

Alex's Story



Alex

My name is Nancy, and I am the mother of five children. My youngest child, Alex, was born deaf. He has the connexin 26 gene mutation. His hearing loss came as a big surprise since no one else in our immediate family has a hearing loss. However, the hearing loss was evident after several failed hearing screenings. (Thanks to Dr. Karl White for these early-detection screenings!) My husband and I quickly immersed ourselves in learning about hearing loss and the options available. We arranged genetic testing so that we could determine if his hearing loss was paired with any other problems typical of some syndromes. It was not. This was an emotional time for us as we explored communication options and wondered what our baby's future would look like. I remember distinctly feeling very sad that my perfect and beautiful little boy could not hear my voice, birds chirping, running water, or music. We read about hearing aids and cochlear implants, visited a deaf preschool, met with a deaf professor of ASL, and arranged private signing lessons for our family. Alex received his first hearing aids at the age of 3 months. I was so happy to finally call him by name and know that he could hear me! We began AVT therapy at this point. We participated in tele-intervention with USU, and we also had an in-home visitor provided by the state. Our training was both wonderful and fun! Alex loved it! Alex responded to my voice, he loved playing with his favorite bell, and he began to talk by his one-year birthday. We really celebrated every decibel of sound he got from his hearing aids. We also continued with our efforts to communicate with sign language. However, Alex would turn the other way when we signed and didn't seem to show the same delight that he did with sound. I personally felt confused and unsure about the need for sign language. Finally, one audiologist recommended to me that we "go with our dream." Our dream was for Alex to be mainstreamed at our neighborhood school in the early elementary years. During the process of accomplishing this dream, we found great value in speaking with other parents who had helpful

insights about audiologists and the surgical experience. We continued to pursue Alex's candidacy for bilateral cochlear implants with medical appointments. When his candidacy for implants was verified, we finally decided to drop our sign language lessons. Alex was implanted at 13 months on his right side and then at 15 months on his left side. I was so nervous to hand him over to the surgeons because he really was my perfect and beautiful boy, but I knew that the cochlear implants would give him another entire way to connect with the world, and I wanted that for him. They did! He was mainstreamed by preschool, entered kindergarten with his neighborhood friends, and was immediately selected to participate in the gifted and talented program. Alex just completed the second grade. He is still part of the gifted and talented program, and the librarian tells me that she's running out of books to recommend to him because he has read so many of them already. This past year, his teacher assigned each student to write a description of another student in the class. A girl named Ella was assigned to write about Alex. I was delighted to see that her descriptive sentences were that Alex loved soccer and reading. That was it. Ella did not define my son by his disability, and I don't believe the other children have either. Alex was selected to play the role of the mayor in *Seussical the Musical* this year and his final line was, "Every voice deserves to be heard." Cochlear implants have been a miracle for my son. He is deaf, but he is not defined by his disability. His voice can be heard!