



Complex Child E-Magazine

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Trystyn's Story by Carrie Stolz

Trystyn Stolz is a beautiful child, so full of energy and always happy. Now 17 months old, she functions at the level of a five-month-old, but she is trying to roll over. I am hoping that her energy will take her far.

Trystyn's Story

Trystyn was four and a half weeks old when she got sick. She started off with fever and only fever. Since Trystyn was still eating and going to the bathroom normally, I didn't take her to her pediatrician. She is our second child and it seemed like a normal virus. I expected that the doctor would say, "it will just have to work itself out."

Later that evening we went out to eat for my husband's birthday, but when we got home her temperature was 102.7F rectally. I then called the doctor's exchange because it was obvious that she just wasn't feeling well, and she was making this noise that just did not seem right. We were instructed to go to the hospital. While the ER doctor told us it was probably just a bladder infection, a very common illness in infant girls, he stated that he was checking us in for two days. It was mandatory for infants that young to be hospitalized while they wait for the cultures that would indicate infection to come back.

The Seizures Begin

All through the night Trystyn kept waking herself up, but she was still eating normally until Sunday morning. This is when the "ticks" started. I kept telling the nurse on duty that Trystyn was having these "ticks" where her hand and eyelids would move to the same beat. At first they were infrequent, but they eventually got to be about every 15 to 30 seconds. The nurse on duty at that time kept telling me that it was nothing and was probably just from Trystyn not getting any sleep and being so unhappy.

At one point Trystyn stopped breathing. I immediately pushed the button for the nurse, but I had Trystyn breathing again before they even came into the room. At this point they put an oxygen monitor on her.

The "ticks" were coming more and more frequently. When a new nurse came on duty I told her of the "ticks" that Trystyn was having and how the prior nurse kept saying it was

from her not sleeping. I explained that I didn't believe that was the correct answer at all. The new nurse stuck around and sure enough not even a minute later the "tick" started.

This nurse immediately grabbed Trystyn's hand and then proceeded to tell me that she has been having seizures. Typically, if you grab an infant's hand it will automatically stop whatever motion it is making. But the motion that Trystyn was making never stopped, meaning she could not control it. That's how the nurse knew that she was having seizures.

Not even 20 seconds later, Trystyn started having another seizure and again stopped breathing. Trystyn was laying in my lap while they were bagging her to try to get her breathing. Within seconds, there were six more doctors and nurses in our room and they were talking about transferring Trystyn to the PICU.

Trystyn's whole body shut down. She couldn't keep her blood pressure up on her own, and she couldn't breathe on her own. She was moved to the PICU, was intubated, and was placed on a slew of medications including pain medications and drugs to keep her blood pressure up. She stayed intubated in the PICU for two and a half weeks until she was finally able to come off of the ventilator and keep her blood pressure up on her own.

The Search for Answers

I think Trystyn has been tested for every single thing imaginable. The only explanation that we were left with is that the virus she had passed the blood barrier into her brain. In my small world, I thought that once the virus was gone then she was going to be just fine. How very wrong I was.

We found out at six months that she has Cortical Visual Impairment and is considered legally blind. An MRI was done, since she had not had one since she left the hospital. I have no idea what to say about the MRI results, but we were told by her Neurologist that she has severe brain damage. He feels that she will probably never walk or talk and that really the only hope is that the good parts of her brain will take over for the bad parts.

Trystyn is now 17 months old and still can't sit up on her own. She just learned how to roll from her back to her stomach. She has no idea how to get from her stomach to her back.

In reality, we have no diagnosis or explanation for what happened to Trystyn because in the world of trying to get help for your daughter, severe brain damage is not a diagnosis, but rather a symptom. The brain damage is the result of something else, something we still do not fully understand. I will now be in the process of trying to get her neurologist to figure it out, in hopes that Trystyn's future will be better.

Obstacles

If we had an explanation, then maybe we could find treatments or support for her. I will no longer be working as of next year and we cannot afford the equipment that she needs to help her become the best person that she can be. Right now we are a part of the Early Intervention First Steps program that is run through our state, but Trystyn will age out of that program at age three.

What amazes me is that after the age of three, unless you are poor, or at least poorer than we are, you basically qualify for nothing. The GI doctor switched Trystyn to Pediasure, which is double the cost of formula, but of course there is no help for us working folk. It amazes me that I have paid into social security since I was sixteen, my husband since he was fourteen, and because we actually have jobs we qualify for nothing to help with the expenses of having a child like Trystyn.

I am scared to see what will happen after she ages out of the First Steps program. We have a \$5,000 per calendar year limit on durable medical equipment and the Kid Kart she needs is \$8,000, retail price. I have no idea where we would come up with \$3,000 to pay the difference. The other problem is that without a confirmed diagnosis, somehow severe brain damage isn't good enough to get qualified for services or any form of help when it comes to equipment. Hopefully, I will see some changes in the way our children with special needs are regarded and the powers that be will realize that there are families out there that need more than just a placating tone.

It absolutely baffles not only my family, but our neurologist as well, that an unknown virus did this to our daughter. Babies have viruses all the time and are perfectly fine. It just goes to show that anything can happen.

Visit Trystyn and her family at www.sbdandmore.com