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Aidan Conway – Personal NF Story

Aidan William Conway was born a healthy full term baby on November 8, 2008. He was a good baby, slept in his own bed early on. I noticed he hit those first milestones a little later than my other children but I just kept a close eye on it. When we went to his 12 month checkup I expressed my concern for his delays, which had now started falling even further behind. The pediatrician... brushed it off and said it was because he was a third child. I gave it a month and decided to call the Tennessee early intervention services. They sent someone out to our house to give Aidan an evaluation. They agreed Aidan was definitely behind and said it would only get worse if left alone.

We immediately started Speech therapy, physical therapy and occupational therapy. I then took Aidan to a Developmental pediatrician for an evaluation. We were sure Aidan had Autism. He would bang his head, scream, not look people in the eyes, etc. She evaluated Aidan and agreed he had Autism. It took a week before this hit me. When it hit, it hit hard, my baby has Autism. I felt so sorry for him and so helpless.

The Developmental Pediatrician advised me to take Aidan to a Neurologist. I chose one that specialized in Autism so he could get the best care. The Neurologist ordered an MRI so she could see his brain before we ever met with her. We received the MRI results from Le Bonheur. It said the brain had typical findings of Neurofibromatosis. Talk about being shocked. What is this? Why am I just finding out about it? We then met with the Neurologist. She informed us he would most likely start having seizures. She also told us with Neurofibromatosis his body didn't have the ability to block tumors from growing like most. We went home with heavy hearts that day.

Less than a month after this appointment Aidan started having early morning vomiting and his words, the few he had, got all jumbled. His balance went from bad to worse. I took him to the emergency department at Le Bonheur on the third day of this. The staff checked him out and sent us on our way saying it was just a stomach virus. I disagreed but what could I do. It continued and three days later I took him back to the emergency department. This time I called his Neurologist before going. When I arrived I told the staff this was not a stomach virus and I wasn't taking my baby anywhere until they figured out what it was. They ordered every test you could think of. The spinal tap was clear and the blood results were good so we were waiting on the MRI.

The doctor came into our room on the neuro floor the next night after 6:00pm. It was just me and Aidan. She told me my baby had a very aggressive tumor on his brain stem and that we would be sent to St. Jude immediately to start high dose radiation and chemo in hopes that we would get more time with Aidan. I was devastated. We buried a baby in December of 2005 and I was not ready to give up another baby. Our life with Aidan had just begun. We stayed in Le Bonheur for three more days while St. Jude went over Aidan's scans. Our neurologist came back on Thursday and told us I am so very sorry our Radiologist made a mistake. They spot on Aidan's brain stem is not a tumor it is a cafe au lait spot. I didn't care that there was a mistake made. I was just ready to go home and spend every minute with my children. We got a second chance! We stayed another couple days for evaluation. Aidan was slowly getting better and the doctors had no idea what happened. This happened again twice in October and December. The doctors still couldn't tell us what it was. When I went home, I said I never wanted this to happen to another family if I could help it. I called Neurofibromatosis Inc. that following Monday morning. I started the first ever walk in Tennessee through Neurofibromatosis Inc. I also did everything I could to learn more about Neurofibromatosis. Our first year we raised \$7,500! I met some amazing people who understood everything we were going through. We are coming up on our third annual walk.

Aidan started walking two weeks before his 2nd birthday. We were so so excited. We were told he may never walk, that we would just have to wait and see. He showed them!

Everything had seemed to be getting better. I said earlier he had another one of those episodes in December of 2010. It was on December 27, 2010 just two days after Christmas. I don't think I will ever forget that date. We went to Le Bonheur. They knew what to do this time and immediately ordered an MRI. We were sent home and our Neurologist made us an appointment to come to her office on December 29. I told John it would probably be nothing so I could go by myself and he could just let the other two kids play with their new toys. Boy was I wrong. Our Neurologist had me sit down and said we have found a tumor on Aidan's right optic nerve.

She didn't want me to worry but she was sending us to St. Jude for "evaluation".

St. Jude called about a week later with Aidan's first appointment. That was the longest week of my life. I walked the floors and every time the phone rang I about peed my pants. We went in, scared to death. I now know from experience you can spot the new families because they have this terrified look on their faces, that was us. They ran all kinds of tests on Aidan. They did another MRI because their machines see more than others. A couple days later we then sat down with Aidan's new doctors, Dr. Qaddoumi and Dr. Cook.

Dr. Qaddoumi specializes in Neurofibromatosis and the tumors that come along with it. He sat us down too. You always know something's wrong when they have you sit down. He said I'm sorry but your son has Cancer. I cannot explain to you the feeling I had after those words. I had been shot through the heart. He said he not only has a tumor on his right optic nerve but on his left optic nerve also. He said the cancer he has is Pilocytic Astrocytoma. He went on to tell us Aidan has a 50/50 chance of completely losing his vision. He also stated that Aidan will need chemo on and off his entire life.

I went around for six months feeling numb. I just thought everything we had gone through before was terrifying. Aidan had a couple of those episodes I talked about earlier, after going to St. Jude. He was finally diagnosed as having Absence seizures.

When I was younger I used to always think St. Jude was this place where little kids went to die but I can't tell you how far I was from the truth. St. Jude is a place of Hope and Love. We have met some of the most amazing people along our journey. Our journey is nowhere near being over but Aidan is the strongest three year old I have ever known. He can always find a reason to smile no matter what is going on. In December of 2011 he caught a stomach virus. We were at St. Jude 12 hours later. He was in Kidney failure, septic shock, his oxygen, blood pressure, and heart rate were all critically low. When we got there they called for the crash cart and the team. In two minutes he was hooked up to all kinds of machines and in ICU. His little body looked lifeless. The doctors were even crying and said if we had been two hours later he would no longer be with us. He slowly got better over the next week. He went home on Christmas Eve. We were so excited to have our family together again just in time for Christmas. He had a bag of fluids connected to him at all times for the next three weeks. We have to watch his kidneys from now on.

Since we have been at St. Jude and on chemo Aidan's tumors haven't grown any but have had times where there was blood flow to them. He has a new tumor in his spinal cord that was found a few months ago. He also has a tumor called a Neurofibroma on his back that has more than doubled in size over the past year. We cherish every day, every moment we have with our children.

Written by **Elisha Conway**, Aiden Conway's mother
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