

PARAGUAY

Caregiver Name: Mercedes
Age at Implantation: 2

Child: José Carlos
Age Today: 3

Our story begins with the arrival of José Carlos. His birth introduced us to something completely unknown. We sometimes believe that we understand certain realities but living them as a family is entirely different. This condition had a profound impact on us—it brought pain and helplessness, but also hope for the future.

In José's first days of life, he was diagnosed with unilateral hearing loss, with the hope that it would not be progressive. At the same time, we were already concerned about his other diagnoses, microcephaly, hypotonia, and very low birth weight.



As he grew, he began to say a few words—six small words in total—but at around a year and a half, he stopped speaking altogether. Doctors began to focus on a possible autism diagnosis, but we, as his parents, believed the issue was related to his hearing.

And we were right. After multiple tests and evaluations, bilateral hearing loss was confirmed at two years and two months of age. That moment brought deep pain and helplessness into our family, the feeling of not knowing what to do or how to help our child.

We also faced the harsh reality that our public healthcare system is slow and inefficient for children with disabilities. Due to limited government funding, many of these children are directed towards sign language education, without being offered alternatives that could improve their quality of life.

But that was when hope arrived. In our case, it came through a hearing loss support organization, its professionals, and the network of parents we connected with. Their support was invaluable and learning that we were still within the window of opportunity because of his age, felt like awakening to new hope.

At two years and six months, racing against time to ensure better adaptation, we began organizing fundraising efforts as a family to afford the device our son needed. At two years and ten months, José Carlos underwent cochlear implant surgery, and at two years and eleven months, the device was activated.

Today, after four months of activation, the babbling has returned. We now accompany signs with sounds, and we can feel that someone is truly there, connecting with the world around him.

Our first and greatest challenge was obtaining a clear diagnosis. In the public healthcare system, this was delayed because they insisted on following protocols without considering early intervention or access to devices. In the private healthcare system, cochlear implants are often proposed immediately, without sufficient explanation of the process, purpose, or long-term commitment involved.



Early intervention was always our greatest concern. When we finally understood what was happening, José was already two years and two months old, and we felt we were running against the clock. This is where the

support of other parents of children with hearing loss became essential. Their testimonies, lived experiences, and guidance were invaluable in helping us make informed decisions. Educational courses about hearing loss and cochlear implants were also fundamental in helping us understand this incredible technology in depth.

To this day, one of our greatest achievements has been obtaining and placing a cochlear implant for our son. Our hope is that, in the future, his greatest achievement will be effective communication within his environment, and that he will be able to live a valuable and independent life, despite his disability.

To all parents facing similar situations, we say this: embrace your children and fight alongside them. Fight together for a better future, so that one day they can be fully independent. May faith and hope always be stronger than any obstacle or adversity that arises, and may you always trust in God.

In conclusion, we truly believe that having a multidisciplinary team and a strong support network of parents and professionals is essential anywhere in the world. Going through the grieving process, rising again, and continuing forward alongside a child with hearing loss is worth it. With support, love, and great effort, everything is possible. From the bottom of our hearts, we hope that one day our son will be able to share his own testimony and become a light of hope for many families.