to now being dependent on an IV, called a broviac that is surgically placed in her chest, and her feeding tube is now used as a stomach drain. She has a chronic cough, her respiratory rate is constantly high, as is her heart rate. Along with oxygen, she gets IV Zithromax three times a week to help with her lung inflammation and is on two inhalers to help with her asthma and NEHI symptoms.

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THE CARE-GIVING CHALLENGE

When you have a special needs child, your life changes in so many ways. It is common for special needs parents—moms especially—to lose friends. When your child is sick frequently, at doctor appointments weekly, in the hospital regularly, and you have to constantly cancel plans, people who don't understand can only take so much of that before they just stop inviting you. That's why Facebook groups came to be a blessing. I could talk to people who could relate to our situation, to vent, and ask for opinions and advice. The big thing was knowing there was someone who understood. As soon as I found out about the NEHI diagnosis, I found the chILD foundation, where I have met so many chILD families and have made so many life-long friends!

Another challenge of having a special needs child is maintaining a job. Taylor isn't able to go to school full time because she becomes too exhausted when doing activities over long periods. I am able to work just the few hours a week she is in school. The other 90% of the week I am caring for her, to make sure she gets her medications, wears her oxygen like she is supposed to, change tubes and drains, draw labs, make IV nutrition, change IV dressing, and so much more. I'm basically her personal nurse. But the blessing in disguise is that I am able to spend more time during the week than any other parent does with their kid who is her age and in school. That's one thing I always strive for—to find the good in every bad situation! It's a priceless lesson for anyone with a special needs child.

TAYLOR, THE KID

Despite all of her challenges, Taylor has always been a bright, positive and smiley kid! She doesn't like the tubes and oxygen, but tells me she knows these things are helping her stay alive. She has always been so positive and understanding about things that are going on in her medical life. Her medical situation has also made her very caring and compassionate with others who are going through different medical journeys and even for those who just experience the normal bumps and scrapes of childhood. We also try to keep her everyday life as normal as possible. She plays sports and has awesome friends who are very supportive of her. She spends a lot of time with her family, including a little brother who keeps her on her toes. Taylor is truly a normal, happy seven-year-old girl just has some stuff going on that causes her to need extra support to help her body thrive. Her positivity and optimism make this whole situation so much easier.



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