David's story; Profound hearing loss

Hello, my name is Keila Armas, my husband Daryl and I have three wonderful children, David, William and Kailyn. But today I want to focus on David, my first son.

David was born with bilateral profound sensorineural hearing loss, caused by connexin 26 (Cx26). When he was born, David failed the newborn screening hearing test. Three weeks later, we went back to the hospital for another hearing test, which also failed. Doctors scheduled a final, more detailed test; one that required him to be asleep. When David was 2 months old, we received his diagnosis, then we were referred to the Early Intervention program.

When David was three months old, he began wearing hearing aids and receiving speech therapies at home. David was my first baby; I was not prepared for his diagnosis. It was difficult for me to understand and accept the situation I was living with him. I felt sad, overwhelmed and hopeless.

After some time depressed by the situation, I realized that I was the only person my son had to help him succeed in life. So, I decided to go to therapies to strengthen myself emotionally, I attended to a Family retreat with The Care Project, I joined some parents support groups in English, and I connected with the Beginnings organization. They gave me information in Spanish and I started learning more about hearing loss in my own language. I read about cochlear implants but I wasn't sure if that was what I wanted for my son, as surgery came with risks. All I knew was that I wanted him to be able to talk, to call me mom and talk to my family who lives in Guatemala and only speaks Spanish.

After some time, I asked the Early Intervention teacher if it was possible to meet another child with the same situation as ours. She was very kind and took me to meet a family with an older child with cochlear implants. Seeing this gave me some relief because I saw him talking to his parents and siblings, but I still wanted to know if my son was going to be able to speak Spanish. Since unfortunately, during this time, we did not know anyone who spoke Spanish and who had any hearing difficulties and the information in Spanish about deafness or hearing loss in the state was very limited.

After receiving his first hearing aids, I noticed that he was reacting to some noises. Very loud noises, like a drum, a motorcycle, or an airplane, but he didn't react to my voice, music or any other soft noises. So, I was still sad, I read his books and only paid attention to the images and the movement. He also paid attention to the vibrations and many times I thought he was listening to me, because of this, but it was the vibration that he was noticing, not the noise. The therapist told me that it was important to stimulate his auditory nerve, so I kept talking to him, reading books and taking him to different places to expose him to different sounds and language.

When he turned one, he received his first cochlear implant, the surgery was scary for me, but I saw big changes in his hearing. He started noticing my voice, he started making more noises, paying attention to my voice when I read books and paying attention to the noises around him. That, made me double what I was doing before, instead of reading 5 to 10 books, I started reading 10 to 15 or more books per day. I started talking all the time, singing all the time, dancing, going to farms, going to different activities with him. It was a very remarkable, wonderful change, and I did it all in Spanish.

A year and two months after his first cochlear implant, he received the second, the second cochlear implant cleared the sounds, which helped him identify where the sound is coming from. I continued working hard with him, every week the therapist came to the house and gave us a new goal, I tried to make that goal fulfilled every week. I put all my effort into helping him.

When David turned 3, he started going to school and started receiving therapies in English. I continued to speak Spanish with him at home, and he started learning English at school. He learned English much faster than he learned Spanish! Now my son is 15 years old, speaks English and Spanish and is learning ASL. He is very confident and enjoys life very much.

I began to get involved and help families who live the same situation that I lived with my son. I opened a support group on Facebook for Hispanic families who have children with hearing loss and/or other disabilities called, "Triunfa Caracol Latino (TCL)." We now have 6 support groups in various areas of North Carolina, with the same name and with the goal of showing the community that they are not alone. I also volunteered with non-profit organizations to support Spanish-speaking families who have children who are deaf or hard of hearing, such as The CARE Project and BEGINNINGS and got involved with DUKE and UNC audiology clinics in our area and joined the efforts of Cochlear Implant centers to reach the Spanish-speaking community, COCHLEAR and MEDEL.

In 2022 I began working part-time with the North Carolina Early Hearing Detection and Intervention Program (EHDI) as a parent consultant.

And recently in 2024 I became a member of the North Carolina Council for the Deaf and Hard of Hearing (NCDHH) to advocate in a higher lever for our deaf, blind and hard of hearing Community of North Carolina.

To the families that are just starting the hearing loss journey I want to tell you that you are not alone, we have agencies, programs, organization, support groups and a lot of more resources that will help you to cope with this situation you are living with your precious child right now, so please contact us, we are here ready to support you.

I would like to encourage you to explore our EHDI website since we have great information that will help you to navigate Hearing loss.