



## Noah's journey: From the sickest kid in the PICU to an active toddler

This is the story of Noah Phelps' who was born with a large omphalocele and suffered from eating and breathing problems. He spent months at the hospital needing extensive care before finally becoming an active toddler at home.

Noah's story comes to us through Sarah Phelps, his mother, and Walter Reeder, BS RRT, the Pulmonary Education Specialist at CHOA (Children's Healthcare of Atlanta).

- We found out that Noah had a rather large omphalocele when I was pregnant. That means that he had a sac on the outside of his belly that had a lot of intestines and half of his stomach and liver, but we didn't know that anything was going to be wrong with his lungs. When he was born, we were very happy that he didn't have to be on a ventilator, Sarah tells.

They stayed in the NICU for about two months related to the feeding problems before taking him home. Then the breathing problems started.

- We quickly found out that we couldn't hardly do anything with him as a normal baby. I couldn't change his diaper. I couldn't give him a bath. Anything that would make him cry or get upset, he would lose his breath and he would turn dusky, his lips would turn blue. I just couldn't treat him like a normal baby, says Sarah.

They returned to the hospital and got a nasal cannula with some oxygen thinking that would be enough. The days went by but he was not improving. Sarah recalls:

- The crying episodes would leave him so exhausted. I finally took a video and I sent it to our local pediatrician who said that I needed to call 911 right away.

Later when she discussed the incident with the pediatrician, he told her that Noah looked so bad he really thought he was going to die.

### **THE SICKEST KID IN THE PICU**

The ambulance took Noah back to CHOA where they spent a long time trying to figure out what was going on. Sarah continues:

- We finally figured out that his lungs were small and he had pulmonary hypoplasia, and we realized that he was struggling to come off the ventilator in the hospital. So the next thing that they brought about was getting a trach and I was terrified of that idea. I just couldn't imagine him being on a trach not being able to talk.

The next couple of weeks were rough waiting for Noah to get used to the pain of the trach. But instead he got even sicker.

- The surgeons came by and evaluated him to see if he could get on ECMO and they said that he's not a good candidate, Sarah remembers.

- We didn't know how bad he was, until one of the doctors came around and told us he is the sickest kid in our pediatric ICU. And there were some pretty sick kids up there. The doctors' said they were not sure if he was going to make it. They did everything they could, but it was up to Noah if he was going to pull it through. We just didn't know if he was going to make it through the night.

On Christmas Eve he coded. The CHOA team jumped into action.

- There were so many people in that room and they were trying to do different things. They didn't know what was happening, but they did everything they could, says Sarah.

They put him on an oscillator [HFOV- high frequency oscillatory ventilation] but Noah really was not improving much. Then one of the doctors suggested to flip him over and try the prone position, and that did miraculous things for him.



*Noah at the hospital together with his stuffed puppy.*

***“Even though he had extra equipment attached to him, it was so worth it because he was thriving instead of struggling for air”***

#### **TRANSITIONING TO THE VIVO 65 AND GOING HOME**

Slowly Noah's condition improved. He transferred from the oscillator to an ICU ventilator. The next step would be to transition to the rehabilitation area known as "technology dependent intensive care." They could not do this while still on the ICU ventilator. They tried an LTV for several days which did not work. Finally, Walter Reeder pressed them to try him on the Vivo 65. He thought the integrated etCO<sub>2</sub> monitoring would help them monitor his elevated CO<sub>2</sub>.

- He was eight months old. Then finally he started to be a normal baby. I could bathe him. I could change his diaper. I could play with him. Even though he had extra equipment attached to him, it was so worth it because he was thriving instead of struggling for air, Sarah says.

In the technology dependent ICU, Walter Reeder and his team were able to teach Sarah and her

husband how to take care of Noah, what to do with the ventilator and the trach to get them ready to take him home. Finally they were able to take Noah home with the Vivo 65.

- At first it was very scary, coming home with all that equipment and all the backup equipment. But it was actually a lot easier with the ventilator than when he was connected to a nasal cannula, Sarah tells.

Life with the baby Noah started to get more normal. They could go outside with the help of the 11.5 hour battery and case of the Vivo 65.

- I love the battery life on it and the weight is not that bad, it was very user friendly. When we go to the hospital and the respiratory therapist needs something, it's very easy for me to direct them to where they go to find the settings or whatever they need, Sarah says.

## BECOMING AN ACTIVE TODDLER

When Noah turned one year old, they returned to CHOA for surgery to repair the omphalocele. During surgery they discovered that a diaphragmatic hernia was allowing his intestines to spill into his chest cavity impacting his lungs. They removed the intestines from the chest cavity and closed up the opening in his diaphragm. The family spent another couple of weeks in the hospital recovering before returning home. According to Sarah, that's when he really started to fly.

Soon they were transitioning Noah to not using the ventilator during the day and only needing it at night. He learned to speak through the Passy Muir valve in-line with the trach. His mom, Sarah is overjoyed.

- He turned two back in May and he is like a normal kid. I mean, you wouldn't know that he has any problems unless you saw that he's got a trach and he's got a G-tube, but he runs, jumps, climbs, dances, I mean, he's all over the place. He's just like any little two-year-old. So he's got his trach, but he's not hooked up to the ventilator.

Their next step will be to wean Noah off the ventilator at night. His tonsils were removed to help correct his sleep apnea. Once he passes his sleep studies, they will start the weaning process.

For now Noah is intent on keeping up with his older brother by 3 years, Jacob, or snuggling with his mother.

- He is the most affectionate kid. He loves to cuddle. He loves giving hugs. He'll go up to Jacob and give him a big old hug and they're so sweet together. But Jacob is all boy, loves dinosaurs, loves climbing on everything and Noah is following right along in his footsteps." Clearly he has come a long way.



Noah Phelps playing with toys with his Vivo 65.