

Kisan's Story



Kisan

My name is Jackie, my son's name is Kisan, and my husband's name is James. My son is 5 years old and we did not know that he would have a hearing loss when he was born. I gave birth through a birthing center so luckily they have mandatory screenings no matter if you give birth in a hospital or a midwife center. The midwife kind of played it down. She did the test and he did not pass it. She came back two weeks later and did the test and he did not pass that one either so we got the referred out for further testing. We did an unseated ABR and got enough testing done to be able to tell us that he had a hearing loss. It was mild to moderate in one ear and moderate to severe in the other. From then on, we tried not to think about it too much. I mean, he was an infant so you kind of put it from your mind. It is something we would have probably put off for as long as possible until he had speech delays because when your kid is diagnosed with a hearing loss or any other disability, any other challenge, sometimes you just do not want to confront the issue. I mean he looks like any normal baby and was doing all the normal baby things. It is easy to tell yourself they do not have a hearing loss when they do. Luckily Kids on the Move came out and were very persistent in contacting us. They followed up with us regularly until we finally accepted an appointment, and then our PIP advisor came out. She was really great. She thankfully presented us with all our options and we decided that since we did not know ASL and wanted our son to be able to communicate with his peers freely, without the need for an interpreter or having anyone learn a different language, we decided to do LSL (Listening and Spoken Language), and we just went gung ho with it. Every assignment our PIP advisor gave us we did it. She was really hard on us sometimes but we just worked and worked with him. It seemed like it was such an effort to get him to speak and keep his devices on. He was fitted with hearing aids at 6 months which was a bit later than they recommend we worked with him to make up any setbacks from that delay. His progress was on par with

hearing kids, his friends. But his pronunciation always kind of suffered a bit. We found out that his hearing was stable but then it would drop every once in a while. Eventually his hearing loss progressed from mild to moderate on one ear to moderate to severe in the other ear, and severe in the ear that had been moderate to severe. He was just losing most of his residual hearing. For a long time, we resisted the thought of having surgery. It seems like such a big step to get surgery for your little child but we finally decided to get the cochlear implant surgery and even right up until the doctor took him back to the room we had a little last minute talk with our surgeon wondering if we should really do this if there is any way we could hold off but we got the CI done when he was four, the first cochlear implant. And after it, it was just amazing once it was activated, he did not have too many problems with the activation or mapping of the cochlear implant. His pronunciation, I looked back at old videos of him and his pronunciation has gotten so much better which means he can hear so much better by the time that we got the surgery done the first year with his implants. With his hearing aids he had only been hearing may be 60%, which is very difficult to work within a classroom environment. We thought before he starts school we get one cochlear implant done see how it goes. He did so well with it that we just barely got the other one done a few weeks ago, and his recovery again has been great. He is hearing from it just wonderfully. I wish I had been able to see how well he is doing now when I had this little baby with a hearing loss. It was just so frightening for us, wondering if he was going to be able to speak, if he would be able to make friends, if he would be able to learn the things his peers can learn. Through the benefit of a lot of hard work on our part and home therapy that the state provides and the modern technology that is available is just amazing. We have a child now who can communicate freely with his friends and speaks to us, there are no barriers or impediments to us speaking to each other. We are just really grateful for that because he is able to have what we feel is like a full life for him and that's priceless. It is worth all the work we had to put in, all the frustrations and fears that we had. With this last surgery and see how well he is doing, I do not really have any fears for his future because we already have come so far. A lot of the struggles that we had getting here were all internal. Any advice for any parent reading this is that you can do it if you work hard enough you can help them have a full and complete life. Whatever modality you choose you will do what is best for your family. Kisan will be transitioning to a main stream kindergarten classroom this year and we see that as a real achievement for us because he really did take so much work to get to the point where he is now. His pronunciation, learning how to listen, learning how to be in a classroom setting. It has taken a lot of work to get to this point. We feel like him going to a regular main stream

kindergarten classroom is a real achievement for us and for him. Talking about challenges that we had, it was a real challenge for him to keep the hearing aids in probably for the first year had to be by him pretty consistently to make sure when he ripped them out I put them back in. I told myself if he was stubborn I could be more stubborn because he had to learn how to speak and we finally found a solution that worked, we found double sided tape and along with the headband that typically kept him from grabbing the hearing aids and ripping them out before I could get to him. We did a kind of reward system for that and it really worked. He started wearing his hearing aids consistently on his own after that year. For the first year, from six months to 18 months we had to be on him and put his hearing aids in every time he took them out which is multiple times a day but it was worth it.