DOMINICAN REPUBLIC

Caregiver Name: Sivelys **Child: Alicia**
Age at Implantation: 3 **Age Today: 8**

Alicia is 8 years old and had a cochlear implantation in both ears at age 3. She was born extremely premature at 25 weeks of gestation with an extremely low birth weight. During her period of internment, the doctors used ototoxic medication, and this, in addition to her prematurity, contributed to the development of deafness.

The hardest part was accepting the diagnosis because I was in complete denial. The neonatal screening tests that should have been done at birth were not possible and here in my country, the doctors never spoke to me clearly. In my ignorance, I thought that my daughter would improve through development. This caused me to spend a lot of money until one day I decided to take it on myself and start doing all the research corresponding to my daughter.

At first, I didn't accept the confirmation that she was deaf, it was so difficult for me. My God, I have cried so much, I have suffered so much, and in this country social security doesn't cover any of that, it's all paid for by the parents. I had to find $28,000, which was beyond my reach at that time. I asked for a lot of help and wrote many letters to my family, friends and the state institutions. I persisted, I searched, I saved, I waited, and then I got support. And that's how Alicia got her first implant. It was a great challenge.

Therapy is another challenge. We need to have resources for each therapy and for each accessory that can be damaged. You have to be very patient. The good thing is that I am very persistent and very insistent.

My family has been my greatest support: my mom, my dad, and my brothers have all been there for me because my daughter's father abandoned us, and I've had to deal with this on my own, and we were left to go through this process alone.

She has achieved so much; before she was a restless, fidgety child, but as her hearing has improved, her behaviour has become more balanced, and she is bettering her cognitive development. She knows her name, my name, her brother's name, her grandparents' names, and recognizes the whole family, which was something that worried me a lot. She already knows how to write some things and is she's almost literate. She can express herself and defend herself, which are the things that give me the most peace of mind.

But in this country, we are still very far behind; a cochlear implant is a luxury, not a government priority. People are not educated on the device that they may be using.

Advice I always give to parents of premature babies is that we need to be there for them; we need to do the hearing screening on time and do everything possible so that the child can have a cochlear implant, and then everything else will work out. The money will appear one way or another; you just have to empower yourself and dedicate yourself.

In my country we are light years behind. The effectiveness of a cochlear implant in our children and even adults with profound hearing loss is questionable. We are a low-income population, and cochlear implants are not yet covered by social security, nor are there auditory rehabilitation programs in schools. Those of us parents who have achieved this have done so entirely through our own efforts and resources, but it is still not included in government programs. Hearing screenings for newborns before hospital discharge is only just beginning, but the year Alicia was born, it wasn't done in hospitals; I had to arrange it myself.

I am joining this community today because my intention and desire is to be part of a team that can help parents make this decision and contribute to the continued development of cochlear implants for deaf children in my country. This will help reduce the number of children with hearing impairments and allow them to achieve better cognitive development. Even here, excellent surgery is performed by certified cochlear implant doctors, but many parents choose to travel abroad to ensure their devices are properly calibrated. Currently, a number of children have benefited from a new program that the first lady is starting, but due to a lack of resources, these children have been left without auditory therapy because they haven't been scheduled or calibrated. This is what we are trying to achieve.

It's a rather long story; it's been a very long and winding road, requiring a lot of persistence and perseverance to get here today. The commitment is to continue helping and guiding parents who are still waiting to get a cochlear implant for their children. Hopefully, we can become more integrated in these countries with limited resources.