

OUR FAMILY JOURNEY

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My husband and I have three wonderful boys. Andrew is eleven, Christopher is 7 (soon to be eight) and Nicholas is two. Christopher our middle son was born September 19, 1997. After typical pregnancy and a repeat scheduled cesarean section our new sweet baby was finally here. Andy was so proud to be a BIG brother, Todd and I were thrilled, and we of course had many visitors to the hospital grandparents, great-grandma, aunts, uncles, and friends. A few days later we were given a clean bill of health and sent on our way.

I had some concerns that he looked a little bit different, he was always upset and his eyes were spaced very far apart. At his two-week appointment the resident filling in for our doctor asked "if my other son looked like Chris" and my

Mom and I both said "no" hoping he would offer us an answer, but he said, "I'm sure he is fine". So we went home and I continued to be concerned.

When he was two months old we were in California for his great grandmother's funeral and took him to a doctor, because he wouldn't stop crying. She seemed concerned about his right eye and wrote a note to our doctor in Colorado to have his eyes checked by an ophthalmologist for strabismus (eye misalignment) immediately. We had it checked and started patching his eyes. As the months went by we took him to the doctor numerous times for ear infections and swollen, bulging, runny eyes. We still couldn't find a doctor to take these concerns seriously. I finally requested a referral to pediatric ophthalmologist when he was seven months old and after quite a discussion we were able to go. She found Chris to be extremely farsighted and gave him a prescription for glasses. He looked so cute and for the first time in seven months he stopped crying and his eyes stopped swelling. What a relief.

Well this short term happiness wore off when we continued to watch his development fall behind and we still worried that he wasn't quite "with it." His favorite past time was watching ceiling fans spin. We met with several more doctors and found out about Child Find, when finally at ten months old a developmental nurse saw us at our clinic. She agreed he didn't seem to be meeting milestones and agreed to make the necessary referrals for him in a month if he didn't start pulling up or rolling over. She also suggested a genetic workup, which our doctor denied, saying "we will wait and see how he does. A month later and still no progress when

he was referred to an Occupational Therapist, a Physical Therapist, and a Speech Therapist, and scheduled for a hearing test.

One morning during breakfast he appeared to have a seizure in his high chair while eating. After a long debate with the doctor and my husband going back to our doctors office and insisting he have an EEG and MRI. They said "okay" and our developmental nurse again requested the Genetic testing, which they did as well. Waiting for the results was horrible, but fortunately we had a hearing test to go to. We were told to bring him very tired so that he would fall asleep during the ABR test. When we arrived they took him into the booth and did an exam and said he did great! We asked if we could still do the other test too. She said "we could do it for giggles". Let me say no one was laughing when it was discovered that he had a moderate/severe hearing loss. I was actually relieved; it explained why he didn't pay attention to us. He couldn't hear. What a whirlwind getting fit for hearing aids, getting the results back that his MRI showed brain cysts, corpus callosum cysts, enlarged ventricles and white matter problems.



Luckily his chromosome testing came back soon and we were able to meet with the wonderful Genetics department at The Children's Hospital. They explained he had a rare chromosome deletion 6p (25) the tiny piece on the end of one his 6th chromosomes had broken off. Who knew this could even happen? I spent a lot of time at the Medical Library researching this chromosome deletion and found that this particular deletion causes hearing loss, vision loss, glaucoma; bone growth delay, brain abnormalities, motor delay, heart problems and Chris had it all.

We spent the next several months visiting many other medical specialists who helped us sort through his syndrome, it still wasn't easy but at least we had a diagnosis and we weren't nuts. Christopher had many early intervention professionals who made our lives so much easier. We met many wonderful people at the Deafblind project, Anchor Center, CHIP, The Listen Foundation and Fletcher Miller, who we would have never known if it weren't for this situation.

Despite such a long first year we are okay. Life is crazy, but we decided that Christopher wouldn't be treated any differently than his big brother (maybe a little more spoiled). He was going to fish, camp and do everything we did. We are so proud of him he has matured into a delightful, funny, smart, silly and excellent brother. He and his brothers are great and we wouldn't change any of them for the world.