

Trinity Davis' Story

In April of 2006 our lives changed forever. Our beautiful blessing Trinity came into this world premature at 35 weeks. What was a normal pregnancy soon turned into a nightmare as Trinity was rushed away from us (first time parents) right after birth. What was wrong? That was a question that could not be answered for three long days until Trinity was transferred to West Penn Hospital in Pittsburgh, PA. It was there that we found out that our sweet baby girl had suffered a Grade IV Intraventricular Hemorrhage (severe brain bleed). Where did this leave us and most importantly what was the outlook on her life? We were told that we really wouldn't know much of what kind of affects the bleed had on her until she was older. She could have motor delays, develop seizures, hydrocephalus and numerous other things the doctors were watching for.

Trinity spent 40 days in the NICU and pediatric unit at West Penn while she gained weight. She also did develop hydrocephalus, which is a disruption in the normal circulation of cerebral spinal fluid that circulates throughout the nervous system. This fluid was not circulating properly causing extra pressure on her brain. Trinity was too small for the surgical procedure used to correct this so she had to undergo lumbar punctures every day to relieve this pressure. When the time came to have to surgical procedure done the doctor could not believe that the hydrocephalus had resolved itself stating that he had never seen this happen. We knew that it was the first of many miracles that we would witness through Trinity.

When Trinity was six months old we took her to Children's Hospital of Pittsburgh (CHP) for a routine EEG to get her taken off seizure meds that she had been put on at birth as a precaution. This day was supposed to be easy, but as we have come to realize, nothing has ever come easy for Trinity. We found out that she was having 60 seizures an hour lasting 30 seconds each. These seizures were only seen on the EEG and did not have any outward effects. She was admitted to CHP for more testing and medication changes. This began our journey with seizures. Doctor appointments, EEGs, blood work, etc., so many new things for Trinity to go through, but she did it all with a smile.

Shortly after her seizure diagnosis, Trinity was diagnosed as having Cerebral Palsy (CP) and Cortical Vision Impairment (CVI). CP is a disorder of movement, muscle tone or posture. CVI is a vision impairment caused by a brain issue rather than an eye problem. All of Trinity's diagnoses are related to her brain hemorrhage. Trinity began to have Early Intervention come to our house to work with her. She had PT, OT, speech and vision therapies all once a week each. She was delayed significantly in all areas. One thing we noticed for sure was that she never gave up and she was always motivated!

Trinity is almost nine years old and attends The Education Center at The Watson Institute in Sewickley, PA. She receives PT, OT, Speech and vision therapies there. She is constantly working hard to reach her goals and is a very happy and motivated little girl despite everything in her life.

Life has always been a rollercoaster journey for Trinity, but the scariest by far have been the seizures. The past three years, Trinity has suffered severe seizures overnight, every time resulting in stays at CHP, twice with life flight rides. Picture this: You put your child to bed, they are happy, healthy-not sick, you go in their room the next morning (which is what we have to

do for Trinity) to get them up for school and you are not greeted by the normal “hi!” Instead, you see a lifeless child lying in a pile of vomit with eyes rolled back into their head, breathing labored (did they aspirate), stomach distended, body limp, not responding. Give you chills? This is our life.

How will an Assistance Dog help?

We have been told try a video monitor-doesn't work, try Emfit monitor-doesn't work, put her in bed with you-she won't sleep, she likes her space. We have asked from the beginning should we get her a Seizure Assistance Dog and have been told no, they are costly, try these other cheaper interventions. Well, the cheaper interventions have done nothing for us. There is no price that can be put on our sweet Trinity's life. It is our hope that this canine friend for Trinity is our next miracle to witness. We hope that with the dog we can get to Trinity in time to prevent her from aspirating her vomit and protect her as she has her seizures, if not stop them with medication as they are occurring. We know that with the dog, at least Trinity will not be alone while she is having a seizure. We also know that the dog will mean so much more than that to Trinity. It will be her true companion.

Thank you for reading her story!

