

Ali's Story



Ali

My heart soared today as Makenzie excitedly pulled out her certificate showing me that her short story was one of the few chosen to represent her school in the districts Young Writer's Celebration. Tomorrow she is performing in a musical theater production with some of her 8th grade peers. She has always excelled in school, is on the honor roll, and is acing honors math. She floods me with stories of lunchtime conversations she has had with her friends and is an all-around happy well-rounded girl. Oh how I wish the me now could tell the me from the past that everything would turn out this way. It would have significantly reduced the sleepless nights, the heartache and guilt and the many tears that were shed due to the uncertainty of what the future would hold for my child 16-month old child who was diagnosed with a severe-profound bilateral hearing loss. Although her diagnosis was almost 13 years ago, I remember the details like it was yesterday. Here is our story... My healthy 7 pound 11-ounce baby was born a month early but things went very smoothly with her delivery. When we were preparing to leave the hospital our nurse mentioned she didn't pass her hearing screening test, but said it was most likely due to the trauma of being born and that kids don't pass ALL the time and not to worry. They had her come back 12 days later and repeated the test. Makenzie was crying during the retest and the nurse was on the phone while testing her. She assured me everything was "A-OK" and I left

the office happy as could be never really thinking about hearing again till my daughter was about a year old. When I went to her 1 year well baby check, I told her pediatrician that I was concerned because she wasn't crawling, had awful balance, didn't say any words, etc. I wasn't thinking hearing loss at this point, I was just concerned that she wasn't reaching her milestones like I thought she should. Her doctor assured me she was fine and pretty much chastised me telling me not to compare her to her brother. He said some children are early and some are late in reaching those milestones. I left the office feeling like I was a horrible mother and I knew nothing. As the months went on, Kenzie still did not crawl, if I wasn't holding her, I was on the floor with her mimicking crawling. She was always connected to my hip, it wasn't until I was visiting with my sister one day and our girls were playing on the floor together and Kenz went to grab a toy from her cousin. I firmly said not to take the toy and she proceeded to take it. My sister asked if I thought Kenzie understood what I said, I burst into tears and said I didn't think she understood anything I said. On the way home that night I had the sudden thought that maybe she couldn't hear me very well. I then started calling her name, then screaming her name as loud as I could while driving. She continued sucking her cute little thumb and looking out the window while her brother had his ears covered telling me to stop being so loud. That was the moment I remembered her not passing her initial hearing screening when she was first born. When we got home I put her on the floor under the bar with some toys and did the whole bang on the pots and pans test, she didn't respond at all to the banging. As devastating as those moments were, it was also relieving knowing that I figured it out. The next day I got her into the audiologist who through booth testing gave us a diagnosis of a profound HL. An ABR a few days later showed a severe-profound loss. Within a couple weeks she was fit with her first pair of Phonak hearing aids. She really was a different child, she began walking the week she got her HAs, up till this point she hadn't even been able to crawl. We were so excited for the progress we were seeing. She was responding to a lot of sounds and she was picking up the signs I was teaching her at an incredible rate. We lived in a small town in Arizona, ASDB began sending early intervention providers to our home. They were so excited that I had taken sign language through college and that Kenzie was grasping it so quickly. As a mother I was trying to make up for lost time. One night I was on the computer and came across a link that sent out free videos about oral deaf education. I received my VHS a couple days later and cried my eyes out. I wanted my daughter to be able to speak and listen like the children in the video. I wondered how much of it might be smoke and mirrors promoting that mode of communication or the schools that taught oral education. When I saw that there was a school

in Phoenix, I felt a glimmer of hope; however, I was trying not to get my hopes up too high. I made the 3 1/2 drive to the school in Phoenix and brought my mom along for moral support. To say I was impressed would be a great understatement. My mom and I both cried yet again as we met young children with cochlear implants who were talking in full sentences, and who understood complex conversation.



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I knew I would do anything to help my child achieve those results. We immediately began driving our daughter seven hours round-trip for her one hour of parent-infant-therapy once a week. I would spend the whole week working on the strategies that our SLP taught us. It was a lot of work, but to see her progressing made it worth every second of it. The school focused solely on listening and spoken language and encouraged us to drop the use of signs until my daughter had a full oral language established. It was tough at first, but until I dropped the signs, Kenzie would not even attempt to say the words I was trying to get her to say, for instance, she'd simply sign "shoe" when I'd try to get her to say it. Once I dropped the sign and focused only on the oral, it was like an explosion happened. She was starting to imitate so many words and then she began spontaneously saying words as well. One of the most challenging parts of her journey was not feeling supported in the method of communication we chose. Our early intervention providers would come over and continue to sign with her when I asked them to please focus on talking instead. They would bring me articles that talked about children growing up and resenting their parents for getting them cochlear implants. It seems that every time they left my house I would be in tears on the phone with my mom. I finally had to ask them to please stop coming. With Kenzie's degree of hearing loss, she had good benefit from her hearing aids, but was still missing a lot of the high-frequency sounds, so we opted to get a cochlear implant. Unfortunately, after two years she had a soft failure and had to be re-implanted, but honestly it didn't slow her down for one second. With the progress she was making

at Desert Voices, we decided it was time to relocate our family to Phoenix so she could have the full benefit of the program. She attended the toddler group there until she was three, and then moved into the preschool program. I ended up teaching the toddler class at Desert Voices for three years until she was ready to leave the program and mainstream into kindergarten. After her preschool graduation, we moved back to our small town of Yuma, Arizona. It was one of those moments when you look back on the journey and can't believe you've made it to that point. Some days I have felt like we would never get there, there was so much to learn for both her and us, but we did it! When Kenzie mainstreamed into kindergarten, she was actually at the top of her class academically. She had had a great start during her early years and had great school readiness skills in place. When the person in charge from ASDB met her she was in complete disbelief that Kenzie was deaf. ASDB asked if I would be willing to work with children in our town who had cochlear implants, so I did that and decided to go back to school to get my Masters degree in special education specializing in working with children who had hearing loss. My daughter was on an IEP, but only to receive her FM and to have 20 minutes of speech a week. She has completely excelled in school and in all aspects of her life up to this point. We often joke that she would have arthritis if she had to sign because she never stops talking. It has been a journey to get to where she is today, but I honestly wouldn't change any part of that journey now. I never thought I would say that, but she is who she is today because of the trials she's faced and all of the hard work she has put into learning how to listen and talk. The journey was definitely difficult at times, but it brought us all closer together as a family. Now the world is an open door for her and she can do anything she puts her mind to. After having been told that her daughter had normal hearing, Belinda's two and a half year old daughter was diagnosed with a bilateral sensorineural hearing loss.