

KID'S PROFILE



Alida

PROFILE:

Born: 2009

Diagnosis: NEHI

Favorite color: Turquoise

Favorite animal: Dogs (of course)

Most prized possession: Her Blue Blankie, Her Doll (Lilyanna), and Mr Gibbs!

What your child wants to be when he/she grows up: scientist

Favorite thing to do: Reading, Singing, and science projects

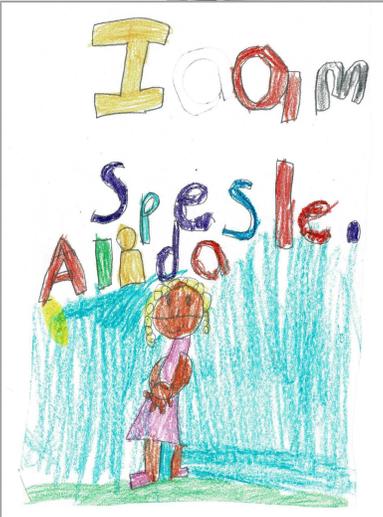
ALIDA'S MEDICAL JOURNEY

Our daughter Alida was born premature at 35 weeks. She struggled from the get go and was immediately taken to the pediatric ICU. Her breathing did not improve until she was given a dose of surfactant. After eight days in the PICU we were sent home with an apnea monitor and oxygen. She was taken off the oxygen at around four months of age, but at six months was hospitalized with what was described as viral pneumonia, and has been back on oxygen ever since. At eight months, we noticed that her heart rate was through the roof! When X-rays of her chest and lungs showed the same viral pneumonia look, it was back to the hospital, and It was at this point we demanded to see a specialist. After two weeks of testing she was diagnosed with NEHI and GERD. It was purely by God's grace that our physician had done his fellowship under Dr. Robin Deterding and had suspected NEHI when he examined Alida.

She began a program of oxygen, thickened liquids and reflux medicine. I transferred to a work position in Georgia, because the altitude and air quality in Utah were not good for her. The move immediately improved her condition, but only marginally. We have noticed more improvement over time, with her breaks from the oxygen growing longer and more frequent, but we notice an increased heart rate whenever she is off the oxygen. She has had her tonsils and adenoids removed to help with her apnea and we continue to have sleep studies done. She has subsequently been diagnosed with asthma. With this combination of factors to deal with, we work closely with our physician to follow a treatment plan: Inhalers as needed for her asthma, plus half a liter of oxygen during the day and one liter at night. We often let her break from the oxygen during recess and other play activities and then we just "tank her up" after she has been off for awhile.

KID'S PROFILE

GENEROSITY
BREATH
CURE
HOPE
FAMILY
CHILD
LOVE



THE CARE-GIVING CHALLENGE

Oxygen is just our normal; we have really never known any different. Alida has been off oxygen for only two months of her life. The biggest factor to help with our situation is Mr. Gibbs, Alida's service dog, constant companion and helper, who joined our family in 2012. He carries her oxygen tanks, which gives her a level of mobility and independence that wouldn't otherwise be possible. After having him for about a year, he actually alerted us one night when her cannula had come off after they had gone to bed. He barked and jumped on the bed until we came, then laid down and relaxed as soon as we put the oxygen back. He started going to kindergarten with her to carry the oxygen tanks full time, and still does it as she enters third grade in 2017. The kids in Alida's class have all gotten used to them working together as a team.

We got connected with the chILD community when we attended our first chILD conference in 2012, plus the story of Alida's and Gibbs' special partnership was covered in USA Today, YouTube, Reader's Digest Online and other national and international media. That has prompted other families to reach out to us, including a family here in the Atlanta area who saw Alida's story and noted that the similarities to their own child's condition were so great that they begged their doctor to test for NEHI. Sure enough, it was NEHI. It has been so gratifying and therapeutic for us to get together to share our experiences to help another family that was in the diagnosis phase!

ALIDA'S SPIRIT AND COURAGE

I know all parents say their kid is special, but it really is true about Alida. She has an incredible faith in the Lord. Her infectious laugh and personality will brighten a room. She has an old soul and a loving heart. She started off behind the curve, but boy has she caught up and grown wise beyond her years! She is very intelligent and reads well beyond her age. She loves, loves, loves books and almost always has one in her hand. She enjoys swimming, has participated in ballet and gymnastics, and this fall will try softball for the first time. She enjoys singing and is an absolute fanatic about anything Disney and Princesses. She wants to be a scientist when she gets older to find a cure and medicine for herself and other kids with chILD. She also wants to study the stars, learn to code, and discover an ancient civilization. She is always thinking of ways to help other people and will literally give away anything she has if she thinks someone else is in need. She is looking forward to the day that she doesn't need the oxygen, but, for now, she doesn't let it stand in her way. The energizer bunny has nothing on Alida!



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