

# The Pee Wee Post

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## Thomas' Story

By Thomas' Mom,  
Meagan Cunningham



Whether or not Thomas yet knows this, the CHKD transport team is at the very top of his (and mom's) super hero list.

Thomas' premature birth came unexpectedly while we were on vacation in the Outer Banks of North Carolina. Upon arriving at the hospital, the doctor informed me that I was ten centimeters dilated and it was too late to stop my labor. The doctor also stated that if Thomas was born now, the Outer Banks Hospital did not have the medical equipment to keep Thomas alive. I needed to wait until the CHKD medical transport team arrived to deliver. Three hours later, the transport team entered the delivery room and Thomas was born at 25 weeks gestation. He weighed 1.7 pounds, and measured 12 inches in length and was transported to CHKD's NICU.



During his NICU stay, Thomas was treated for NEC, underwent two surgeries, and had several blood transfusions. While in the NICU, it often felt like we were forever treading water in the deep end. However, no matter what setback we faced, at the end of each day I tried to find a celebration. Some days it was a poopy diaper or a small vent wean, other days it was the feeling of comfort in knowing his favorite night nurse was on duty. One of my favorite NICU memories was the first time I held Thomas. He reached out with his tiny hand to touch my cheek. It was such a special bonding moment that I will always treasure. After 105 days in the NICU, Thomas came home on his due date— and my birthday!

A year after Thomas' birth, his sister Madeleine was born. Though being pregnant after having a preemie was very scary, we were so thankful when Madeleine was born full-term. They have a special bond and are the best playmates.

Thomas is now a thriving three year old. He has a way of making those around him as happy as he is, and always comes to the rescue when his little sister is upset. He's happiest when he's running around outside. He insists on reading eight bedtime stories every night, has the biggest zest for life and is the ultimate super hero and best friend to his little sister. ♥



# Dealing with a Difficult Diagnosis

Parents of NICU Grads share their stories and suggestions for dealing with difficult news.

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WILL

involved in the life/care of a child who has had a high grade IVH, the child has better outcomes. Along those same lines, our pediatrician told us that every interaction you have with your child can help to make connections and rewire your child's brain. It made me feel a little less helpless to think that while I can't undo the damage done by the bleed, I am facilitating the best outcome possible just by loving on my kid. -Allison, mom of Will



BENNETT

or tell me if there even was a future. Receiving a diagnosis meant that finally someone could say "we have reason to believe he will make improvements." Sure, he has HUGE challenges ahead of him and this life is not at all what I imagined for him, but huge

## Dealing with an Intraventricular Hemorrhage (IVH) Diagnosis

One of the toughest parts of receiving the diagnosis of a grade IV IVH was learning that you won't know the full

impact of the damage for a long time. I found it helpful to ask what the doctors were looking for each week during our scans, like what optimal healing should look like on the imaging, and what things would be not as favorable. Learning some of the factors that could influence the outcome helped me to feel some sense of control and understanding regarding my baby's progress. Another thing that I found immensely encouraging is that there is research that shows that when families are

## Coping with a Genetic Diagnosis

When you are the parent of a NICU baby, you will likely be faced with difficult news on more than one occasion. Everyone handles this news differently, but for me, I chose the always positive and optimistic route. A genetic diagnosis was something we waited almost 6 months to receive. Prior to a diagnosis, no one could give me a prognosis for Bennett's future,

*I don't let this diagnosis define my son. He defines his own future. -Sarah*

challenges ahead means that he has a life ahead of him. I also believe that he can sense my emotions so I save my ugly cry fest for behind closed doors, in the shower, and red lights during rush hour traffic. He needs cheerleaders and cheerleaders he shall have! I don't let this diagnosis define my son. He defines his own future based on how he feels, what he wants, and how hard he wants to work for it.

-Sarah, mom of Bennett

## Finding Hope after a Grade IV Brain Bleed

At one week old, Catherine was diagnosed with a grade IV IVH, or bleed in her brain. Her doctors discussed potential long-term consequences of this brain injury, including serious physical and cognitive disabilities that would affect her for the rest of her life. We were absolutely devastated. After processing this information overnight, I went in the next day with specific questions to ask the doctor. During this conversation

the doctor explained that with every diagnosis there is a range of possible outcomes. While so many things were out of our control, the doctor told us the things we could do to impact Catherine's future— participating in rounds, advocating for her, getting her the therapy services she needed, reading to her, loving and caring for her, and providing her with a full, rich life no matter what challenges she faced. One of the most difficult aspects of a diagnosis like this is the waiting. Waiting years to find out what kind of challenges we might face seemed unbearable. However, focusing on the things that we were able to control and celebrating every micro-milestone helped tremendously. At almost four, Catherine is thriving and doing so many of the things we once worried she wouldn't do. We still have challenges, but so many great triumphs— like playing ring-around-the-rosie at preschool with friends, crossing the finish line at the CHKD Run/Walk, and loving

books more than any kid I've ever met. If you are facing a difficult diagnosis, don't lose hope. Focus on how you can help your child thrive and celebrate everything! -Megan, mom of Catherine

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-Sarah, mom of Bennett



CATHERINE

*Focus on how you can help your child thrive and celebrate everything! -Megan*



## Dealing with a Brain Injury Diagnosis

At 3 weeks old, our son Isaac was diagnosed with cystic encephalomalacia, likely due to a stroke damaging the left side of his brain. When the neonatologist sat us down to talk about Isaac's brain scans, the news was overwhelming and left us wondering if our child would be able to walk, talk, develop cognitively, etc. We'd already

been told his IVH bleeds were

grades 1 and 2, so we thought his damage was limited and mild. Following the news of this unexpected brain injury, I clung to my faith in the Lord Jesus and continued to place my hope in what I believed: that God would continue to be with our family, sovereign over our circumstances, and our ever-present help amidst all the grief and uncertainty. For other parents going through a similar diagnosis, here are a few tips:

- Lean into the grief process: it's normal and helpful to grieve what has been lost
- Remain hopeful and let the nurses and doctors encourage you with stories of other preemies who are doing amazing things as they've grown older
- Remember that the love and support your child gets at home after discharge is the largest factor in the health and developmental progress of your child
- Utilize resources available to you: Early Intervention, NICU follow-up clinic, etc.
- Don't wait! Start right away with therapies when you are discharged
- Find a support group or a professional counselor to walk through the grief, uncertainty, etc. with you
- Take it one day at a time

-Laura, mom of Isaac

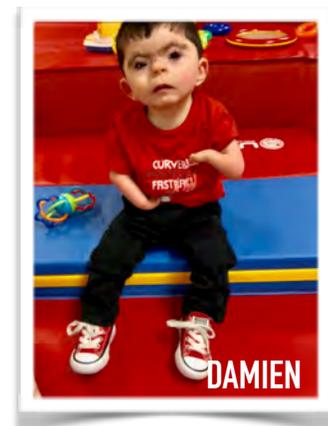
## A Rare Diagnosis

When I was 20 weeks pregnant with Damien, we were told during a routine ultrasound that he was not developing as a normal baby should. He was measuring roughly 5-6 weeks behind, and missing bones in his arms, his hands, and fingers. We declined doing further testing before birth because we knew that no matter the outcome, Damien was our child, and that we'd love him and give him the best outcome at life no matter what.

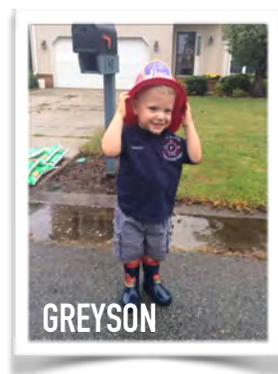
Damien was just one day old when CHKD's genetic doctor, Dr. Samantha Vergano, came in with a social worker and gave us the news of his diagnosis; Cornelia de Lange Syndrome (CdLS). We were in shock. We quickly found the CdLS foundation website, which provided lots of information about CdLS and where to find resources. We joined a Facebook discussion board with

hundreds of other families with Damien's same diagnosis. We shared pictures of him, and posted about our struggles with Damien's NICU stay; GERD, slow weight gain, feeding intolerance, heart murmur, polycystic kidney disease, hypospadias, tethered spinal cord, and the list goes on and on. We were informed right away we were NOT alone.

Our NICU journey was definitely a long one; 232 days to be exact. Damien didn't just have to grow and drink 8 bottles/24 hours to go home. In order for him to be discharged from the NICU, he had to weigh 5kgs to have G-tube & Nissen (to correct reflux) surgery. That day felt like it would never come, especially with him only weighing 1.2kgs at birth and his slow weight gain from his syndrome.



Adapting to life after discharge has also had its challenges. We have to plan our days between physical, occupational, and speech therapy visits; tons of medical appointments (he sees 10+ specialists); and a feeding pump schedule. Connecting with other parents has been so important. Find a Facebook group with your child's diagnosis. Although not everyone is the same, it's good to see that we're not alone. I'm also excited to be a part of a new project where moms of NICU graduates with special needs provide support for families with special needs children who are about to be discharged from the NICU. -Emily, mom of Damien



## Helpful Tips for a Necrotizing Enterocolitis (NEC) Diagnosis

- Ask the medical team questions about your baby's diagnosis. NEC progresses differently for different gestational ages so be sure to get information that pertains to your baby.
- Be assured your baby is still getting nutrition (through IV) even though they are no longer being fed. A few days of rest for

the bowels will not affect your length of stay in the NICU.

- If you are pumping/breast feeding, continue to pump and store your milk. This is the best thing you can do for your baby when they recover from NEC.
- Ask if Prolacta, a human milk fortifier is right for you baby, whenever your child recovers and is able to be fed again.

-Leah, mom of Greyson

# Spring Fun for NICU Grads!



Top row from left: Olivia (29 weeker, now 2) with her dad, Eloise (29 weeker, now 3) helps with gardening, and NICU Superheroes at the CHKD Run/Walk– Isaac (27 weeker, almost 3), Charlie (30 weeker, now 9), Catherine (25 weeker, now 4), Scarlett (27 weeker, now 22 months) and Hayden (27 weeker, now 22 months).



Bottom row from left: Twins Scarlett and Hayden (27 weekers, now 22 months) enjoy some sunshine, Izaiah (25 weeker, now 3) paints some rocks.



## Who's Who in the NICU? MEET NURSE TAYLOR HANNAH

**How long have you been a NICU nurse?**

I have been a nurse in the NICU for almost 3 years now.

**What made you decide to go into neonatal nursing?**

I grew up in a family of nurses from all different concentrations so I always knew that nursing was what I wanted to do and as cliché as it sounds, I really just always knew I wanted to work with babies. I never thought I could be a NICU nurse until one of my professors pushed me to look into working in the NICU. The thought of the "ICU" made me a little nervous, but when I saw what the NICU was about it was an easy decision and I love what I do!

**What do you find most rewarding about your job?**

How much I learn from these babies and families is very rewarding. This job keeps you on your toes and I learn something new every day. Also being able to see a micro-preemie grow and graduate from start to finish makes me feel like what I am doing is really making a difference; that this was a life we saved.

**What advice do you have for the family members of NICU babies?**

Stay strong. This journey is full of 1 step forward and 3 steps back no matter how hard we try. As hard and frustrating as it may be, these babies need your support and faith.

**What do you like to do when you are not at work?**

When I'm not working, I love to stay active and play sports (mainly soccer), hang out with my husband, and cuddle and love on my furbaby Paisley!

**What is an interesting fact that most NICU parents don't know about you?**

I am 1/4th Japanese. :)