COCHLEAR IMPLANT INTERNATIONAL COMMUNITY OF ACTION. AISBL

Parents' Voices

in low and middle income countries

Project Overview: Raising awareness of CI for infants and children in low and middle income countries

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Cochlear implantation has provided access to sound for tens of thousands of children with severe to profound hearing loss globally. When cochlear implants are obtained early along with long-term audiologic management, appropriate speech and language intervention, educational support, and family-centered services, children with hearing loss can achieve age-appropriate language and listening outcomes, attend mainstream schools, and become fully integrated members of their families and communities.

Eighty percent of the world's 34 million children with hearing loss live in low- and middle-income countries (LMICs) where cochlear implantation can be prohibitively expensive and the costs of maintenance and follow-up care can be disheartening. In many low-resource settings it can also be difficult to find trained professionals to support listening and language development after surgery. Without access to cochlear implantation and the necessary aftercare, these children will needlessly struggle to participate in their communities.

In an effort to define the ways in which CIICA can advocate for children with severe to profound hearing losses in LMICs, we turned to those families who have successfully obtained a cochlear implant. In December 2025, CIICA put out a global call asking families of children with cochlear implants living in LMICs to share their stories. They disclosed their biggest challenges, successes, supports, and advice. In this compellation, you will find 75 stories from 19 countries across five continents. Individually, they celebrate the uniqueness of each child and their families' love. Together, they underscore the inequality of hearing healthcare and the lengths families travel to ensure their children can reach their highest potentials. CIICA's goal was to document the salient barriers to cochlear implantation in LMICs and build pathways to cochlear implantation for more families.

The opinions expressed in these stories are those of the individual contributors and not necessarily those of CIICA.

A note on terminology:

The essays presented in this collection have been lightly edited for clarity in English and the anonymity of the storytellers and their support systems. Throughout the stories, families use technical terms to describe hearing loss, hearing technology, and the professionals who support them. These words vary between countries, cultures, and narrators. We have not standardized the language used across stories as it reveals how each parent positions themselves as caregivers and in relation to their clinicians and educators. A glossary is included to clarify some technical vocabulary.

Acknowledgements:

CIICA would like to thank all of the families who were willing to share their stories on this platform. We would like to acknowledge the work of the LMIC Project Team, Vahishtai Daboo, Carolina Der, Katalin Gal, Steve Kittur, Eddie Mukaaya, Tanya Saunders, Lusine Stepanyan, Paige Stringer, Ekaterine Tortladze, Giovanna Troncoso, Marcela Varela Vargas, and Liubov Wolowik, for assistance in developing this project, inviting caregivers to share their stories, and reviewing the final product. CIICA also thanks Myia Bennett, Mya Booker, Haleigh Grant, Ashleen Hale, Eryn Hussey, Jesna Magno, Ashley McNaughton, and Merit Omedo for editing and organizing the stories.

This project is supported by Federación AICE

Glossary

ABR (Auditory Brainstem Response) A non-invasive test of the inner ear and auditory brain pathways

APGAR A rapid standardized assessment of newborn health immediately after birth

Audiogram A visual graph used to display the results of a hearing test

Audiologist A medical professional who assesses and treats hearing and balance disorders

Audiometric evaluation A comprehensive hearing test

Audiometry See Audiometric evaluation

Auditory evoked potential testing (AEP) A non-invasive measure of the brain's electrical response to sound

Auditory nerve (cranial nerve VIII; CN8) Transmits auditory and vestibular information from the inner ear to the brain

Auditory rehabilitation Therapy to help people with hearing loss maximize their listening and language skills that may include the family centered implementation of communication strategies, auditory techniques, audiologic management skills, and advocacy.

AVT (auditory-verbal therapy) A family-centered early intervention approach to teaching children with hearing loss to listen and talk through audition alone

Babbling An early stage of child speech and language development in which the child produces repeated nonsense syllables (eg. bababa)

BERA (Brainstem Evoked Response Audiometry) A non-invasive test of the inner ear and auditory brain pathways

Bilateral hearing loss Hearing loss in both ears

Cerebral palsy A permanent neurological disorder affecting movement, balance, and posture

Cochlear implant (CI) An electronic device implanted to bypass a damaged inner ear and provide sound perception to the listener

Deaf culture A distinct culture built around the use of sign language, history, and common values

Decibel A logarithmic unit of measure to represent perceived volume

Down syndrome A genetic condition causing developmental delays, intellectual disabilities, and distinct physical traits

Eardrum (tympanic membrane) A thin cone-shaped tissue that transmits soundwaves from the outer and middle ear

EHDI (Early Hearing Detection and Intervention) A public health program to identify and treat children with hearing loss

Encephalopathy Damage to the brain causing disfunction

ENT (ear, nose, and throat) A medical and surgical doctor who treats head and neck disorders

FM system An assistive listening device designed to help the listener access speech in noise and at a distance

Hearing aids An electronic device worn on the outer ear to amplify sound

Hearing screening A quick non-invasive assessment of hearing to determine if a full evaluation is necessary

Hepatoblastoma Pediatric liver cancer

Hypotonia Low muscle tone

Language therapy Therapy to help people with language delays and disorders improve their language and communication skills

LMIC (Low- and middle-income country) An economic classification used by the World Bank based on Gross National Income (GNI) per capita

Mapping The process of programing cochlear implant software to the user's unique hearing needs

Mastoid The bone at the base of the skull behind the outer ear

Meningitis An infection causing swelling of the membranes covering the brain and spinal cord

Meningoencephalitis An inflammation of the brain

Microcephaly The infant's head is small than expect for their age and sex

MRI (Magnetic Resonance Imaging) A diagnostic assessment using magnetic fields and radio waves to create cross-sectional images of organs, tissues, and bones.

Necrotizing enterocolitis Inflammation of the intestines

Neonatal screening A public health program designed to detect genetic disorders shortly after birth

Neurologist A doctor who assesses and treats disorders of the nervous system

NICU Neonatal intensive care unit

OAE (otoacoustic emissions) A quick test of measuring the health of the inner ear often used for newborn hearing screenings

OT (occupational therapist) A medical professional who assesses and treats physical, cognitive, or mental health challenges to daily activities

Otitis media An infection of the middle ear

Otolaryngologist See ENT

Otologist (See ENT) A doctor specialized in ear care

Ototoxic medications (amikacin, gentamicin, cisplatin) Prescribed medications that can cause hearing loss and balance issues as a side effect

Phonological awareness The ability to recognize and manipulate speech sounds

Physical therapist A medical rehabilitation professional who assesses and treats movement disorders

Physiotherapy See Physical therapist

Profound hearing loss Hearing thresholds higher than 91db

Psychologist A medical professional who assesses and treats mental health conditions

Sensorineural hearing loss A hearing loss caused by damage to the inner ear or auditory nerve

Severe hearing loss Hearing thresholds between 71 and 90dB

SLP (speech-language pathologist) A medical professional who assesses and treats communication and swallowing disorders

Speech and language therapist See SLP

Speech language therapist See SLP

Speech therapist See SLP

Teacher of the deaf An educator specialized in supporting children with hearing loss

Torticollis The baby's neck muscles tighten, tilting the head at an awkward angle

Type 1 cochlear hypoplasia A malformation of the cochlea (inner ear)

Unilateral hearing loss Hearing loss in one ear

Ventilation tubes (pressure equalizing (PE) tubes) Small tubes placed in the eardrum by and ENT to drain middle ear fluid build-up.


ANGOLA

ANGOLA

Caregiver Name: Edson **Child: Alice Sophia**
Age at Implantation: 1 **Age Today: 2**

This story is about Alice Sophia, an Angolan girl born in July 2023, after a smooth 39-week pregnancy, with an Apgar score of 9, until she was 6 months old. Alice Sophia developed healthily and reached the expected milestones for her age.

However, at 6 months of age, in February 2024, she developed a high fever and, as the days passed, her symptoms intensified and she began to show irritability, drowsiness, and skin spots. On the 21st of that month, she developed stiffness in her neck and paralysis of her right limbs, which led to her hospitalization and diagnosis of meningoencephalitis and acute otitis media. During her hospitalization, we realized that the disease had left sequelae, as she had lost body movement and had also stopped reacting to sounds, to which she had previously reacted attentively. In this regard, we were referred to a physical therapist for treatment of her loss of body movement, which began to take effect after two months.

Regarding her hearing loss, we were referred to an ENT specialist for treatment of otitis media, as Alice Sophia had a lot of discharge in her ears and we believed that this was impairing her hearing. However, due to the limitations in our country for the diagnosis and treatment of hearing loss, we decided to travel to Cape Town in search of better healthcare.

In May, after a road trip of approximately 2,500 km, and after undergoing several examinations and hearing tests, she was diagnosed with profound bilateral deafness. At that moment, we were shocked and devastated, as we believed it was a less serious situation. However, in addition to profound bilateral deafness, little Alice Sophia was facing a severe infection of the right mastoid and perforation of the left eardrum that required surgery.

Given little Alice's delicate health situation, we learned about the cochlear implant program, but it required financial resources that were beyond our means. And because her hearing loss was a result of meningitis, we needed to have the implant done quickly. So, we researched cochlear implants and sent emails to different hospitals in different countries (Portugal, Spain, Namibia, and South Africa) and thank God we got a response.

In July 2024, we learned the cost of the cochlear implant, which, given our financial situation, was impossible to afford. However, determined to fight for the health and well-being of little Alice Sophia, so

that she could receive a cochlear implant in one of her ears, we requested assistance from various institutions, but unfortunately received no response.

In this context, due to the urgency of the surgeries, our family's lack of financial resources, and the sharp devaluation of the Angolan currency, we decided to sell the land we owned, take out bank loans, and ask family and friends for loans with extended payment terms.

In August 2024, even though we did not yet have all the necessary financial resources, we travelled to Cape Town, and after covering 2,500 km, we had the great opportunity to meet a doctor in person, an incredible, kind and caring professional who certainly made the impossible possible by referring us to a fantastic team, securing unimaginable discounts and presenting us with two donations from two different foundations, which effectively allowed us to realize this great dream.

We also had the opportunity to meet an ENT Professor, to whom we are deeply grateful for his professionalism, kindness, affection, and for taking such good care of Alice Sophia and making the impossible possible.

During our journey, we also had the privilege of meeting and working with both a Speech-Language Pathologist and an Occupational Therapist. To the Speech-Language Pathologist who is a kind and empathetic professional to whom we are deeply grateful for teaching us how to communicate with little Alice Sophia during her deafness and after her cochlear implant. And the Occupational Therapist, for her support and affection in motor coordination.

After the eardrum repair and severe mastoid infection surgeries performed in September 2024, it was in October, that we finally had the privilege of having the cochlear implant surgery performed, and after a few days, the cochlear implant was finally activated. We were able to see the connection to the world of sound.

Currently, despite the distance we need to travel by road to comply with the cochlear implant program, the difficulty in obtaining passports in Angola, and having to leave Thiago, her younger brother, at home at 3 months old, we are very happy and excited to reconnect with the wonderful people who embraced us during the most

difficult times, and we feel grateful because every day we are surprised by Alice Sophia's cognitive and speech development.

So, 16 months after the cochlear implant surgery, thank God we can say that the cochlear implant has changed our lives, and with the implant in her left ear, we are very satisfied with the benefits of the cochlear implant program, because little Alice loves to listen, loves to communicate, already speaks sentences of up to 6 words, can understand and be understood by different people, without us having to interpret.

Finally, without a doubt, the best decision we have made in our lives was the decision to fight tirelessly to join the cochlear implant program. As it will allow Alice Sophia to have access to school, better social interaction and a better quality of life. **We would like to encourage other parents, relatives and patients with hearing loss to consider cochlear implants, as they significantly change the quality of life of patients and their families.**


ARGENTINA

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Argentina

Caregiver Name: Mónica **Child: Celina**
Age at Implantation: 1 **Age Today: 17**

Hello, my name is Mónica and I am Celina's mother. Celina has bilateral cochlear implants. She became deaf after having meningitis when she was only five months old.

I will never forget the day the doctor told me that my daughter had profound bilateral hearing loss and that she would need a series of tests because she may have consequences from the meningitis. I remember feeling that I could not imagine a future for her. There was simply too much information for one mother to process at once.

I knew nothing about hearing loss. I didn't know cochlear implants existed. I thought hearing aids were only for elderly people and I had never heard of something called auditory-verbal therapy. The only image in my mind was of someone who could not hear or speak. I started looking for an ENT specialist who was an expert in hearing loss. That was the first time I learned about cochlear implants and that many children with implants do very well and live lives just like any other child.

They recommended that Celina started using hearing aids as soon as possible so her auditory nerves would not become inactive and to prepare her for a possible cochlear implant. They also advised me to begin auditory rehabilitation therapy. The only sentence I truly remember from their explanation was "we teach children with hearing loss how to listen". **Fortunately, they helped me a great deal.**

Everything seemed almost magical, perhaps too good to be true, but I placed my daughter in the hands of the specialists with complete trust. I was still in shock and unable to make decisions on my own. She was my first child and it was a lot to take in. I managed to get the hearing aids when Celina was just seven months old. We began auditory verbal therapy while we waited for the day of her cochlear implant surgery.

And the 'miracle' that had been promised in some way slowly began to happen. When Celina was just one year and three months old, she underwent surgery in both ears. **The operation was successful, it was not traumatic at all and her recovery was very quick.** The day after the surgery, she was already walking around as if nothing had happened.

I knew it would be a long and demanding road, but one full of hope. After her implants were activated, she began responding to sounds. Later, she started dancing to music, speaking and singing. I learned to act as a co-therapist. At home we always spoke to her normally and still do. Time passed and she never stopped progressing. I never stopped working with her or taking her to therapy. **Important advice for parents: never stop taking your child to their therapy sessions! I**t requires a lot of sacrifice, but the reward is enormous.

Today, my daughter is 17 years old. I can say that the expectations I once had when I first heard the diagnosis were shattered and became a beautiful reality that I see every day.

Celina has given me the great joy of becoming the person I always imagined she would be. She manages very well in life. She is independent, sensitive, cheerful, strong and thinks for herself. She works hard to overcome challenges. She has just moved into her fifth year at secondary school. She is also rebellious, stubborn, restless and causes the kinds of problems any teenager does. And yes, she is deaf. That was the only thing I never expected. But today, it does not make any difference from the daughter I had always dreamed of.

Writing her story comforts me and I believe that sharing it may help someone else, especially during those moments when it feels like your strength is gone. But it is not true. Strength never disappears, sometimes it just fades for a moment before returning so we can keep moving forward.

Thanks to her implants, Celina has learned to listen, process, remember, understand and speak. She enjoys music and every sound of life. She plays the guitar, plays sports and loves to dance. She can express what she needs and what she feels.

It is incredible to say that she hears through her devices that she takes great care of and have made such a difference in her life and ours.

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Argentina

Caregiver Name: Natalie **Child: Lucía**
Age at Implantation: 2 **Age Today: 6**

I am Lucía's Mother and as a mother, **the greatest challenge I faced throughout this process was reaching a diagnosis.**

I felt that something wasn't right. I noticed that Lucía did not react to certain everyday situations and every time I mentioned this to the pediatricians she had or the speech therapists who evaluated her, they always found some explanation to reassure me. For a while, I trusted their words.

Until one day I said 'enough' and went directly to an otolaryngologist, something that, unfortunately, should have been suggested much earlier. That was when something I had suspected was confirmed. Lucía was hearing far less than I had imagined. In her left ear, she could not hear any sound at all and in her right ear, only one tone.

Everything happened very quickly. At the end of September 2021, we received the diagnosis, and in February 2022, Lucía received her first cochlear implant. Just as her surgeon had told us, from the moment it was activated, everything was wonderful. Lucìa loved her implant from the very beginning. She started discovering each sound and associating what she has seen during the first three years of life with a noise. It was a completely new world—for her and for us as a family.

We never doubted that the implant was the solution. Her hearing could not have been worse, so whatever came next, whether a lot or a little, was going to be positive. We searched for a surgeon who gave us confidence and peace of mind, and Lucía connected with him the very first moment they met.

On August 2 of that same year, she received her second implant. By then, everything was already different. Lucía could hear, **she began saying her first letters and then some words. She learned her name was Lucía, and little by little we kept moving forward. Today, she forms sentences and expands her vocabulary every day.**

The journey is not easy. It requires a great deal of dedication from both the family and professionals. But everything, absolutely everything is worth it. I waited so long to hear her say 'Mom', to have her turn around when I called her name, or her to answer 'what, Mom?'. There are truly no words to describe everything we have lived through.

Along this path, fortunately, we met wonderful people who supported and accompanied us throughout the process and continue to do so today. Talking with mothers who had already gone through this experience helped me tremendously. Everything was new to me, and I didn't really know what it was all about.

Learning to hear does not happen overnight; it is truly a team effort. Lucía gives it her all and even when she is very tired, she keeps going. I am deeply proud of every one of her achievements. She has beautiful implants, which we decorate and take care of with so much love.

The implants gave Lucía back a sense she was missing. Many times, I say they are magical, but the truth is they are not. Many people work every single day to make this magic possible, and for that, I am immensely grateful. **If you are a parent and have fears or doubts, think about all of the good that will come from the moment the processor is activated. Don't give up. It is always worth trying.**


ARMENIA

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Armenia

Caregiver Name: Margarit
Age at Implantation: 4

Child: Alen
Age Today: 9

There are moments in every person's life when it feels as though the whole world has turned against you. Yet from a mother's love is born that indescribable strength that pushes you to fight. Our family's story is exactly that—a chain of love, dedication, struggle, hope, and boundless hard work that has led us to today's victory.

The year 2020 became a time of immense trials for our nation. The pain of the Artsakh war, uncertainty, and the global COVID-19 pandemic created a reality in which the future seemed blurred and fragile. In those difficult days, we stood before the most important decision of our lives. My son was already four years old, and we understood that the time for cochlear implantation surgery was running out. Specialists warned us that four years old was already quite late for such an intervention, and achieving results would be twice as difficult.

But the greatest blow was financial. In the absence of state support, we had to cover the entire cost of the surgery and the expensive hearing device ourselves. Imagine living in a country at war, facing an economic crisis, while trying to raise a huge amount of money so your child can hear. We did not give up. We tightened our belts, gave up everything, and focused all our strength on that one goal. It was the hardest decision of our lives—but also the most correct one.

When people ask what my greatest source of support has been, I answer: my faith and my knowledge. Realizing that the surgery was only the beginning of the journey, I decided to become my son's best specialist. I began to study deaf education and speech therapy in depth. I studied at night and worked with my son during the day. We became a team. I learned how to "let him hear" the world—how to build his first sounds, words, and sentences. Our home became a small school where little miracles happened every day.

Today, when I look at my son, I see a wonderful boy who is already in the fourth grade. He not only attends a regular school but also fully participates in his classes and can read and write. Although his speech has not yet reached the crystal clarity we once dreamed of, his activity at school and in communication is simply astonishing. He has no complexes. He is friendly, disciplined, and incredibly caring.

His greatest love and way of expressing himself is drawing. He creates with colours and images that reflect his rich inner world. Art has become his language—a way to communicate with the world when words are not enough. **To other parents, I would say: Never lose hope because of your child's "diagnosis."** A diagnosis is not a sentence—it is a work plan. Stand beside your child not only as a loving parent, but also as their best teacher. Educate yourself so that you can educate them. I dream of a system where support for children who undergo cochlear implantation

is more accessible. We have walked that difficult financial path ourselves and know how important it is for the state to stand beside parents. I would like to see more specialized centres and greater public awareness so that society accepts these wonderful children with love and equality. Our story is still unfolding. Every day we learn a new word, create a new drawing, and celebrate a new victory. Because love does not ask whether you can hear it,

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Armenia

Caregiver Name: Naira **Child: Erik**
Age at implantation: 1 **Age Today: 6**

I want to tell the story of my son, Erik. He was only 9 months old when I first suspected that his hearing was weak. Why at 9 months? Because after he was born, he did not undergo the hearing screening — the device was broken. They called us back a month later, but even then, it was still not working. Day by day he seemed active; he reacted, he even fell asleep to the "shhhhh" sound, but my inner voice would not let me rest. One day he was playing with his back to the window.

I entered the room and called his name several times, but he did not respond. When I clapped loudly, he jumped. At that moment, we decided to take him for examination. In Yerevan, at a medical centre, we learned the hardest and most painful news of our lives — our miracle had grade 4 severe hearing loss. **The doctors told us that there was no surgery that could restore his hearing. This was the biggest challenge for our family.**

Not only to accept reality, but also to fight against it when you are told there is no solution. But we, as parents, could not accept it. We began searching for possibilities and found a solution — cochlear implantation.

We learned that this surgery was already being performed in Armenia, and many children were already hearing and speaking thanks to it. We registered at a medical centre. The doctors' optimism gave us strength, and we decided that no matter what, we had to operate on our son. **However, a new and very serious problem arose —the financial issue. We did not have the necessary amount of money. It was during COVID, my husband was a serviceman, and soon the war began.**

My husband was sent to the front line. Those days were full of fear and uncertainty. This was the hardest period of our journey. After the war, when we learned the surgery date, we started fundraising.

And here we felt our greatest support — the support of people. Our call for help spread on social media, and the whole world came to help us. In just four days, the necessary amount was raised.

That support gave us faith that we were not alone. On November 27, 2020, the long-awaited surgery was finally performed. We thought everything was over, but in reality, it was the beginning of a new and difficult journey. We started attending sessions with a teacher of the deaf so Erik could learn to hear and speak. At first, it was very difficult. He did not want to sit, he cried, he was nervous. We also visited a psychologist.

The conclusion of all specialists was the same — he had a delay in age-appropriate development but no intellectual or behavioural disorders. Over time, everything began to change. Erik said his first words, then phrases, then sentences. Today, he is almost 7 years old and has great achievements. He plays chess, does pottery, and plays sports. At school, I would not be mistaken to say that he is one of the good students. He especially loves mathematics. He creates his own problems, solves them, and asks me to give him new ones. His achievements are our greatest victory.

This journey taught me a lot as a mother. And my advice to other parents is this: Never ignore your inner voice. Early diagnosis and early intervention can completely change a child's life. Do not be afraid to ask for help and never give up. Your faith and your work can create miracles. At the same time, it is very important that families receive greater support after cochlear implantation. Not only is the surgery important, but also the long-term rehabilitation—the support of teachers of the deaf, psychologists, and specialists, as well as state and social programs that will help children fully integrate into society.

Our journey was difficult, but today, when I hear my son's voice, I understand that the whole struggle was worth it. Erik is our proof that faith, love, and perseverance can change destiny.


COLOMBIA

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COLOMBIA

Caregiver Name: Maria **Child: Alejandro**
Age at Implantation: 2 **Age Today: 16**

As the mother of a cochlear implant user, the challenges we faced as a family emerged mainly during the initial stage. **Limited knowledge about healthcare procedures related to deaf people who use hearing devices sometimes made the journey more complex.** I believe that in Colombia, there is still a need for broader and more accessible guidelines—not only in terms of technology, but also in the understanding of terminology, policies, and available solutions. In addition, there is a lack of proper training for medical service personnel in healthcare centres, as well as a lack of awareness among doctors, surgeons, and ENT specialists. Some professionals work almost in isolation from the broader processes involved. This type of training and sensitization should be mandatory within the regulatory framework, to ensure that deaf people can achieve a good quality of life and shape their own life projects. This was Alejandro's initial expectation: whether his life could resemble that of most hearing people.

Taking ownership as a family, with full commitment, and becoming the axis that brought together an interdisciplinary team was essential. **The school, therapists, the implant brand, and especially families who had already walked this path became the oxygen that sustained and strengthened us day by day, both before and after the surgery.** Everything that followed—rehabilitation and school inclusion—began to make sense, and our son's response to the world filled us with joy.

If I must highlight the most meaningful support in our journey, beyond his father and brother, it was the families and their life stories. Their strength, their resilience, and their willingness to do everything possible—and even more—to help their children move forward has been truly invaluable.

Our son's greatest achievement has been allowing himself to be an active participant in building his own dreams. He knows what he likes, and even when his daily life demands greater effort, he trusts in his ability to move forward. He understands that life sometimes requires a higher level of self-discipline, and he commits to it fully. He is an athlete—a passionate and talented soccer player. And without even trying, he gives us hope and joy every day. He is a good human being; whenever he has the opportunity to help or encourage someone, he never hesitates. His motto is, *"Everything is going to be okay."*

The advice I would give to other parents is to open their minds to the infinite possibilities and joys they can build alongside their children. Do not compare your child to anyone else, as this can affect their motivation and confidence to learn and achieve

new goals. The true benchmark will always be the child themselves. Each one is unique and perfect, exactly as they came into our lives. They are a gift, and they teach us to become better human beings and stronger families.

Observe them with patience, time, and dedication from infancy. Learn from them and discover what they truly enjoy—this is a powerful tool to support their learning pace, language development, and ability to express themselves. Remember that they are not meant to be "like others"; they are meant to be "themselves." Do not be afraid of not knowing. Ask questions, seek information, and stay close to—or build—your own support network. A strong support network is one of the most effective ways to stay connected to the world, as it provides emotional well-being, practical support, a sense of belonging, and resilience to face challenges, ultimately improving quality of life through affection, companionship, and stability.

To access cochlear implantation as a family, we went through several interviews and conversations with healthcare professionals, therapists, and educators. As we explored the benefits of the implant, we recognized the positive impact it would have not only on our child's cognitive and communicative development, but also on his social growth and overall well-being. With this understanding, we decided to give him the opportunity to "hear the world."

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COLOMBIA

Caregiver Name: Diana **Child: Cristian**
Age at Implantation: 2 **Age Today: 23**

Response from Diana,
My greatest challenge was ensuring that Cristian received his implant while he was still very young.

Although we live far from Bogotá, **my greatest support has been his therapy and the professionals who have provided help and guidance at home**, so that Cristian does not miss his sessions.

My greatest achievement is that Cristian is able to hear us and manage many aspects of daily life independently.

My advice for other parents is to show dedication, patience, strength, and above all, a great deal of love.
I have realized that many children do not have implants due to a lack of information known by their parents

Response from Cristian,
My name is Cristian and I am 23 years old. When I was two, I was diagnosed with profound bilateral sensorineural hearing loss and received my first implant.

I have attended therapy sessions with various specialists over the years. **It has sometimes been challenging due to travel, but my parents have always done their best to find the easiest way for me to continue without missing any sessions.**

With the support of my speech and language therapist, who is not only highly skilled but also a wonderful person, we decided to proceed with an implant in my left ear a year ago. Thanks to her guidance and dedication, the process has been much easier.

COLOMBIA

Caregiver Name: Esmeralda **Child: Juan**
Age at Implantation: 16 **Age Today: 17**

We are often unaware of the challenges that shape the lives of others of how the world is designed for those without disabilities, and of the inequalities that arise even in the simplest daily activities. Some people are born with medical conditions, while others encounter them later in life. Such is the case of Juan.

This story begins in 2013. Juan was only five years old when he became ill, suffering from high fevers and irregular breathing. He was hospitalized for four days and later discharged into the care of his parents, who hoped his health would soon improve.

Over the following six months, Juan's parents began to notice unusual behaviours. He did not react to loud noises, such as a door slamming, nor did he turn when his name was called. His speech changed slightly, and he began turning the television volume up to the maximum. Concerned, his mother took him to several specialists. For months, the responses were always the same: "He's spoiled," or "He's just seeking attention."

Eventually, a specialist conducted a series of thorough tests and delivered an accurate diagnosis: profound bilateral hearing loss. It was then that Juan's parents understood the invisible barrier separating their son from the world of sound. Shortly afterward, Juan received his first hearing aids technology that became far more than a medical device; it became a bridge to communication and understanding.

As Juan grew, so did the technology that supported him. At school, he used an FM (Frequency Modulation) system, in which the teacher wore a microphone that transmitted sound directly to his hearing aids, eliminating distance and background noise. This allowed Juan to learn at the same pace as his classmates, strengthen social relationships, and support his cognitive development.

Like many parents of children with disabilities, Juan's parents feared rejection or discrimination from peers. **Fortunately, with the support of teachers and school administrators, an inclusive environment was created where his condition was normalized.** Over time, Juan developed a strong interest in sports and, with the encouragement of his family, joined a soccer training school, participating like any other child.

At the beginning of 2025, during a routine audiometric evaluation, doctors recommended bilateral cochlear implants, as Juan's hearing loss had progressed. A series of medical evaluations followed in preparation for surgery, an important step toward improving his quality of life.

In June 2025, at 17 years old, Juan successfully underwent the procedure. The journey had not been easy, but the results were promising. In the weeks following surgery, Juan was unable to hear, which is a normal part of the recovery process.

After the cochlear implants were activated, Juan continued attending school while participating in auditory rehabilitation sessions. When necessary, he relied on lip reading to support his learning. **His perseverance paid off: he completed his final year of high school successfully, receiving a medal for academic excellence and a diploma as the best volleyball athlete. These achievements were the result of his determination, effective auditory rehabilitation, and the dedication of an interdisciplinary medical and educational team.**

My advice to other parents is this: while cochlear implants are powerful tools designed to compensate for severe hearing loss, it is family love, patience, and support that truly make the difference throughout this long journey.

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COLOMBIA

Caregiver Name: Tatiana **Child: Juanita**
Age at Implantation: 2 **Age Today: 16**

When we received my daughter Juanita's diagnosis, I felt as though my entire world had fallen into silence. **If I were asked what the greatest challenge of my life has been, without hesitation I would say this: accepting her hearing loss** and facing the uncertainty of not knowing whether she would ever hear my voice or be able to integrate into society in the same way as other hearing children.

However, I later realized that I was mistaken. She did not integrate in the same way, she did so in her own way, a better one, with the tools that over the years, I learned to provide her. Fear of the future and the hope for a different outcome were constant shadows during those days, as I struggled to process a reality, I was not ready to accept.

I must acknowledge that throughout this journey, I was never alone. **My greatest source of support has been my family; their strength kept me standing** when I no longer had my own. **In addition, a team of dedicated professionals and other parents who had already walked this path became my guides**. Together, we formed a network where listening to the experiences of others provided the support I needed to move forward.

Today, as I look back, I am deeply moved by my daughter's growth. **Her greatest achievement to date has not only been the moment her cochlear implant was activated and she discovered sound, but also her remarkable ability to communicate and learn another language, her confidence in speaking, and the way she has excelled academically and in sports**. Every word she speaks is a small victory; one we celebrate as if it were a world championship.

My advice to other parents walking this path is a reflection I would share with my younger self from fourteen years ago, when I was just beginning this journey. Now, all I can say is **patience to wait through each stage and perseverance to never give up will be your greatest tools**. **The journey is not linear; there will be difficult days, but we made the best decision of our lives when we chose to embark on this emotional roller coaster**. The adaptability of children is truly remarkable. Trust the process, trust in your child, and above all, never stop nurturing and encouraging them; this will be key throughout their entire life.

Finally, my struggle has not remained confined to our home. **I have come to understand that for my daughter to thrive, the world around her must also change.** To help bring about these changes, **I have joined parent associations to raise awareness about hearing loss** and have studied it from multiple perspectives, seeking ways to support my daughter and other children in developing communication skills. My focus is on helping

the world understand the lives of people with hearing loss. It may sound ambitious, but from my perspective, if we help everyone understand hearing loss, we can build a more inclusive society and, consequently, ensure proper access to hearing support.

My dream is that no child should be left in silence due to a lack of resources, political support, or awareness. I have dedicated much of my journey to volunteering, sharing my daughter's story to help others understand this reality and to offer them the reassurance that with purpose and dedication, success is possible.

Likewise, through my professional roles in various companies, I have actively helped more families gain access to cochlear implants and hearing aids, transforming my personal experience into a driving force for positive change for others.

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COLOMBIA

Caregiver Names: Martha & Juan Carlos **Child: Juanita Isabella**
Age at Implantation: 3 **Age Today: 8**

We are Martha and Juan Carlos, Juanita Isabella's parents. She is eight years old, and together with our older son, Juan Esteban, we are a Colombian family blessed by God through cochlear implantation.

At the age of three, Juanita Isabella received a cochlear implant in her left ear in Bogotá, Colombia. Prior to implantation, she had been using a hearing aid in her right ear since she was just under twelve months old.

Throughout our journey, we have faced and overcome multiple challenges. One of the earliest and most significant being the limited knowledge about cochlear implantation among some healthcare professionals in our city. Many were unfamiliar with this technology and lacked accurate, sufficient, or up-to-date information. On several occasions, we were advised against cochlear implantation, largely as a result of limited professional expertise surrounding it.

Fortunately, we were able to consult specialized otologists, audiologists, and auditory–verbal therapists with expertise in cochlear implantation. These professionals addressed our concerns in a respectful and evidence-based manner, helping us understand that cochlear implantation would enable our daughter to overcome her auditory limitations and develop spoken language.

This guidance allowed us to broaden our perspective and make an informed decision. We chose cochlear implantation, through which our daughter has developed age-appropriate spoken language comparable to that of her hearing peers. She has also demonstrated excellent academic performance and has not required curricular adaptations. For these reasons, we consider cochlear implantation to have been a significant blessing in our lives.

Our primary sources of support throughout this process have been, first, God, second, strong family cohesion, and third, an interdisciplinary medical and educational team of specialists who provided timely information and emotional support from the outset—an essential component of this journey.

Juanita Isabella has demonstrated remarkable resilience, completing five years of individualized auditory–verbal therapy with a Listening and Spoken Language Specialist Certified Auditory–Verbal Therapist. She has since been formally discharged and continues in an auditory–verbal follow-up program. **She has achieved fully age-appropriate spoken language development comparable to that of her hearing peers and attends a mainstream school within a traditional educational model. She does not require specialized educational support, as her auditory and language skills allow her to participate fully in the regular curriculum.**

Based on our experience, we advise other families to remain confident and not lose faith in God. Active parental involvement in a child's treatment process is essential, as it strengthens the child's sense of security, self-esteem, and confidence when facing developmental and social challenges. Equally important is the involvement of specialized professionals with extensive expertise in cochlear implantation, who can provide individualized, family-centered support. We strongly believe that the continuous training and education of healthcare and educational professionals in our country are critical to ensuring that families

receive timely, accurate, and clear information. In turn, this, facilitates early and appropriate access to cochlear implantation and helps prevent fear,
misinformation, and uncertainty among families.

Finally, we would like to recognize the otologists, audiologists, and therapists who remain committed to ongoing professional development and stay at the forefront of advances in auditory technology. Through cochlear implantation, they have transformed the lives of countless children and families worldwide—our family being one such example. These specialists, too, have been a blessing from God in our lives.

COCHLEAR IMPLANT INTERNATIONAL COMMUNITY OF ACTION. AISBL
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COLOMBIA

Caregiver Name: Islena **Child: Laura Vanessa**
Age at Implantation: 18 months **Age Today: 21 years**

I am Islena, the caregiving mother of Laura Vanessa, a young woman who lost her hearing at 18 months of age.

Laura Vanessa is a 21-year-old young woman who was born prematurely at six months of gestation. During my pregnancy, I was undergoing treatment for uterine cancer, which required extremely delicate medical decisions focused on preserving life. Laura was born with hearing; however, for reasons that remain unclear (possibly related to her extreme prematurity), she gradually lost hearing in both ears.

At 18 months old, Laura was diagnosed with bilateral hearing loss. As a result, she was scheduled for cochlear implantation. On May 18, 2005, she received her implant and began a comprehensive rehabilitation process.

From the moment my daughter was implanted, a new challenge began for me as a mother: learning how to support her and how to face her inclusion within the family, society, and the educational system. This journey has not been easy, especially because I never had a strong family support network. I had to completely rethink my life, and this involved leaving my job in order to dedicate myself fully to her rehabilitation and inclusion.

One of the greatest challenges has been confronting attitudinal and institutional barriers while constantly advocating for equality in every aspect of her life.

My greatest support has always been my older children and, at one time, my mother. They have been my encouragement to keep going. Their support inspired me to create a foundation, through which I now support parents of individuals with all types of disabilities.

I live happily with my daughter and am grateful to God for blessing her with intelligence and strength. These qualities have allowed her to become independent from a very young age. Since the age of six, Laura has taken responsibility for her cochlear implant and processor, always attentive to their care and functionality, guided by the specialists who support.

Laura is responsible, committed, and active. When time allows, she practices sports such as soccer and swimming. **One of her greatest achievements, after many struggles, is her strong independence**. She actively seeks support networks that help her resolve educational challenges. Today, she is in her fourth semester of Mechatronics Engineering, is studying English at Level 7, and participates in workshops that strengthen her professional development.

Through everything we have experienced as a family, and through the work I do at my foundation, where we have a Listening and Support Centre that provides guidance not only to parents of children with hearing loss but also to families of individuals with other disabilities, I always encourage parents to first have faith in God, confidence in Him, and confidence in themselves.

It is essential to build trust in our children, to actively support their processes, to educate ourselves on these conditions, and to participate fully in family, social, and institutional spaces. Only then can we face the many difficulties encountered along this journey.

My message to parents of children and young people with hearing loss who use cochlear implants is this: support them, do not limit them. With love, help them become independent. Give them confidence. More important than the implant itself is helping them develop self-confidence and emotional security.

To help my daughter reach her goals, I had to make profound changes to my life project. I changed my role in every environment. **In her early years, I became her ears and her strongest advocate for her fundamental rights. I even changed cities in search of better opportunities for her development, changed friendships, distanced myself from family to avoid discrimination, and changed her school many times, until we finally found environments of adaptation, respect, and appreciation.**

Living with a disability is challenging, and being a woman with a disability presents even greater challenges. It requires fighting against stigma every day.

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COLOMBIA

Caregiver Names: Marcela & Alejandro **Child: Nicolás**
Age at Implantation: 3 **Age today: 10**

Nicolás was born hearing, and every day he would speak on the phone with his maternal grandmother. When he was two and a half, his nursery teachers began telling us that he wasn't following instructions. It was the year of the 2018 Football World Cup, and every time we shouted "Goal!", he no longer reacted or joined in the celebration. Nico had always played football with his brother, happily shouting "Goal!" whenever they scored.

As we began noticing small changes—and with the teachers expressing concern about his ability to follow instructions—we decided to take him for an immediate hearing test. The last audiometry he'd had before entering nursery had shown normal hearing, yet this new one revealed a 30% hearing loss.

From that moment, we began a series of tests to understand the cause. He underwent surgery to place ventilation tubes, and we started the process of using hearing aids. A month after receiving them, he had another audiometry, which showed that his hearing loss continued to progress. The cause was still unknown.

During a routine follow-up, the ENT specialist informed us that Nico already had severe hearing loss in his right ear, and referred us to an otologist, as he might be a candidate for a cochlear implant. We received thorough explanations and guidance, and we immediately began navigating the authorization process with our health insurance.

Nicolás received his cochlear implant in June 2019. Today, six years later, it continues to be nothing short of a miracle to witness him hearing again and living his life fully and joyfully.

Today, Nicolás is one of the top students in his class. He has begun learning several languages, and above all, he radiates happiness, confidence and love in his everyday life. His achievements are our greatest pride. His hearing loss profoundly changed our lives, gifting our family a deep sense of patience, perseverance, generosity and resilience.

At the beginning, our greatest challenges were our lack of knowledge about hearing technologies and the uncertainty surrounding the correct functioning of both the implant and the hearing aid. We did not know how much the surgery or the device would ultimately cost, nor whether our health insurance would authorise such a significant investment.

Finding the right speech and language therapist also took time. Many of the professionals recommended to us by the insurance provider had limited experience with cochlear implants. And, perhaps most importantly, we worried endlessly about giving Nicolás every possible tool to ensure an independent and fulfilling future.

Once the administrative hurdles were resolved, and after an exhaustive search, **we were fortunate to find an exceptional group of specialist's ENTs, an otologist, speech therapists—who have become far more than healthcare professionals. They are guides, companions, and honorary members of our family, helping us navigate this journey with greater peace and confidence.**

As volunteers, we have been able to share our story with other families. This has become a meaningful way to support parents facing the same fears and questions we once had, and to help them approach each stage of this beautiful process with trust and hope.

For our family, choosing the cochlear implant as Nico's hearing solution has been the best decision we could have made. It has been the greatest gift for our son. Having access to technology capable of restoring a child's ability to hear is truly invaluable.

Our advice to parents starting this journey is simple but essential: be persistent, be patient, and encourage your children to wear their implant as consistently as possible to achieve the best results. And with all the love in the world, teach them that their implant is their ear, something precious, something to protect like a treasure.

In the end, the purpose shared by all families should be to raise awareness about the importance of hearing. A cochlear implant is not simply a medical device. For Nicolás and for countless children like him, it is the beginning of a life filled with sound, possibility and dreams.

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COLOMBIA

Caregiver Name: Alejandra **Child: Rafael**
Age at Implantation: 1 **Age Today: 2**

My name is Alejandra, and I am Rafael's mother. Rafael is a 2-year-and-9-month-old boy who was born prematurely at 28 weeks. One of his complications was severe bilateral sensorineural hearing loss, for which he received a cochlear implant in his right ear in 2024. **Throughout this process, one of the biggest challenges has been that he was diagnosed with cerebral palsy.** However, despite everything, he has progressed remarkably well in his auditory therapies. Luckily, with a very strong support network, we as a family have been able to keep moving forward and fighting for his progress every day.

Despite his diagnosis, Rafael is a very intelligent child and already says words like "papa" and "mama," he waves "hello" and "goodbye" with his little hand, he can point to his eyes and he is very observant. However small his achievements may be, for him and for us as parents, they are the greatest; we celebrate everything. Not only do we have to attend auditory rehabilitation twice a week, but because of his condition, we also must attend other therapies.

Based on his diagnosis, the otologist has decided to leave only the right implant. At first, it was difficult to accept that he wouldn't have both implants, however, we now consider it a good decision because it is a great challenge to have a child with special needs and have to manage two implants, since sometimes, due to his motor skills, it falls out a lot or he also takes it out a lot.

I know there are parents who may be going through similar situations right now, with children who have more than one disability. When the diagnosis comes, it feels like you're dying, but God gives so much strength, and I believe that each child arrives and is exactly where they're meant to be. **They chose us as their parents because they knew we would take care of them and that we had the strength to face any situation**. Many times, we feel alone, living on an indescribable emotional rollercoaster, but in the end, the greatest reward is seeing them smile and witnessing their progress each day. Ultimately, the most beautiful thing of all is the immense and boundless love that you feel and receive from that being. **So, to all the parents who read this, I just want to say that we must keep going because our children chose us to raise them with love and strength.**

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Colombia

Caregiver Name: Andrés **Child: Samantha**
Age at Implantation: 4 **Age Today: 13**

This is our story from Colombia. When our daughter was diagnosed with hearing loss, our lives changed completely. **The biggest challenge was not just understanding the diagnosis but accepting that her path, and ours as a family, would be different from what we had imagined.** Fear, uncertainty, and many questions about her future, her education, and her communication in a world that is not always ready to include her all at once. The challenges did not end with the diagnosis or with the cochlear implant.

Samantha was implanted in 2017 when she was 4 years old, and although that was a fundamental step, we faced a very big difficulty: access to speech therapy and auditory rehabilitation. In our country, health insurance does not cover these therapies, and where we live there were no private options available on a consistent basis either.

For several years we received therapy intermittently, always privately, doing the best we could with the resources we had. However, it was not until 2021 that we were able to access consistent and structured therapy. That is when we understood how much continuity could make a difference in the rehabilitation process. That was a turning point in Samantha's development.

Our greatest support has always been ourselves, as parents. We decided to be truly present, not only emotionally but also with time, commitment, and dedication. In 2021 we made one of the most difficult and important decisions of our family life: Andrés decided to resign from his job as a police officer.

Our jobs consumed almost all of our time, and we realized that Samantha needed more from us, more presence and more support. I changed careers to dedicate the time she required, accompany her to her therapies, and be actively involved in her rehabilitation process. That sacrifice made a great difference in our daughter's life.

That same year we also started virtual therapy sessions, which allowed us to access specialized professionals who were not previously available to us. Consistency, family support, and commitment made Samantha begin to progress in a way we had not seen before.

Samantha's greatest achievement to this day is her ability to communicate, connect with others and carry herself with confidence. Seeing how she has developed her language, how she expresses her emotions, how she progresses at school, and how she interacts with other people is something that at one point seemed very far away. Every word, every step forward, and every small achievement is a great victory for our family. Beyond academics or speech, her greatest achievement is her confidence.

Samantha is now 13 years old; she knows who she is, she knows she is capable, and she understands that hearing loss does not define her limits. **To other parents who are beginning this journey, we would say, "Do not give up."** Trust your instincts, educate yourselves, demand your children's rights, and be present. Consistency, even when it seems difficult, changes everything. No effort is in vain when it comes to the well-being of our children.

In Colombia, access to cochlear implants and, above all, to post-implantation rehabilitation remains a great challenge. Sharing our story, talking about these realities, and making visible the barriers that families face is a way to raise awareness and open paths for others. Our journey continues, but it is full of hope. Samantha has taught us that hearing is not just about listening but about connecting, loving, and being resilient. And for that reason, despite everything, we are deeply grateful for this path we walk together.


DOMINICAN
REPUBLIC

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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.


GEORGIA

Georgia

Caregiver Name: Shorena **Child: Shio**
Age at Implantation: 3 **Age Today: 6**

We are from Georgia. Shio is 6 years old and he is hearing impaired. We are all hearing in the family.

The biggest challenge for us was Shio's diagnosis. Support from the government was minimal. Only the implantation and very little rehabilitation were carried out at the government's expense, which was not enough. **A great achievement for us was the cochlear implantation** and permanent rehabilitation of hearing at an organization where we were also provided psychological support.

I would advise parents not to give up and to fight every day to protect the rights of their children. By sharing our story, I want to encourage families who are just starting this journey and give them hope, as an experienced parent who, despite many challenges, calmly and strongly guides her child on the path to success and happiness.

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Georgia

Caregiver Name: Juju
Age at Implantation: 11 Months

Child: Shio
Age Today: 2 Years

This is the story of my super boy, Shio, and I am his mom. It is an honour to share his journey — one that has reshaped our understanding of resilience, hope, and the remarkable abilities of children. Shio was born prematurely at 34 weeks and faced significant health challenges from his first days of life. He spent his first three months in the NICU. On the day he was finally discharged, we were informed that his newborn's hearing screening had not been completed. Because of several risk factors, doctors advised us that he had a high likelihood of hearing loss and urgently needed evaluation. From that moment, our lives became filled with uncertainty. We questioned every sound, every reaction, every movement. We constantly wondered: Did he hear that? Did he respond to my voice? We searched for reassurance in the smallest signs. Shio failed five rapid screening tests. We continued to hope, but when he was eight months old, we received the final diagnosis: bilateral profound hearing loss.

That day felt devastating. It seemed as though the future we had imagined disappeared instantly. We felt overwhelmed and unprepared, with no prior expectations or understanding of hearing technology or support systems. After a few difficult days, we began researching and discovered our local hearing support centre. Reaching out to them became a turning point — a small but powerful light during an extremely dark time.

At an institution, we learned about our options and ultimately chose to pursue a cochlear implant. One of the most meaningful aspects of this process was connecting with people who truly understood our experience. The centre's director is also the parent of a child with a cochlear implant. We educated ourselves about cochlear implants, prepared for surgery, and joined a large support community of parents walking a similar path. Reading their stories provided comfort, solidarity, and hope.

The day of Shio's activation marked a profound change in our lives. It remains one of the most unforgettable moments we have experienced. From that point forward, every day felt like a new discovery. Gradually, Shio began recognizing voices, understanding words, enjoying music, and developing a deep love for book reading—still his favourite activity today.

Shio is now almost three years old. He understands everything around him, loves to play, and enjoys listening to people. Our next goal is to hear his first words. It is taking longer than we expected, but we are waiting patiently and with hope. We continue to walk a demanding road filled with daily therapy sessions, knowing that each small step in his development is meaningful. This journey is long and, at times, challenging, but we are confident it is the right one. We are moving steadily toward the full, independent life we want for our son.

None of this would have been possible without the extraordinary technology of cochlear implants. This innovation opened a world that once felt unreachable for our family. Because of it, Shio can explore sound,

language, and connection in ways we once feared he might never experience. We carry immense gratitude for the technology, the professionals behind it, and the community that supports families like ours.

With time, our fear gave way to belief. We began to see that Shio's future was not limited; it was filled with possibilities. **Looking back, I would tell myself—and any parent facing a similar journey—never lose faith.** Children possess extraordinary strength and adaptability. Their potential often exceeds what we can imagine.

Our children are fighters. They are capable, determined, and inspiring. They remind us of every day that challenges do not define them, courage does.

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GEORGIA

Caregiver Name: Ekaterine **Child: Tatia**
Age at Implantation: 18 **Age Today: 29**

My story is not only about a medical diagnosis. It is about a “train” that began its journey in the middle of a desert and, through determination, built its own tracks toward a world full of sound.

It began 29 years ago, in 1996, during Georgia’s “dark years” - a time of unrest, economic collapse, and little access to information. When my daughter Tatia was born, the joy of motherhood was quickly replaced by hard news. A doctor told us, “Your daughter has profound bilateral sensorineural hearing loss.” Today, those words would lead to early intervention. **In 1996, Georgia offered nothing - no newborn screening, no cochlear implant programs, and no trained speech therapists.** Doctors prescribed vitamins and sent us home. I felt deeply alone. **I understood that if I wanted my daughter to hear, I could not wait for the country to change. I had to change it myself.**

At that time, there was no one to guide me, so I had to become the expert myself. **My greatest support came from international solidarity. Through our local service club and a kind audiologist from Miami, we received our first high-quality hearing aid.** It was a turning point. But technology alone was not enough - it was only a tool in a country with no rehabilitation services. I spent years searching for information, connecting with specialists abroad, and trying to bridge the gap between silence and speech.

The path was not easy. Much of what I learned came too late for my own daughter. In early childhood, timing is critical, and some information reached us after key developmental windows had closed for Tatia. Still, I refused to let those losses be wasted. The knowledge I gained - through both success and painful delay - became a rare and valuable experience, and the foundation for everything I later built for others.

The journey was hard, but I was not alone. I met dedicated professionals, parents, and international partners who helped remove barriers. Their support, knowledge, and belief kept my “train” moving. What began as a personal struggle became systemic change.

In 2012, together with other parents, I founded Georgia’s first non-governmental organization focused on the rights, family support, and inclusion of children with hearing loss. The organization’s advocacy efforts helped inspire the creation of other parent-led initiatives and contributed to major systemic changes, including mandatory newborn hearing screening and the development, expansion, and improvement of state-funded hearing care and rehabilitation programs that now support hundreds of children and families.

Throughout this journey, I sought partnerships to expand our work, but not all cooperation matched my values and ethical standards. When a partnership threatened integrity or transparency, I made the difficult decision to step away.

Staying true to these principles led to a new chapter. Together with professionals who shared my vision, we founded and created a new rehabilitation centre built on transparency, care, and international standards.

Today, it is a strong institution where children receive high-quality rehabilitation based on trust and professional ethics

My advocacy now reaches beyond Georgia. As a member of CIICA, I represent the country internationally and work with the international public health organization and a global assistive technology partnership to expand access to hearing care. I connect local realities with global expertise.

Today, Tatia is 29—an independent, successful woman and a committed civil activist. She proves that a diagnosis is not a destiny. **To other parents, I say: be your child's strongest advocate. Do not wait for the system. Seek knowledge, build allies, and never accept "no."**

My train is still moving. It no longer crosses a desert, but a landscape we helped build. Every mile matters.

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GEORGIA

Caregiver Name: Sopho **Child: Zakaria**
Age at Implantation: 3 **Age Today: 6**

My name is Sopho, and I am the mother of 6-year-old Zakaria. Zakaria has severe bilateral hearing loss. He uses a hearing aid in one ear and a cochlear implant in the other, attends auditory and speech rehabilitation therapy, goes to kindergarten, hears, speaks, and I believe he lives a full and happy life, just like his peers.

However, before we got here, our whole family went through many difficult and emotional moments. **From the very beginning, we faced numerous challenges. Zakaria was born at 35 weeks of gestation, spent two months in the intensive care unit, and fought until the very end to survive.** When I learned about his diagnosis, he was five months old. I did not know what I was dealing with, so I started visiting clinics, had many consultations, searched for as much information as possible, and decided that he should be fitted with hearing aids at the age of one. This decision changed our lives.

Together with Zakaria, our family learned what was important for him to live a typical life, so we began auditory and speech therapy. This was a very interesting process that did not end in the therapy room—it continued at home, during walks in the yard, while visiting others, during play, and while carrying out daily routines.

Zakaria used hearing aids for two years; however, at some point I realized that his progress had stopped. What we were doing was no longer enough. After consultations, gathering information, and a lot of consideration, my child underwent cochlear implantation in 2023. We moved on to a new stage—new technology, new rules. Rehabilitation continued, and his progress became faster and faster. **After the implantation, I look at my child and realize that he is a different person—more confident, more cheerful, and happier.** He is able to communicate with everyone: he plays with his peers, meets new people, and is preparing for school.

The most important thing the implantation gave us is that Zakaria learned how to make hearing part of his everyday life—during play, conversation, and in kindergarten. **To all parents whose children have a similar diagnosis, I want to say that these children have amazing potential and need our support. We must teach them self-acceptance and how to live together with assistive technologies.** The work does not end with cochlear implantation or hearing aid fitting—the work truly begins after they are fitted.


GUATEMALA

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Guatemala

Caregiver Name: Paola **Child: Abby**

Age at Implantation: 18 months **Age Today: 15 years**

My name is Paola. My daughter is Abby. She's 15 years old and received a cochlear implant in her right ear at 18 months of age, and then in 2020 she got an implantation in her left ear. **Our biggest challenge was getting her to speak and catch up with other children her age.** We relied on speech therapists, and the school she started at just two years old. At home, as a family, we've given her all the support she's needed.

Her achievements have been academic: she's completed her school years without any setbacks. She's currently in her fourth year of high school, specializing in science and humanities. In sports, she practices speed skating.

We've always been willing to help those starting on this path of cochlear implants for their children. We've met with families to share how it worked for Abby.

The best advice I can give to other parents is to be persistent and very patient. It's a long road, and often the results are slow, but they do come.

We thank God for having achieved everything we have been able to do with Abby so far and for every person placed in our path to make it possible.

GUATEMALA

Caregiver Name: Astri **Child: Esteban**
Age at Implantation: 4 **Age Today: 16**

I am Astri, mother of Esteban, an extraordinary young man with a cochlear implant living in Guatemala; a low-income country where access to hearing health remains unequal for many families.
When Esteban was born, we did not imagine that silence would be part of his early years. **The diagnosis of profound bilateral deafness confronted us with an unknown world, with our greatest challenges being emotional, economic, and accepting that the path to granting him access to hearing would be long, uncertain, and filled with barriers**. In 2013, after much effort, we managed to schedule his first surgery; the procedure lasted over 6 hours, making it a very traumatic experience. The medical team could not place the implant in his right ear due to a congenital malformation; we left the hospital with our spirits crushed but with something intact; our determination.

We did not give up! In 2014, Esteban was implanted on the left side, and I remember that day as the brightest one after the darkest moments. It was not just a successful surgery; it was the promise of a world that would finally open its doors to him through sound. The subsequent rehabilitation was constant, and we learned to celebrate advances that might seem small to others, but for us, were monumental, such as detecting sounds, turning when he heard his name, recognizing voices, feeling music as a vibration of the world and not just of the heart.

However, the journey was shaken again in 2018, four years after Esteban was implanted; the processor stopped working, and we had to undergo a new surgery to replace it. It was a time of anguish and fear; it was not just returning to the operating room but holding onto hope with trembling hands. Nevertheless, we pressed on because we understood something essential: although Esteban's language development has been slow, his ability to hear, simply to hear, means so much more than any perfection in speech.

But there is something even greater than his access to hearing, his spirit. Esteban is a young man who never gives up, never feels bad for not being able to express himself like others. On the contrary, he seeks means, invents paths, and finds ways to express himself. If he cannot say something one way, he tries another. If he cannot pronounce it perfectly, he communicates with his body, with signs, with gestures, with creativity, with persistence. He not only learned to hear sounds; he learned to make himself heard.

He is an excellent son, a student, and a spectacular human being, dedicated and committed to everything he undertakes. He is a chess player, swimmer, and baker; his chocolate cake and cookies have sweetened more hearts than speeches ever could. He is brave, a traveler, and always curious about the world. He has even traveled alone on a couple of occasions, something that was a tremendous act of faith for us; seeing him cross airports without fear made us understand that hearing disability was never a limit to his independence, just a reminder that he needed more tools and fewer prejudices.

He is also a gamer, a lover of games, and above all, a passionate football player; his greatest passion is to dream it, play it, live it, and feel it. On the field, he does not need translation; he communicates with strategy, movement, teamwork, and silent leadership that is understood without words. He is an athlete, a teammate, and a worthy rival. He has participated in tournaments, celebrated goals, cried over defeats, and has always risen with more strength.

Guatemala did not have, and still does not fully have, accessible processes in the public system for cochlear implants, so we had to build part of the path ourselves.

If I could give advice to another parent or guardian, it would be this: do not measure your children by the speed of their development; measure them by the strength of their spirit. Do not compare, do not give up, and do not isolate yourselves. Seek a tribe, seek information, demand what is necessary, celebrate the small victories, and defend the essentials. Hearing is not just sound: it is access, it is the world, it is opportunity.

Today, Esteban's greatest achievement is not speaking quickly; it is advancing without stopping. It is not pronouncing perfectly; it is communicating with courage. It is not about fitting into the world; it is changing it with his example.

Our story is not perfect, but it is real. And if sharing it lights a spark or opens a door for other families, then every hour of effort will have been worth it; not once, but every time. **None of what we have achieved would have been possible without God above all things, and without our family, who have been our engine, our refuge, and our strength at every step of the way.**

GUATEMALA

Caregiver Names: Iván and Pamela
Age at Implantation: 2 Age Today: 5

Hello! We are the parents of a 5-year-old girl; a 42-year-old father and a 40-year-old mother, whose world changed completely in 2022. Since that year, we have been users of cochlear implants. Our daughter was born through normal delivery at a private hospital in the capital city, after a pregnancy without complications and with no medical history of hearing loss. She is the daughter of hearing parents. However, at 6 months of age, we noticed that something was not right with her learning and overall development; she did not babble, did not turn when called, and only said a few words. Unfortunately, this period coincided with the COVID-19 pandemic in our country, and due to government health restrictions, we had to delay both her care and diagnosis.

It was not until 2021 that she was diagnosed with severe bilateral hearing loss. She was immediately fitted with hearing aids to improve her condition, and we noticed some progress, although slow in her listening skills and vocabulary. One year after starting treatment with hearing aids, we were informed about the possibility of a cochlear implant. Determined to improve her condition and to be more than just a source of support, we wanted our daughter to begin developing independently and confidently. **Our greatest challenge was making the decision to accept the cochlear implant procedure for several reasons**: primarily, **fear of the unknown**, as it was a procedure we had never heard of before; the possible risks and complications; and the fact that our daughter was very young to undergo such a procedure. Secondly, there was the **financial challenge**. Although it is true that money can be earned and worked day by day to cover the costs, we cannot ignore the fact that we live in a developing country where the economic conditions of most of the population are limited and the cost of the procedure is significant.

With great faith and determination, we decided to proceed with the procedure, always counting on the support of a non-profit organization, and team of professionals who consistently provided help and information, making us feel supported throughout this entire stage of uncertainty. Thank God, the procedure was a complete success. **It is also important to mention the unconditional support of our family, without whom this would not have been possible**.

One month after the cochlear implant surgery, we truly felt the great change and witnessed the miracle that such a small processor could bring into our lives. A whole world of possibilities opened up for our daughter. Her vocabulary expanded from about 20 words to approximately 1,000 words in just a couple of months. Our family dynamic changed completely: before, we had to be constantly attentive to her, communicate with her through signs, and never leave her alone. Later, as we observed her listening abilities and saw her gradually become more independent and autonomous, we began to give her more freedom.

Today, she has achieved what we never imagined: she can hear like a hearing child, has age-appropriate vocabulary, attends a "regular" school, socializes with hearing children, takes ballet, English, and swimming classes without any problems, and performs any activity without restrictions. Nothing stops her!

Our advice to parents who are currently unsure about whether or not to proceed with a cochlear implant would be: DO IT!!! It is worth it! **It is completely safe in expert hands, and the benefit it will bring to your children is invaluable**. It is a decision that can change a child's life and will surely help them develop in the best possible way, becoming independent human beings and contributing to the development of their country.


INDIA

INDIA

Caregiver Name: Neha **Child: Aashi**
Age at Implantation: 3 **Age Today: 9**

I am a mother from India, and this is the story of my daughter, Aashi—a journey filled with uncertainty, resilience, and hope.

Our biggest challenge was late diagnosis. Aashi was diagnosed with hearing loss at the age of 2.5. Before that, we believed she was simply a late talker and that it was only a language delay. Like many parents, we were unaware of the early signs of hearing loss. We consulted multiple doctors, tried medicines, and explored other treatments, hoping her speech would one day come on its own. Unfortunately, this lack of awareness cost us valuable time.

When we finally understood that Aashi needed a cochlear implant, another major obstacle appeared, it was the COVID-19 pandemic. Hospitals were closed, elective surgeries were postponed, travel was restricted, and therapy services were almost all unavailable. Leading to her cochlear implant surgery to be delayed. However, Aashi was finally implanted at the age of 3 years and 4 months. Even after implantation though, access to receive therapy support was still extremely limited due to lockdowns, which continued to make our journey even more challenging.

In this phase of struggle, **our greatest support entered our lives. A woman came from the USA and came to us like a blessing—truly like God in human form. She became our biggest supporter, mentor, and motivator. Words are not enough to express our gratitude.** She guided us step by step, taught us even the smallest therapy techniques, and helped us understand how to build listening and speech naturally in daily life. She gave us free online therapy and guidance. She never took a single penny. Her selfless support transformed our journey and gave us strength when we felt lost. Along with her, our local audiologist in Bhopal was also extremely supportive and played an important role in Aashi's consistent progress.

Despite late implantation and limited therapy during COVID, Aashi showed remarkable growth. Today, **our greatest achievement is not just her speech and listening skills, but her confidence and overall development. Aashi has developed strong expertise in chess and has won many trophies. She loves dance, performs confidently, and is doing well in her studies**. Watching her express herself, compete,

and shine fills our hearts with pride. Every small milestone—responding to sound, saying a new word, expressing emotions—felt like a victory.

To other parents, **my advice is simple but heartfelt: do not wait. Early diagnosis and early intervention can change a child's life.** Start rigorous speech and auditory therapy but keep it playful and joyful. Make listening and speaking a part of everyday routines. Seek the right guidance, stay consistent, and believe in your child, even when progress feels slow.

To achieve better access to cochlear implantation, **we made several important changes. First, we educated ourselves thoroughly about hearing loss and cochlear implants instead of depending only on assumptions or partial information. We actively sought second opinions, connected with experienced professionals, and reached out to parent networks for guidance. We learned to advocate for our child**—asking the right questions, following up persistently with hospitals, and not accepting delays silently. We also reorganized our family priorities, emotionally and financially, to ensure that Aashi's surgery and post-implant care were not compromised. Most importantly, we changed our mindset from "waiting and hoping" to taking timely action, even in the most difficult circumstances.

Aashi's journey taught us that delays do not decide destiny. With awareness, timely action, and the right support, even a late start can lead to a powerful future.

INDIA

Caregiver Names: Nagaraj & Padmavathi **Child: Aishwarya**
Age at Implantation: 6 **Age Today: 25**

My name is Nagaraj and my spouse's name is Padmavathi. We are the parents of Aishwarya, who is now 25 years old and who is a deaf and mute child. We live in India, from the state Karnataka and resides in the Ballari District. We are writing this to share our experiences as parents of a child with hearing and speech disability.

The biggest challenge we faced was communication. In the beginning it was heartbreaking to not hear our child speak or respond to our sounds. As parents, we struggled to understand our child's needs and emotions. Learning sign language was not easy for us, but we realized that it was the key for building a strong bond. With time, patience, and practice, communication improved and our connection with our child grew deeper.

Another major challenge was education. Finding a school that could understand and support a deaf and mute child was very difficult. Often, our child was left out in classrooms that were designed mainly for hearing students. Watching our child struggle was painful, but it also motivated us to never give up.

The greatest support in our journey has been our family and a few kind educators and professionals. Doctors, therapists, and special educators who guided us during the early stages played an important role. Government support such as disability certificates and scholarships helped reduce some financial burden. However, accessing these services was not always easy due to lack of awareness and complicated procedures.

At the age of nine, our daughter was able to communicate verbally due to continuous effort, training and support from our family. Though she could speak, she was unable to hear, which remained a major challenge. After undergoing cochlear implantation, she was able to both hear and communicate more effectively. This improvement helped in her early education. However, from her second year of pre-university (PU) education, the cochlear implant stopped functioning. Despite studying without any hearing device, she continued her education with determination and self-effort. She successfully managed her academics and completed her degree without the use of any hearing machine. If a cochlear implant is provided to her for her further education, she will be able to hear and communicate properly. This support will help her pursue higher studies, perform confidently and achieve her dream job without any hesitation of fear related to her hearing disability.

Our greatest achievement as parents is seeing our daughter complete her undergraduate educations despite many difficulties. She is a deaf student, yet she successfully completed her Bachelor of Commerce (B. Com) degree. Her journey was not easy. Communication barriers lack of proper support, and social challenges made her education very difficult. Still, she never lost confidence or gave up. With strong determination, family support, and hard work, she proved that disability is not a barrier to education, Today, she is preparing for her Charted Accountant Intermediate Examinations. This is a proud moment

for us as parents. Her journey from a salient struggle to a strong academic path inspires us and shows that with courage and support, children with disabilities can achieve great success.

To other parents who are raising deaf and mute children, our advice is to stay strong and patient. Accept your child as they are and believe in their potential. Learn sign language, communicate openly and encourage independence. Early intervention, proper education and emotional support can change a child's life. Most importantly, to remember that a child's disability does not define their worth.

As parents, we also made changes in our lives to improve our child's access to opportunities. **We adjusted our routines and learned new ways of teaching at home. We became advocates for our child through speaking to schools, communities and authorities whenever needed. These efforts helped our child grow more confident and independent.**

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India

Caregiver Name: Kavitha **Child: Akshaya**
Age at Implantation: 6 **Age Today: 23**

When we first learned that our child, Akshaya, was diagnosed with bilateral profound hearing loss our world paused. Like most parents, we were filled with questions, fears and an overwhelming sense of responsibility. What would her future look like? Would she be able to communicate clearly, learn confidently and live independently? At the time, we did not have all the answers.

After detailed consultation and guidance, Akshaya underwent right ear cochlear implantation surgery in 2007 and left ear cochlear implantation surgery in 2009. These surgeries marked the beginning of a long journey that required patience and commitment. After the surgeries, Akshaya's mother decided to leave her job and give full attention to her child's therapy.

After completing two years of regular hospital therapy, she continued training at home. She spent time every day working on listening, speech and correct pronunciation. With constant care and practice, she supported our daughter throughout the day and night, playing an important role in her progress.

The years that followed were full of therapy sessions, consistent practice and gradual milestones. Akshaya started improving in responding to sound, speech clarity, confidence in classroom participation and independence. Progress was steady, sometimes slow but always meaningful. Every small achievement reinforced our belief that the journey was worth every effort.

Along the way, we faced many challenges. **The biggest challenge in Akshaya's journey was accepting the diagnosis and navigating the uncertainty that followed**. Understanding profound hearing loss and making decisions that would shape her entire life was demanding emotionally and financially. It was also time consuming as she needed long term rehabilitation and regular follow-ups.

At that time, there was no government support or assistance for cochlear implantation. As parents, we faced many difficulties but we knew cochlear implantation would help Akshaya build a better future. We put in every possible effort to ensure she received timely surgery, regular therapy and continuous rehabilitation. Progress was gradual, but we had hope. Despite the challenges, we remained determined to provide the best possible access to hearing and communication resources to our child.

Today, we are truly proud of her. We no longer see through the lens of hearing loss, we see a confident, capable and independent individual. She travels on her own, manages her responsibilities and no longer depends on us, which gives us great pride as parents. **Akshaya is an MBA graduate working in a hospital with cochlear implant recipients. This is a full circle moment for our family and we are so proud.** Through her role, Akshaya supports and inspires cochlear implant users and their families. Her personal experience allows her to guide patients with understanding, empathy and hope.

We are deeply grateful to the medical team who supported us throughout this journey. **Their professional support played a vital role in my child's hearing and speech development, allowing us to move forward with confidence.**

To another parent beginning this journey, our advice is simple yet powerful; believe in your child, start early and stay consistent. Cochlear implantation is not a miracle, it is a tool. Its success is dependent on encouragement, patience, support and rehabilitation. Do not limit your child's future based on their diagnosis. Celebrate progress, even small and remember that comparison serves no purpose. Every child's journey is unique. Trust the process, collaborate closely with professionals, and most importantly, let your child grow with confidence, dignity and independence.

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India

Caregiver Name: Dimple **Child: Akshita**
Age at Implantation: 13 months **Age Today: 20 years**

I am a mother from India, and this is the story of my daughter, Akshita, who is a cochlear implant recipient. She was born on April 16, 2005. At the time of her birth, we had no idea that she had hearing loss. Like any new parents, we were raising her normally, full of dreams and hopes for her future.

After a few months, her grandfather noticed that she was not responding to sounds. That was the moment her journey began. **With the help of her grandfather, who is a pediatrician, we were connected to doctors that guided us step-by-step through the cochlear implant process.** Within two months of detection, on May 3, 2006, Akshita received her first cochlear implant in her right ear. She was only 13 months old and was one of the youngest babies in North India to receive a cochlear implant at that time.

Our biggest challenge during those early years was managing therapy, travel and family responsibilities. For speech therapy and mapping sessions, I had to travel 3-4 hours from our town to the city twice a week. At the same time, I had another young daughter at home who was just 4 years old. Leaving her behind with her father and grandparents was emotionally difficult. Financially, we were not very strong. At the time, we could only afford one implant.

But we were never alone. **Our greatest support came from our family, who supported us morally and financially.** Our doctors and therapy teams were also a huge source of strength. Because of speech therapy, mapping sessions and continuous practice at home, Akshita slowly started hearing and communicating. She went to school, made friends and participated in extracurricular activities like any other child.

As she grew older, we noticed she still struggled with detecting sounds from all directions. After consulting doctors again, we were advised to go for a second implant for her left ear. This would help her hear sounds from both sides and improve her overall sound awareness.

Ten years after her first implant, on January 28, 2016, she received her second cochlear implant. Initially, she felt discomfort but with regular mapping sessions and support, she adapted well. Through this journey, we understood the importance of bilateral implantation at a younger age, as children adapt more easily.

Today, our greatest achievement is seeing our daughter live confidently and independently. She is now 20 years old and is pursuing her bachelor's degree in computer science. For the last 4 years, she has been living independently in a hostel, managing her studies and daily life on her own. For us as parents, this is the biggest success, seeing her grow into a strong and confident young woman.

To improve access to cochlear implantation for our child, we made many changes, such as regular travel for therapy, strict therapy routines at home and learning how to support her communication development daily. Awareness, persistence and family unity helped us overcome many barriers.

Our journey has had many ups and downs, but it has been full of learning, strength and gratitude. We are deeply thankful to our family and the medical team involved for guiding and supporting us through this journey.

India

Caregiver Names: Srinivas & Padmaja **Child: Anusha**
Age at Implantation: 7 **Age Today: 28**

In 2005, our daughter Anusha was seven years old and had been living with profound hearing loss since birth. At that time, cochlear implantation for children was still very new in India. **There was limited awareness, very few experienced centres, and almost no examples for parents to look up to. As parents, we were worried, confused, and uncertain about what the future would hold for our child.**

After many consultations and discussions with doctors, we decided to go ahead with cochlear implantation. In 2005, Anusha underwent unilateral cochlear implant surgery in her left ear. This decision was not easy, especially because she became the second paediatric cochlear implant patient in the states of Telangana and Andhra Pradesh, India. Being among the earliest cases meant there were many unknowns, and we had to rely on trust, hope, and professional guidance. The journey after surgery required a lot of patience and commitment. Regular follow-ups with the help of an audiologist, therapy sessions, and continuous support became a part of our daily lives.

Progress was slow in the beginning, but we learned to value every small step forward. Education played a major role in Anusha's growth. **With consistent effort from family and teachers, she slowly gained confidence in her communication skills.** She learned to express herself, take part in class and interact socially. Her cochlear implant helped her access sound, but it was her hard work and determination that helped her succeed.

Living with a cochlear implant made her curious about hearing, sound, and communication. She developed a strong desire to help others who were facing similar challenges. This interest later guided her academic and professional path. **Anusha went on to complete her master's degree in audiology, a significant achievement that required dedication and focus.** Through her studies, she gained deep knowledge about hearing assessment, diagnosis, and rehabilitation. Her journey reached a historic milestone when she became the first cochlear implant user in India to become an audiologist. This achievement not only marked personal success but also created hope for many children and families in the cochlear implant community.

Today, Anusha is working as an audiologist at a hospital, where she received a cochlear implant in her left ear. In her professional role, she supports children and adults with hearing loss by conducting hearing tests, diagnosing conditions, counselling families, and guiding cochlear implant users. Her personal experience allows her to connect deeply with patients and parents, offering understanding, patience, and reassurance.

For families who are just beginning their cochlear implant journey, would give advice to another parent, it would be this: do not delay intervention. Trust the process and commit fully to therapy. Choose professionals who see your child's abilities, not limitations. Anusha stands as proof that children with hearing loss can grow into confident, independent professionals. Her journey shows that

cochlear implantation, when combined with consistent therapy, education, and family support, can open doors to meaningful careers and purposeful lives. As parents, we look back on this journey with pride and gratitude. The path was not easy, and there were many moments of uncertainty. However, every effort we made was for Anusha's future. Seeing her now as a professional helping others gives deep meaning to every challenge we faced.

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INDIA

Caregiver Name: Gita **Child: Chayanika**
Age at Implantation: 5 **Age Today: 12**

This is the story of girl who was delivered full-term with no apparent medical issues, she seemed healthy. However, as months passed, her parents noticed delays in her developmental milestones. She began sitting near ten months and did not walk until she was over fifteen months old.

Her parents also grew concerned about her hearing, as she did not respond to sounds or voices in the way her elder sibling had at that age. At nine months, they took her for her first hearing test. The results indicated partial hearing loss, but subsequent visits to multiple doctors yielded inconsistent reports ranging from normal hearing to single-ear loss. Lacking concrete guidance, the family watched as the jolly child began communicating primarily through gestures. Meanwhile they tried various rituals, offerings and herbal treatments advised by relatives and acquaintances.

In 2015, when the girl was two and a half years old, the family travelled for a BERA test. The results confirmed severe to profound hearing loss. She was fitted with hearing aids and began speech therapy, but the device offered no observable benefit, and she rarely used it.

In 2016, when the child was three, her father suffered a stroke and his ability to work was restricted. **The family was forced to depend on a small pension, and amidst this medical and financial turmoil, the child's hearing treatment took a backseat.**

It was not until the end of 2017, when the girl was five, that they revisited an ENT specialist. He advised them to pursue cochlear implant surgery at a hospital which could provide funding assistance. The logistics of this decision were extremely difficult. Since the father could not travel due to his condition, **the mother had to take the child to alone. Unfamiliar with the city and not knowing the language, she had to hire guides to help her navigate. Before the surgery could take place; they had to make three to four separate trips for various tests and administrative processes.** Financial constraints and the need to care for the husband and elder daughter back home meant they could never stay for long periods. Finally, in 2018, at the age of five, the child underwent cochlear implant surgery.

Upon returning, their referring ENT doctor directed them to a newly established cochlear implant clinic in the region for auditory rehabilitation. The centre was far, requiring a travel time of up to 90 minutes each way, but provided them the much-needed support and

guidance. Slowly, the child began to listen, ask for her device, and imitate sounds. **The mother fondly recalls her daughter calling her "Ma" clearly and meaningfully for the first time in July 2018, two months after her implantation**. As a later implanted child, she needed added efforts for which her mother transformed her own habits, becoming constantly talkative to expose the child to language. She noted down every new word, mistake, and milestone.

Today, the girl is a chatty 12-year-old who attends a mainstream school and she's a graceful dancer. However, as she progresses to higher classes, she struggles with the advancing curriculum, particularly with multiple language courses and classroom instructions that are not always adequate for her needs. She currently relies on private tuition to keep up.

The parents live with underlying anxiety and fear of possibility of the implant failing someday. The financial burden of maintaining the external device and purchasing spare parts remain a tough struggle, sometimes forcing the family to compromise on the needs of other members. Even so, they are ever thankful to cochlear implants changing the course of their daughter's journey.

BE0798.221.710

INDIA

Caregiver Name: Nathuram **Child: Hindavi**
Age at Implantation: 3 **Age Today: 7**

When my daughter Hindavi was born on July 22nd, 2018, we never imagined the hurdles we would face. In June 2019, our world changed when she was diagnosed with bilateral profound hearing loss. Because of an inner ear anomaly, she also had delayed motor milestones due to Klippel-Feil syndrome, meaning that traditional hearing aids offered no benefit. We were told a cochlear implant was her only hope for sound.

The primary obstacle for our family was the cost of the devices. As a worker at a private company, I faced significant financial pressure, as cochlear implants are expensive, often ranging from ₹6 lakh to over ₹10 lakh per ear in India. Families in similar situations often find it difficult to collect such large sums through savings alone, and the struggle for funds was constant.

To overcome this, we relied on multiple sources. We sought out help from various charitable trusts and individual donors who generously contributed to her cause. Furthermore, because institutional funding and government schemes often have caps or long waiting lists, we turned to our personal network for support. I had to borrow significant money from relatives to bridge the gap and ensure the surgery happened at the right age during Hindavi's early childhood.

We were not alone in this fight. **The combined support of our extended family and the donors who stepped up during our fundraising efforts became our lifeline.** Additionally, the teams at the hearing clinic and the hospital's audiology department provided the essential expertise and rehabilitation guidance we needed to navigate the complexities of bilateral implantation.

Hindavi's surgeries took place in December 2021 and November 2022. While the surgeries were successful, the real victory was her dedication to rehabilitation for her speech and language development as well as her motor development. **Her greatest achievement to date is her successful transition into a regular mainstream school. Today, she listens and can communicate her needs and wants during daily routine with our family, friends and at school —a milestone we once feared she might never reach.**
To achieve better access, we had to become proactive advocates for our daughter. We changed our approach by aggressively pursuing every available financial resource and making language therapy a 24/7 priority at home. My wife became her primary teacher, ensuring that every moment was a learning opportunity to help her catch up to her hearing peers.

To any parent starting this journey: do not lose hope. Deafness is no longer a permanent disability if you act early and stay persistent. **The path is exhausting, especially regarding the financial burden and the years of therapy required, but seeing your child flourish in a world of sound makes every sacrifice worth it. Trust the process, seek help from your community, and never stop talking to your child.**

BE0798.221.710

INDIA

Caregiver Name: Dhruti **Child: Jiyaan**
Age at Implantation: 2 & 4 **Age Today: 10**

As a parent, **the biggest challenge I face is the problem of explaining to people what an implant is**. They are aware of hearing aids but unaware about what Cochlear Implants are. People have doubts about whether he would speak if the machine were not placed on his head. People are sceptical at times; social awareness is less. They wonder if the hearing loss can be cured or if it is a disease. Is it a lifetime condition, can he listen without the implant placed in his head, and many such questions are common in people's mind.

My biggest help and support have not come from one person, but many people. The 1st and foremost support are my family. They have been a constant source of inspiration and motivation when the road seems tough and light diminishes, the care, support and encouragement of my husband, his side of family as well as my side of family has been tremendous. My second biggest support is the team of audiologist, doctors, and speech therapists. The initial audio verbal therapy session has been very helpful for listening, understanding and acquiring knowledge as well as hearing. I learnt many techniques and strategies of doing speech therapy when I attended the speech session along with my child. We got the right path and guidance at each stage. From speaking 2 -3 words to now reading books and novels, my child's progress has been remarkable. I can't tell you how happy I am. I am so proud of him, you know!

My child's greatest achievements have been countless. He loves playing chess and he has taken part in many local chess competitions. He is also a badminton player and has participated in badminton tournaments. He loves to sketch, paint, and draw. He loves doing maths and he is passionate about world geo-diversity, learning about cities and new places. He also loves robotics. In school, he studies French and robotics. Robotics has been his favourite subject since then. **His biggest achievement was winning the national level Team Spirit Award 2025**; a robotics award. He and his team previously won trophies and stood in 1st position on other national and international level robotics championships.

My advice to other parents would be that every child is unique. **Never compare your child with another child.** Sometimes what we mistakenly do is, we compare our child's unfinished acts with someone else's finished products. So, avoid doing that. Always motivate and encourage them to go ahead and pursue their dreams. Provide opportunities for success. **Let your child learn to be independent**. That will help them lifelong.

How we made change happen, since we lived in a small city in Gujarat back then in 2017, we didn't have many resources for medical help, surgeries or even therapies in our town, so, **we moved** to Mumbai. My parents live in Mumbai. Since, Mumbai is a metro city, we had access to many facilities, and easy access to all required therapy sessions. We moved, for two years, to Mumbai and after the surgery and continuous speech therapy, we saw wonders in his growth and development. Then we moved back to Jamnagar (Gujarat). Then came the COVID wave where, suddenly, all learning happened online. From Zoom school meetings to family meetings, everything was online. Life changed not only for the cochlear implant (CI) kids but also for the normal kids all over the world.

But taking that time positively, and accepting it as a challenge, we also overcame the hurdles of listening on speaker, speaking on a mic and also learning many new skills in those two years.

Currently, in 2026, he is studying in Grade 5 at a school where English is the primary language of instruction. Since then, he has developed a liking for robotics, and French, which are taught at his school. He has also learnt to read, speak, and write in Gujarati and Hindi, which are our local languages. He is studying in a boarding school where the teachers are very supportive. He is preparing for his Primary Grade Checkpoint.

No obstacle is too big if met with the right dedication and determination. The collaborative work and efforts of my son, his teachers, his school, our parents, our family, professionals and the team have made a huge impact. He dreams and aspires to become the best he can be. We will continue to support him to bloom in his own way and at his own pace!

India

Caregiver Name: Guru **Child: Kalaiselvi**
Age at Implantation: 3 & 8 years **Age Today: 12 years**

My Daughter's Success Story with a Cochlear Implant I am a proud mother, Guru from Vadodara, India, and I would like to share my daughter Kalaiselvi's inspiring journey with a cochlear implant. Our experience is not only a personal story of hope and perseverance but also a message for parents and communities to believe in the limitless potential of children with hearing impairment. When my daughter was one and a half years old, we discovered that she had significant hearing loss. Like many parents, we were overwhelmed with fear and uncertainty. Questions about her future, education, communication, and social life occupied our minds. The emotional impact was intense, but we decided that fear would not define our response. Instead, we chose acceptance, early intervention, and active involvement in her development.

At the age of three and a half, Kalaiselvi received her first cochlear implant. While the surgery was an important medical step, we soon realized that implantation alone was not enough. The real journey began after that—with therapy, continuous practice, patience, and consistent parental support. Alongside professional therapy sessions, I trained my daughter at home using art and music as learning tools. I strongly believe that children learn best when education is joyful, engaging, and stress-free.

Over time, we began to witness remarkable progress. Kalaiselvi developed a deep interest in Bharathanatyam, a classical Indian dance form that combines rhythm, expression, discipline, and body coordination. This art form played a significant role in improving her listening abilities, concentration, and self-confidence. Dance became not only a passion but also a powerful learning medium for her.

She also started learning the piano, which further strengthened her auditory perception and focus. Music helped her recognize sounds, improve timing, and develop patience. In addition, her love for art and craft, swimming enhanced her creativity, fine motor skills, and emotional expression. These creative activities became essential tools in her overall development.

Academically, Kalaiselvi made steady and impressive progress. She showed a strong aptitude for Mathematics and became proficient in reading and writing Hindi, Gujarati, English, and basic French. Today, she performs well in her studies and actively participates in school activities. Through consistent practice, encouragement, and a supportive learning environment, she developed independence, confidence, and a positive attitude toward challenges. At the age of 8, she received her second cochlear implant, which further enhanced her hearing and learning abilities. This additional support helped her communicate more effectively and strengthened her academic and social skills. Today, she interacts confidently, studies well, and enjoys a happy and fulfilling childhood—just like any other child.

As a parent, my journey has taught me that a cochlear implant is not merely a medical device. Its success depends greatly on early diagnosis, timely intervention, parental involvement, professional therapy, and emotional encouragement. When families, therapists, educators, and communities work together, children

with hearing impairment can reach their full potential. I share my daughter's story to inspire other parents who may be facing similar challenges. A child's disability should never be seen as a limitation but as a different path that requires understanding, patience, and belief. Kalaiselvi's journey has taught me one powerful lesson—one that I hope reaches many families through this platform: Disability does not define a child's ability.

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INDIA

Caregiver Name: Tara **Child: Ovi**
Age at Implantation: 2 **Age Today: 2**

In our small farming village in India, silence was the only language my family ever knew. My husband, our eldest daughter, and I are all deaf. When our youngest, Ovi, was born, we realized she shared our silent world. While we loved her dearly, we dreamt of a different future for her—one where she could hear the birds chirp and, most importantly, speak for herself.

Our biggest challenge was a paralyzing combination of fear and financial pressure. As farmers, our income is tied to the unpredictable cycles of nature. In India, a cochlear implant can cost between ₹6 lakh and ₹12 lakh—a sum that felt like an impossible fortune to us. For a family living off a low agricultural income, this financial barrier was an absolute wall. We feared that pursuing the surgery would lead us into a debt trap or cost us our farmland, which is our only source of livelihood. In our community, deafness was something you simply lived with; a "medical miracle" felt like a luxury reserved for the wealthy.

Our greatest support came from the kind principals at Ovi`s school, who intervened. Their generosity was not just financial, but deeply emotional because she had once been my principal too. They recognized Ovi's potential and bridged the gap that we could not cross alone. By securing funding through one of the esteemed schools committees and coordinating with a fellowship at the hospital, our financial worries disappeared. This act of institutional courage shifted the focus from our empty pockets to Ovi's future. They provided "handholding" advocacy, explaining the science to us in a way we could understand and taking full responsibility for the procedure's success.

Ovi's surgery took place on September 8th, 2025, and it marked the first time the cycle of silence in our family was broken. **Her greatest achievement to date is her incredible spirit during speech therapy. In a household where four members are deaf, seeing Ovi respond to her name and mimic sounds feels like a victory for all of us.** This success is only possible because the institution's generosity extended beyond the surgery and into the long-term commitment of Auditory Verbal Therapy, ensuring the implant translates into a voice.

To achieve better access, we had to change our mindset and trust in the kindness of organizations. **My advice to any parent around, is to not let the fear of cost silence your child's potential. The path is long and the financial hurdles are real, but with the right support system, the "silence" of disability can be transformed into a "voice" of opportunity.** Ovi is now the bridge between our silent home and the hearing world.

INDIA

Caregiver Name: Diya
Age at Implantation: 3 **Age Today: 20**

My journey as a parent began with a clear choice to fight for my daughter's voice. When she was diagnosed with profound hearing loss at a young age, I knew the path ahead would be difficult. I was a single mother, raising my daughter with the help of my own mother. As a single parent, the road to her hearing was a mountain I had to climb through sheer persistence and hope.

The greatest obstacle was managing the financial and physical aspects of her care. Raising a child with high needs as a single parent meant I could not maintain a traditional job, yet her medical requirements were relentless. For years, we had to travel 500 kilometres every week for surgeries, mapping, and therapy.

The costs—fuel, lodging, and the maintenance of the cochlear implant—were expenses I could never have met alone. I want to be very clear this journey was only possible because of donations facilitated through the hospital. **Without the generosity of strangers who contributed to her implant, my daughter would still be living in silence.** Those donors didn't just buy a medical device; they funded a future that seemed unreachable.

My greatest support was my mother and the community of donors who stepped in when we needed it most. They provided the "village" that made it possible for us to keep traveling those long distances. Professionally, the audiology team at the hospital who worked with us through those weekly 500km trips became our anchors, guiding us through the complexities of her rehabilitation.

Despite the hurdles, we refused to let my daughter be sidelined. She entered a mainstream school and thrived, moving through her education alongside her hearing peers. She shattered every low expectation and proved that with the right technology, there are no limits to what a child can achieve. **Today, she is an adult pursuing a degree in medicine. The child who once lived in silence is now learning how to help others.** She also uses her platform on Instagram to advocate for the deaf community, showing the world the true impact of a cochlear implant.

To achieve better access, I had to become my daughter's strongest advocate. I had to manage the logistics of a massive cross-country journey every single week for years, making her hearing and speech my primary mission. **We have proven that even in a low and middle-income country, distance and financial status do not have to define a child's potential.**

India

Age at Implantation: 21 months Age Today: 24 years

I am a mother from India, and my son, who is now 24 years old, received a cochlear implant at the age of 1 year and 9 months. Our journey has been full of questions, fears, learning, and, eventually, hope.

We came to know about our child's hearing problem when he was just six months old. At that time, the biggest challenge for us was not only accepting the diagnosis but also worrying about his future. One question kept running in my mind again and again: How will my child compete with other children across the nation? As parents, we feared whether he would be able to speak, study, socialize, and live confidently in a world that largely depends on sound.

Living in a low-resource setting made this journey harder. Awareness about hearing loss and cochlear implants is limited, and many people do not understand the importance of early intervention. Information was scattered, and every decision felt heavy. Financial concerns, access to specialists, and long-term rehabilitation were also major worries. At times, the road ahead looked uncertain and emotionally exhausting.

What helped us most during this phase was support. We are fortunate to live in a joint family, and my family stood by us strongly at every step. Their belief in our child gave me strength on days when I felt weak. Family played a very important role in our journey. Their patience, guidance, and constant encouragement helped us move forward with confidence. They not only supported our child but also supported us as parents, teaching us how to help him every single day.

Our greatest achievement is a moment that still brings tears to our eyes. When our child spoke his first word — "pa-pa-pa-papa" — my husband and I became extremely emotional. Even today, when we think about that moment, our eyes fill with tears. That one word erased months of fear, doubt, and struggle. It reminded us that all the effort, therapy sessions, and sleepless nights were worth it.

Speech therapy played a major role in our child's progress. But we also learned that therapy does not end inside the clinic—it must continue in daily life. When he was very young, we made special efforts to expose him to different sounds in natural environments. We took him to zoos so he could recognize animal sounds, made him watch monkeys dancing, helped him listen to duck sounds in the pond near India Gate, and encouraged him to notice sounds around him. At home, we would ring a bell from different directions so he could learn to identify where the sound was coming from. These small activities made learning fun and meaningful for him.

To achieve better access to cochlear implantation, we educated ourselves, followed professional guidance strictly, and made changes in our daily routine. Travel for therapy sessions, consistency in device use, and active parental involvement became part of our life. It required discipline, patience, and sacrifice—but we were determined to do everything possible for our child.

If I were to give advice to another parent, I would say: do not lose hope. Progress may feel slow, but every small step matters. Trust your doctors and therapists, stay consistent with therapy, and most importantly, believe in your child. Early intervention and parental involvement can change a child's life. Connect with other parents, ask questions, and never feel ashamed or afraid to seek help.

Our journey shows that even in a low-resource country like India, with the right support and awareness, children with cochlear implants can thrive. Our story is one of struggle, learning, and deep emotional strength—but above all, it is a story of hope.

INDIA

Caregiver Name: Meenu
Age at Implantation: 3 & 5 **Age Today: 22 & 27**

My journey as a mother of two children with hearing loss spans over more than twenty years, filled with fear, courage, learning, and heartbreak. What remained, despite all odds and at every step, was hope. And as I sit down to look back on these twenty years today, it is with hope that I write my story. I hope that, through my story, another mother might find some semblance of strength.

When my son was born, we noticed very early that he didn't respond to sounds. He was diagnosed with profound hearing loss at birth. At the time, we had no family history of hearing loss and very little awareness of what one did in such circumstances. We did not know what the future would look like for our child. Doctors advised hearing aids and speech therapy, and we followed every instruction with full faith, hoping things would improve.

Our own lack of awareness, guidance, and facilities was one of our biggest struggles. Rehabilitation services were limited, information was scarce, and social acceptance was lower than one would like to think. The emotional toll of seeing our child struggle, while we ourselves were still learning how to support him best, was almost unbearable.

The biggest challenge of my life came when I was searching for cochlear implantation options for my son. During one of those hospital visits, we decided to get our daughter's hearing checked as well—almost randomly, thinking it would just be a routine test. The moment her results came back, revealing profound hearing loss, will always be etched in my memory as one that still sends chills down my spine. Five years later, having to face the same reality again left me completely shattered. I didn't think I was prepared to go through the same fear and uncertainty again.

Our son received his cochlear implant at the age of five and a half years, which was considered late. The decision was extremely difficult—financial stress, fear of surgery, lack of social support, and uncertainty about outcomes all weighed heavily on us. The hope that this access to sound will secure him a future was worth every struggle. With our daughter, we had experience. It helped us act faster and make quicker decisions. She received her cochlear implant at the age of three. Although the pain was the same, we were stronger, more informed, and more determined this time.

The greatest support throughout our journey came from dedicated doctors, rehabilitation professionals, and speech therapists. Rehabilitation has become a part of our daily life — but not just as something done in clinics. As parents, we learned that consistency, patience, and belief are as important as technology.

One of our greatest achievements today is seeing both our children live confident and independent lives. Our son, now 27 years old, is working in a government job in the communication sector. Our daughter, now 22 years old, is working in a multinational company, managing her professional life with confidence and pride. **Watching them communicate, work, and stand on their own feet feels like a dream that once seemed impossible.**

Over the past twenty years, I have seen many positive changes in society. Awareness has increased, acceptance has improved, and schools are more inclusive than before. Yet, this journey remains challenging for parents. The first step must always be self-acceptance. Parents must focus strongly on rehabilitation and

be prepared to face discrimination and societal challenges. We need to be ready at all times—to fight our own fears first and then stand up for our children against the world.

My advice to other parents is simple: identify hearing loss early, do not delay intervention, trust the process, and never underestimate your child's potential. The journey is long and difficult, but with timely support, rehabilitation, and unconditional love, children with hearing loss can achieve more than we ever imagined.

INDIA

Caregiver Name: Rashmi
Age at Implantation: 1 year **Age Today: 12 years**

Our daughter is now 12 years old, but when she 14 months old, she received a bilateral cochlear implant. We found out about her hearing impairment when the newborn hearing test was done at the hospital she was born in. Of course it came as quite a shock to us as parents, but we both were ready to take on the situation. We started researching the best options for the future of our child. We sought advice from doctors and specialists as well as the internet, and it was then we came to learn about cochlear implants as a prosthetic for people with a hearing disability.

In India, we only knew of one doctor in Chennai as there wasn't much awareness on hearing when our child was born. The hospital she was born in was one of the best in the city, but they did not have a lot of information on how to handle our daughter's hearing loss and there were no parents support systems for such situations. However, by doing our own research and meeting with the right professionals, all of this worked out in the end.

Another challenge was the huge cost of the implants. We did not have access to any loans, government support, or insurance coverage for this situation and to manage these funds on our own was a huge financial burden for us. However, we were able to manage with financial support from family through personal loans.

Our greatest support has been our positive mindset, along with close collaboration with the cochlear implant team—especially our surgeon and speech therapist—which has served as a guiding force, alongside the continued support of our family. Family plays a very crucial role in supporting rehabilitation, as complete involvement of us as parents is essential.

A key point to emphasize is the importance of early detection and intervention, along with consistent rehabilitation in the years following surgery and regular follow-ups with an audiologist, all of which are essential for success.

Our proudest achievement is our daughter becoming an award-winning author of three books. She wrote her first best-selling book at age 10, and her next two works also received accolades in their genres. Our child is an example of hope and resilience for many parents on similar journeys to ours.

She goes to mainstream school and participates in all extra co-curricular activities and sports. She is also a swimmer. At one point, all of this seemed impossible, but with hard work and determination it became possible. As parents, we strive to advocate for cochlear implants, raise awareness, and support other families by serving as mentor parents to those navigating a similar journey.

Both of us played active roles in nurturing and empowering of our daughter. As the sole earner, her father ensured she had access to the best resources, while I, as her mother, took on the role of advocating for positive parenting and supporting families of children with cochlear implants by guiding those on a journey like ours.

In 2023, I began running online storytelling sessions for children with cochlear implants. These sessions aimed to help parents understand the critical role of storytelling in developing listening and language skills, in tandem with professional therapies. This initiative was inspired by my desire to share with other

parents what had greatly benefited my own daughter. Importantly, my intention was to help others, not for financial gain. In January 2026, I presented a research paper at an international conference in India titled “The Impact of Storytelling as a Tool for Children with Cochlear Implants Using Theatre Practices to Build Language and Auditory Skills – An Explorative Case Study.” We hope that parents’ belief in themselves and in their child, combined with a positive mindset and early intervention, can empower their children.


INDONESIA

INDONESIA

Caregiver Name: Dyah
Age at Implantation: 2 & 7

Child: Annisa
Age Today: 16

It hasn't always been easy, but when I look at my daughter, Annisa today, I feel a sense of pride that is hard to put into words. When we first started this journey, I saw her cochlear implants as a challenge to overcome. Now, I see them as a bridge she crossed with incredible grace. Seeing her navigate her world, laughing with friends, singing along to her favorite songs, and advocating for herself reminds me that her superpower ears are just a small part of the brilliant, confident person she has become. She isn't just a success story; she is my greatest teacher.

In those early days, I was the one constantly searching for answers, feeling overwhelmed by the technicalities and the uncertainty of the future. I used to lean so heavily on others for a glimmer of hope. But as she found her rhythm, I found my purpose. I realized that all the sleepless nights and the steep learning curves gave me a language to speak to other parents who are just starting out.

I spent so long worrying about whether my daughter would ever find her place in a hearing world, only to realize that while she was busy finding her voice, I was busy becoming the mentor I once so desperately needed.

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INDONESIA

Caregiver Name: Tita **Child: Mikayla**
Age at Implantation: 2 **Age Today: 7**

In 2020, my world suddenly became quiet. Mikayla was two years and two months old when we received the diagnosis: severe hearing loss, 100/90 decibels in both ears. Those numbers were more than medical terms to me. They felt like a wall standing between my little girl and the sounds of laughter, music, and even her mother's voice.

December 2020 marked the first major step in our journey. Mikayla underwent her first cochlear implant surgery on her right ear. Hope grew slowly, but the process was far from easy. At home, I became more than just a parent—I was also her teacher, therapist, and protector. Each day came with small goals that felt enormous. Teaching Mika to understand simple instructions often felt like climbing a steep mountain. **Anxiety was constant: the high cost of the device, therapy expenses that were not covered by government support, and the feeling of isolation when Mika struggled to interact with children her age.** The stress was real. Yet, in the middle of it all, kindness found its way to us. **Family, friends who helped financially, patient therapists, and a community of parents became my support system when I felt close to giving up.**

Mika grew up with one "magic ear." Her speech improved, but new challenges appeared, especially in noisy environments. Too many sounds made it harder for her to focus. At first, we hesitated to take the next step. Then the decision came from Mika herself. She asked for surgery on her left ear. She no longer wanted to use a hearing aid on that side because, to her, the sound was "noisy" and unclear. In December 2024, Mika entered the operating room for the second time. She was finding balance in her world. The results were beyond our expectations. Her confidence grew rapidly. Her speech became clear and natural, without the need for sign language or lip reading. In crowded places, she was no longer lost in sound—she could follow conversations easily.

Today, what once felt like an impossible dream has become reality. Mikayla attends a mainstream school, learning and playing alongside her peers. Most importantly, she is never ashamed. When classmates ask about the device on her head, she explains it proudly and with confidence. She has grown from a toddler surrounded by silence into a cheerful and caring child. Often, she encourages other children who are just starting to use hearing devices. With bright eyes and a sincere smile, she says, "Keep practicing. Don't give up."

Through this journey, I want to share this with every parent walking a similar path: do not be afraid to ask for help. We were never meant to carry this burden alone. Hearing loss does not define our children. They are unique, valuable, and whole. I hold a strong hope for the future: that technology will become more child-friendly—smaller, more comfortable, and sweat-resistant, so children can move freely. I hope that access will improve, with government and insurance support covering not only surgery but everything needed to keep the implant working, so therapy is never stopped due to the cost. I hope that early detection will be available in every city, so no child's critical developmental time is lost. Mikayla has shown us that with love,

technology, and perseverance, silence can turn into a beautiful symphony. Keep practicing. Keep learning. Somewhere ahead, sound is waiting to be heard.


KENYA

KENYA

Caregiver Name: Mary **Child: Kenzi**
Age at Implantation: 2 **Age Today: 3**

We did not know our daughter had hearing loss. To us, she was just a quiet and peaceful baby. We had no reason to suspect anything was wrong.

Everything changed the day her grandfather came to visit. He was outside splitting firewood using a loud power saw machine. The noise was extremely loud. But our daughter did not jump, turn, or react in any way. Grandpa immediately sensed something was not right. He mentioned it to her father, and that simple observation began a journey we never expected.

We started moving from one clinic to another — first a pediatrician, then an ENT specialist, and finally to a children's speech and hearing loss organization. After several tests, we were told the words no parent is prepared to hear: profound hearing loss.

We were crushed. We felt confused, scared, and helpless. Some family members were in denial and questioned the diagnosis, while others advised us to wait for a miracle. We were told, "Maybe she will speak later," or "Just pray and give it time." Deep inside, we wanted to believe that too.

But the hearing loss organization stood by us. They explained everything patiently and clearly. They connected us with other parents who were walking the same path. Seeing other children with hearing devices gave us hope. It helped us move from denial to action.

Our daughter was fitted with donated hearing aids. We were told they might not bring much improvement because of the severity of her hearing loss, but they were important to stimulate her ears while we explored the option of a cochlear implant.

Then we heard the cost of a cochlear implant, it was in the millions of shillings. For an ordinary family like ours, that felt completely impossible. We wondered how such a life-changing opportunity could be so far out of reach.

The hearing aids did not seem to make much difference, and that was painful. Still, we were encouraged to keep using them consistently. At the same time, we prayed and searched for help. We visited many religious and spiritual leaders. We received all kinds of advice — some comforting, some confusing, and some strange. We were simply desperate for anything that would change our child's situation.

Then one day, the hearing loss organization told us that donated cochlear implants had arrived in Kenya. **We moved quickly; completed all the required medical tests and waited anxiously at the national hospital. There were more than 300 families hoping for the same opportunity.**

When we were told our child had been selected, we cried. She was chosen because of her young age and because we had used hearing aids consistently. She received one implant. We felt incredibly grateful — and also aware that many families went home disappointed.

The surgery itself was not the hardest part. The real work began afterward — switch-on day, mapping appointments, learning how to care for the processor, attending therapy, and planning for school. Accessing rehabilitation services is still a major challenge. We travel long distances and spend money we do not always have. Many parents in our support group face the same struggle.

But despite everything, **we have seen a beautiful change in our daughter. Her personality has blossomed. She now enjoys making sounds and listening to herself. Every morning, she wakes up and asks for her processor to be put on. It is her way of telling us that sound is sweet. Watching her respond to sound fills our hearts in a way we cannot fully describe.**

If we could speak to another parent at the beginning of this journey, we would say: trust the testing, seek help early, and do not delay. Use hearing aids consistently. Connect with other parents. Do not walk this journey alone.

We are thankful for the chance our daughter received. We hope that one day, access to cochlear implants and therapy will not depend on donations or luck. Every child deserves the opportunity to hear and to reach their full potential.

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KENYA

Caregiver Name: Moses **Child: Samara**
Age at Implantation: 4 **Age Today: 6**

Samara's birth was a distressful process. She had been strangled by her umbilical cord, a situation which caused her to be deprived of her vital body functionalities. Even though she had attained her full gestation cycle of nine months, she was rushed into the Neonatal Intensive Care Unit. They provided essential support during her substantial 2.2 kg weight loss, enabling her to breathe and feed successfully. She was subjected to strong antibiotics and other medications to keep her fully alive. She progressed well within the next 14 days and met all her growth milestones and goals. No hearing issues were detected within her three years of check ins at pediatric clinics.

Up until she was four and started school we had not realized she had a profound hearing loss. Several hearing loss concerns emerged from her first quarter of school, which led us to hire a speech therapist on the assumption that she was only delayed in speech development. However, several referrals to ENT doctors/audiologists emerged, which advanced to involving an auditory specialist. With a final referral to an audiology centre, Samara was diagnosed with profound hearing loss. A cochlear implant was immediately recommended, a term we had never heard before. This created many difficult experiences and challenges.

Families raising children with cochlear implants navigate a complex interplay of medical, educational, social, emotional, and financial challenges. Successful rehabilitation goes beyond the surgical procedure—it requires ongoing therapy, family involvement, supportive schools, and well-coordinated systems to foster listening, communication, and participation across the lifespan of the individual.

1. Medical and Pre-Implantation Challenges

Diagnosis and Decision Making:

- Timing of detection: Early diagnosis of profound hearing loss is ideal, but delays occur due to limited newborn screening or late referral. Samara's case is our example of this, and the screening should have been done in earlier stages.
- Complex decision process: Choosing whether to proceed with cochlear implantation involves weighing benefits (access to sound) against surgical risks and long-term commitment.
- Parental uncertainty: We experienced anxiety and guilt, asking: Will it help? Is it the right choice for our child?

Medical Access & Surgical Concerns.

- Access to specialists: The experts are few and not well known in the vast area of Kenya and Africa. Not all families can easily consult ENT surgeons, audiologists, or pediatric neurologists.
- Surgical risks: Concerns about anesthesia, device complications, and future surgeries (especially in very young children) made me almost cancel the whole process out of fear.
- Costs and insurance: Even when supported financially, we still have out-of-pocket expenses for the implant, mapping sessions, therapy, and equipment. We are still paying a loan taken in 2023 for the surgery which makes it difficult to support the rehabilitation required and hinders a second cochlear implantation in the right ear.

2. Major challenge: Financial and Practical Constraints

Direct Costs

- **Surgery, mapping, therapy sessions, accessories, and travel add up. Even with insurance, co-pays and non-covered services strain family budgets.**

Indirect Costs

- Time off work: Both parents had to alternately leave for appointments and parental home therapy, leaving for at least four hours per day. At school, she also had a daily professional speech therapist for two hours.
- Transport: Long travel to specialised centers increases expense and fatigue.

3. Post-Implantation Rehabilitation Challenges.

Auditory and Speech Development

- Relearning hearing: After activation, children must learn to interpret sound. This takes time and varies widely.
- Speech therapy needs: Most children require intensive, ongoing speech-language therapy to develop spoken communication.
- Progress variability: Some children progress rapidly, others show delayed or plateauing skill development which is often frustrating for families.

Access to Quality Rehabilitation Services

- Geographic limitations: Families living outside urban centers may have limited access to trained therapists.
- Service costs: Rehabilitation sessions (speech therapy, auditory training) can be expensive and are not always covered by insurance. Most of the insurance firms don't support the CI and the therapy. Creating proper awareness should be done to handle this problem.
- Coordination of care: Scheduling and maintaining consistent therapy across multiple providers can be overwhelming.

Device Maintenance & Technical Issues

- Equipment breakdown: External processors and accessories are fragile and repairing them causes stress.
- Battery management: Especially in young children, keeping batteries charged and functioning consistently is a daily challenge.
- Upgrades: New technology may outpace what families can afford or access. How compatible will the current implant support/adopt the changing technology?

4. Educational and Social Challenges.

School Environment

- Inclusion vs. support: Mainstream schools may lack accommodations like FM systems, quiet classrooms, or trained staff.
- Teacher awareness: Educators may not fully understand how to support children with hearing loss effectively.
- Academic gaps: Even with implants, children may lag in literacy, language complexity, or phonological awareness.

Peer Interaction and Social Identity

- Communication barriers: Difficulty in noisy environments like playgrounds can lead to withdrawal or misunderstandings.
- Bullying and stigma: Children with visible differences (e.g., wearing processors) may face teasing or exclusion.
- Cultural identity issues: Some families grapple with deaf identity, navigating between deaf culture and hearing world expectations.

5. Family Dynamics and Psychosocial Stressors.

Emotional & Psychological Impact

- Parental stress: Caring for a child with hearing loss and rehabilitation demands often leads to anxiety, fatigue, and emotional strain.
- Sibling concerns: Siblings may feel neglected or confused about the extra attention directed to the child with a CI.
- Hope and disappointment cycles: Progress can fluctuate, leading to emotional highs and lows for families.

Communication within the Family

- Language choice conflict: Families may disagree about spoken language vs. sign language or taking a bilingual approach.
- Consistency at home: Effective rehabilitation requires daily structured communication practice, which can be hard to maintain.

6. Samara Joy's Key Greatest Achievement to Date
   - **To hear and speak – OUR ALL TIME MIRACLE**
   - **Being able to associate and socialize well in a normal societal environment**
   - **The ability to attend and participate at home, school, church and other outdoor whereabouts with almost no support.**

7. Changes We Made to Achieve Better Access to Cochlear Implantation.
   - **Conducted research on the best ENT surgeon nationally**
   - **Adoption of the referral to the best audiologist and found an audiology centre. Listened and followed their guidelines to date and as the support center.**
   - **Selling the family valuables, taking loans and subscription to insurance to mitigate the high cost of the CI.**
   - **Emotional alignment to the new CI and rehabilitation journey - Acceptance and adoption.**

8. Recommendations To Families/Parent from Our Experience.
   - **Engage in early, consistent therapy. More so consistent parental, house manager and dedicated speech therapist to the child with CI.**
   - Building routines around auditory practice is fundamental.
   - Join parent support networks
   - Advocate in schools for accommodations. Involving class teachers and creating more awareness. More so, educating the teacher on how to handle the kid.

KENYA

Caregiver Name: Stephen
Age at Implantation: 3 **Age Today: 13**

I am a parent from Kenya of a child who is now 13 years old and uses a cochlear implant. My son was implanted when he was 3 years old, but the journey to that point was long, expensive, uncertain, and frustrating.

When we first realized that our child was not hearing, options in Kenya were very limited. Information was scarce, services were few, and the cost of cochlear implantation was far beyond what most families could afford. At that time, accessing a cochlear implant in Kenya felt almost impossible. After many consultations, we made the difficult decision to travel to India for the implant, because it was more affordable and because the options locally were extremely limited.

This decision meant multiple international trips. We traveled first for diagnosis and assessment, then again for surgery, and later for rehabilitation and reviews. Each trip came with financial strain, emotional stress, and time away from other children and work. **The cost of the implant itself was our biggest challenge,** though long-term rehabilitation was equally demanding. Auditory Verbal Therapy (AVT) was essential for our child to learn to listen and speak, yet services were not available close to home. For a long time, we traveled seven hours one way every week to access AVT therapy. This was physically exhausting, emotionally draining, and financially straining, but we knew it was necessary.

Other challenges followed. We worried constantly about device safety, especially in environments where awareness of cochlear implants was low. Finding the right school environment was another hurdle—one that would support listening and spoken language. We also had skeptics-many around us doubted whether cochlear implants worked at all. Some believed that spoken language was impossible for a deaf child. As parents, we had to learn to stand firm in the face of doubt.

Our greatest early support came from family, friends, and fellow parents of children with cochlear implants. Connecting with parents who had already walked this journey gave us hope and practical guidance. Professional support was also critical. AVT specialists from India, the USA, and Ireland provided guidance—often virtually—showing us that technology could bridge geographical gaps even when local services were scarce.

Today, our child's greatest achievement is the confidence he has in his use of listening and spoken language. He is thriving in a mainstream school and classroom, communicating, learning, and participating fully alongside his hearing peers. Watching this 'family miracle' is the greatest joy and reward of our journey.

This experience also changed me as a parent. Inspired by our struggles and successes, I went back to school to train as a speech therapist and later became an Auditory Verbal Therapy trainee. What began as a personal fight for my child's future grew into a calling to support other families facing similar challenges.

Out of this journey, I also helped establish a community organization, which has introduced the first public Early Hearing Detection and Intervention (EHDI) program in Kenya. Through this work, thousands of children and families have benefited from earlier identification, better referrals, and improved access to hearing services. We also actively advocate for better access to cochlear implants and have connected several families to CI donations, both locally and internationally.

If I were to advise another parent, I would say this: hearing loss is a correctable disability if identified and addressed early. Do not wait. Work closely with qualified professionals, trust evidence-based intervention, and remember that technology has greatly reduced geographical barriers. Most importantly, do not walk this journey alone—other parents can be your greatest strength. Today, technology has nearly eliminated geographical barriers, and support can come from anywhere in the world.

Our story is one of challenge, resilience, and hope. It shows what is possible when families persist; systems begin to change, and children with hearing loss are given the opportunity to reach their full potential.


KYRGYZSTAN

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Kyrgyzstan

Caregiver Name: Asel **Child: Aida**
Age at Implantation: 1 **Age Today: 9**

My husband and I were only 23 years old when we learned about our daughter's diagnosis. We had married for love- the kind people describe as "forever". We were both hearing, young, and certain that only happiness was ahead. I was studying medicine at the time and during my pregnancy, I mentally reviewed dozens of possible complications. But hearing loss never crossed my mind. It felt distant, something that happened to other families, not ours.

Then came her birth. Her first cry. Tiny fingers, sleepless nights, and the overwhelming joy of becoming parents. Then the doubts began. There was silence when there should have been a reaction. More tests followed, then confirmation. A shock so strong it feels as though the ground disappears beneath your feet; you are standing yet inside you are falling. I remember walking out of the doctor's office. Life around us continued as usual; people talking, laughing, and cars passing by. But for us, it felt as though someone had switched the sound off. The irony was painful.

A new chapter began with cochlear implantation. We understood that time was critical. For a child, time means development and opportunity. **With charitable support, we were able to arrange the surgery. It was more than just assistance, it was hope.** The operation was successful. The first activation of implant is impossible to fully describe. It is not a dramatic movie moment, it is careful listening, adjustment and patience. It is the beginning of a long road built from small, determined steps.

With a child who has hearing loss, every day brings small victories. We celebrate what many parents take for granted: a new word, a clearly spoken sentence and a joke at the right moment. Sometimes we repeat things several times. Sometimes we realize we naturally speak more slowly and clearly than others. Progress comes quietly, but it does come.

Today, our daughter is in the second grade. She has friends and favourite subjects, such as art, robotics and science. She practices taekwondo and swimming. She has won medals for her forms in competitions. Inside me, I have two conflicting mothers: one proudly shouting "Bravo!", and the other whispering "Please be careful…the implant…"

At times, it feels as though we are raising not only a child, but also a delicate piece of technology that must always be kept safe. Still, we try not to let fear define her world. School brings challenges such as a teacher speaking while facing the board and classmates talking all at once. We encourage her to ask people to repeat themselves. We teach her to be resilient.

When Aida was seven, our second daughter was born. Soon after, she was also diagnosed with hearing loss. I will never forget the day we told Aida about her baby sister. She cried and said "I wanted her to hear". Her words pierced my heart. **In that moment, I realized she had been carrying her own struggles deeper than we understood.** She did not want the same path for her sister. Even with her strength and bright smile, parts

of her journey had been hard. That day I saw how much she had grown. There was no self-pity in her words, only love and a wish for her sister. Alongside the pain, I felt pride. Pride in her empathy and in her heart.

Each year brings new questions. Adolescence still lies ahead and sometimes I worry about what it might bring. But, alongside worry comes pride. Our daughter is growing into a strong, open-minded, determined young person. She laughs loudly and dreams without limits. As a family, we have learned to value both silence, sound and patience. We have learned to not compare our path with others. Our family has grown stronger through this journey.

If I could say one thing to parents who have just heard their child's diagnosis, it would be this; do not give up. In the beginning, it may feel as though everything is falling apart but it is not. Life is not ending, it is simply becoming different. You will become stronger than you imagined. Your child will look at you and believe in you. So, believe in your child, yourself and the road ahead. Even on the hardest days, try to find a reason to smile, because after every "this is hard", there comes a quiet and powerful "we did it".

Kyrgyzstan

Child: Kanykei

Age at Implantation: 18 months **Age Today: 6 years old**

We got married in 2010.
Kanykei was our long-awaited child.
We waited for her for ten whole years… ten years of hope, prayers, and tears.

One routine visit to the gynecologist divided our lives into “before” and “after.”
The doctor measured my blood pressure and looked at me strangely.
She asked me to stay in the office.
Fifteen minutes later, an ambulance arrived — I was urgently taken to the perinatal center.

There, a team of doctors met me. After consultation, they said the baby had to be delivered immediately.
My baby was only 29 weeks.

I did not agree…
But no one asked me.

On February 27, 2020, at 5:27 p.m., our Kanykei was born by cesarean section.
She weighed only 1,600 grams.
She was immediately taken to the neonatal intensive care unit.

She was diagnosed with NEC — necrotizing enterocolitis.
She couldn’t digest milk on her own, and internal bleeding began.
The doctors fought to save her life, administering strong antibiotics — amikacin and gentamicin.
And it was those medications that caused her deafness.

We stayed in the hospital for exactly one month.
Then we were discharged.

At that time, a COVID-19 outbreak began in the country.
The city went into lockdown.
Checkpoints. Curfew.
We cared for Kanykei at home and had almost no opportunity to show her to doctors.

One day, I accidentally dropped my phone next to her crib.
The sound was loud — it even startled me.
But Kanykei continued to sleep peacefully.

In that moment, my heart tightened.

I began testing her reactions to different sounds — while she slept and while she was awake.
There was no reaction.

We went to an audiologist.
We were referred for an ABR test.
And there we heard the terrible diagnosis — bilateral deafness.

She was only three and a half months old.

They told us about cochlear implantation.
But the surgery cost an enormous amount of money — money we did not have.
We registered and simply waited… and prayed.

In the spring of 2021, surgeons from Qatar came to Kyrgyzstan.
They performed the implantation for our daughter on a charitable basis.

Today, my daughter hears.

After everything we went through — intensive care, fear, quarantine, tears, sleepless nights — she hears.

And every sound she hears is like a miracle to me.

Like an answer to ten years of waiting and thousands of prayers.

And in the end, I want to say this:

This diagnosis is not the end.

It is not a sentence.

It is the beginning of a difficult but great journey.

There will be sleepless nights.

There will be tears in your pillow.

There will be exhaustion so deep you will want to disappear.

But one day…
You will hear your child's voice.
The first sound. The first word.
And in that moment, you will realize —
you have become stronger than you ever dreamed you could be.

Your child is not broken.
They are not "less."
They are a special gift entrusted specifically to you.

Do not give up.
Even when you are afraid.
Even when it hurts.
Even when it feels like you have no strength left.

Because beyond that pain — there is light.
And I know this.

I walked through that darkness…
and today I hear my daughter say, "Mama."


MONGOLIA

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MONGOLIA

Caregiver Name: Dagiisuren
Age at Implantation: 2

Child: Egshiglent-Od
Age Today: 2

My daughter is 2 years 5 months. She received the cochlear implant, and it was activated on September 11, 2025.

I experience difficulties in conveying understanding of myself and others to my child and in establishing effective communication.

The speech therapy sessions have been highly beneficial. She looks when called by name and is pronouncing a few phonemes and letters.

It is important to set aside time every day to engage in play and conversation with your child. I am trying to encourage interactive conversation by using age-appropriate games and books. I also try to keep the child free and unrestricted, without imposing strict limitations on activities.

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MONGOLIA

Caregiver Name: Khash-Erdene **Child: Enkhtaivan**
Age at Implantation: 2 **Age Today: 4**

My son is 4 years old. He received the cochlear implant, and it was activated on March 21, 2024. He is very active which makes it difficult for him to stay still, listen attentively, and imitate actions.

The greatest support comes from the kindergarten teachers, the speech therapist, and our family, including the older brother and father.

He is startled by sounds, then listens attentively and shows joy.

Please try to talk with your child regularly. Having frequent conversations with each other is very important.

As of right now, there have been no noticeable changes. This is because my child is not yet able to clearly express himself or introduce himself. He also has difficulty sitting still, has poor attention, and is very active.

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MONGOLIA

Caregiver Name: Bayarjargal **Child: Sumiyabazar**

Age Today: 5

My son is 5 years old. He received the cochlear implant, and it was activated on April 8, 2021. Besides the difficulties in understanding and communicating with my child, I am worried about his developmental delay compared to peers. **The main challenge currently is enabling him to communicate freely and express himself.**

The speech therapy lessons and educational instruction offered by the teachers at his kindergarten have been highly beneficial for my child's development. **My child's greatest achievement to date is that he has begun to respond to sounds. In addition to recognizing and responding to the voices of his father, mother, older brother, older sister, grandfather, and grandmother, he has learned to say some simple words and recently started to say several short phrases.**

My recommendation to other parents is to act promptly and enroll their children in speech therapy as early as possible, without unnecessary delay.

Enrolling my child in speech therapy has been an important and appropriate step to enhance the effectiveness of the cochlear implant. I have placed great emphasis on developing my child's speech, and I am collaborating with professional doctors and teachers, following their guidance and implementing their recommendations.

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MONGOLIA

Caregiver Name: Etkhtuul **Child: Zorig**
Age at Implantation: 2 & 6 **Age Today: 12**

Years ago, during a traditional Lunar New Year family visit, a relative casually asked about our toddler son, who had not spoken a word: “Could he be deaf?” That simple question marked the beginning of a life-changing journey for our family.

Medical evaluations soon confirmed significant hearing loss. At first, we did not understand what this truly meant. We compared it to needing glasses — something that could simply be corrected. But we learned that hearing loss affects far more than sound, it influences language, learning, social connection, and a child’s sense of belonging. Like many parents around the world, we suddenly had to face fear, confusion, and uncertainty about our child’s future.

Guided by dedicated doctors, we learned about cochlear implants. Accessing care, understanding options, and making decisions felt overwhelming, yet timing was critical. Early intervention would shape our son’s ability to develop spoken language. With professional support and the help of many people, our son received his first cochlear implant before age two. He heard sound for the first time — a quiet miracle that changed everything.

But surgery was only the beginning.

Like families everywhere, we discovered that rehabilitation — the daily work after implantation — required constant effort. Consistent device use, auditory-verbal therapy, communication practice, and emotional support became part of everyday life. I paused my career to focus on his development, and we followed medical guidance closely. Small milestones — turning toward sound, humming along with music — became victories we celebrated deeply.

Progress brought hope, but also anxiety. I often wondered whether we were doing enough, whether he would keep up with peers, and whether he would feel different. These questions are shared by parents of children with hearing loss worldwide, regardless of country or culture.

Before starting school, our son received a second implant, allowing him to hear with both ears. Bilateral hearing improved his speech understanding and confidence. **On his first day of school, he came home smiling and said, “I can learn.” That moment reflected not only his achievement, but years of medical care, rehabilitation, family commitment, and educational support.**

Today, he is a confident middle school student, respected by classmates and proud of his accomplishments. Yet we know many families worldwide still struggle with limited access to early diagnosis, surgery, devices, mapping services, therapy, and inclusive education. Even when technology is available, the emotional, financial, and practical demands on families are immense.

Our experience taught us important lessons we share with other parents: early action matters. Trust professional guidance. Ensure consistent device use. Speak with your child constantly. Encourage independence. Celebrate small progress. And just as importantly — support yourself as a parent. This journey requires strength, patience, and hope.

Cochlear implants do more than provide access to sound. They open doors to language, education, friendships, and participation in society. But no family should walk this path alone. Medical teams, educators, communities, and global organizations are essential to ensuring children receive not only implants, but also the rehabilitation, and long-term support needed to thrive.

We are deeply grateful to the medical professionals who guided us and extend our heartfelt appreciation to the educators who supported our son's inclusion. Their patience, encouragement, and belief in his abilities helped him grow academically, socially, and emotionally.

Their work does more than restore hearing — it restores hope, dignity, opportunity, and connection.

Our son now fills our home with laughter and music — sounds we once feared we might never hear. His story is ours, but also part of a global story shared by families everywhere: one of challenge, resilience, partnership, and the transformative power of early intervention and collective care.


NEPAL

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NEPAL

Caregiver Name: Parbati **Child: Luvina**
Age at Implantation: 9 **Age Today: 10**

Luniva is a 10-year-old child with hearing loss. She previously used hearing aids, but based on doctors' recommendations, she underwent a cochlear implant surgery last year to improve her hearing. Luniva is raised by her mother, who is a single parent. Her mother works hard to support Luniva's education, medical care, and other daily living expenses.

At the beginning, **the greatest challenge for Luniva's mother was arranging the financial resources required for the cochlear implant surgery, as the operation is extremely expensive**. As a single parent, bearing the full cost of such a major medical procedure was difficult for her. Although the family sought funds from numerous individuals and organizations for the operation, securing sufficient financial support proved to be very challenging. Despite these obstacles, Luvina's mother remained determined to pursue the treatment which would benefit daughter's future development.
In her efforts to manage the high cost of the surgery, she reached out to numerous individuals and organizations for financial support. She also used social media platforms to share Luniva's condition and medical needs, appealing for support from the wider community but she was not successful. Even so, she continued trying to raise the necessary funds so that Luniva could undergo the cochlear implant surgery and have a better chance at improved hearing.

After undergoing cochlear implant surgery, Luniva has shown visible and positive improvements in her hearing and overall behaviour. She is now able to understand conversations that take place within the family. This improvement is evident in her responses and curiosity, as she asks her mother questions like, *"Why did she say that to her grandmother?"* She has also started interacting in the classroom and shown improvement in education. These indicate growing language development, attention to spoken communication and awareness of social context.

Luniva's mother highlights that consistent speech therapy and proper mapping of the cochlear implants are important to understand sounds clearly after the surgery. While the implant provides access to sound, meaningful improvements in language and communication depend heavily on regular speech therapy sessions and accurate mapping of implants.

Based on her experience, **Luniva's mother strongly encourages all parents of children with hearing loss and cochlear implants to enrol their children in regular speech therapy sessions**. **She emphasizes that the surgery alone is not enough, and without consistent speech therapy, children may not develop proper language skills or meaningful communication skills**. Early and regular intervention is essential for maximizing the benefits of the cochlear implant.

She also advises other parents to be patient after the surgery for a few months **and not to expect quick changes in children**. Based on her own experience, she did not see noticeable changes in her daughter for the first three months. She was already losing hope. Now after seeing gradual progress, she emphasizes that **pressurizing children during this period is not the solution, as progress takes time.**

She also expressed that without these therapy sessions, progress in Luniva's language skills and responsiveness would be minimal. She also shared that access to speech therapy services can be difficult. In Nepal, there are limited speech therapists and audiologists who specialize in cochlear implant mapping. Due to this shortage, she and other parents experienced long waiting periods. The delays made it difficult to provide timely and consistent intervention for Luvina.

Although she faced several struggles and difficulties, Luvina's mother is grateful that her daughter was able to undergo cochlear implant surgery. She remains hopeful for her daughter's future growth and development.


PANAMA

Panama

Caregiver Name: Giovanna **Child: Christopher**
Age at Implantation: 3 **Age Today: 34**

“Is there anything we can do, doctor?” He answered, “No ma’am, I am sorry. There is nothing to do.” It has been 32 years, and still, I often wonder what would have happened if I had accepted those words as I walked out of the doctor’s office the day my son Chris was diagnosed as bilaterally profoundly deaf.

That morning had started like any other. I was working full-time and juggling responsibilities, so I arranged for Chris (1 year, 5 months) to be brought directly to the hospital for his ABR exam. This test was meant to confirm—or rule out—the suspicion of hearing loss that had been lingering for months. I arrived calm and trusting. Both his pediatrician and the ENT specialist had reassured me repeatedly: “Don’t worry.” Chris was a boy, and boys speak later, they said. Besides, he was growing up bilingual, in Spanish and English, which surely explained the delay.

The exam itself was long and emotionally draining. Getting a toddler to sleep under sedation took hours. When he finally did, he looked like a little angel. I remember thinking this would all be over soon, and we would return to our normal day—me to work, Chris back home. That illusion shattered when the doctor repeated the test and saw the same flat, non-responsive result.

"Ma'am, I’m sorry,” he said. “Your son is bilaterally profoundly deaf. Hearing loss can be mild, moderate, severe, or profound—and his is profound. There is nothing to do.”

The diagnosis was devastating. But almost instantly, something stronger took over: unshakable determination to make sure Chris would be a happy child; as I have usually described it, it I wanted this so bad it literally felt like having “fire in my guts.” At first, I didn’t even fully grasp what being deaf meant. I didn’t understand that it could affect speech. But very quickly, helping him hear and speak became my life’s mission.

At that time, in Panama, cochlear implants were virtually unknown. They were neither available nor discussed. Every door we knocked on—doctors, therapists, insurance companies, schools—led to the same answer: no. **No, we don’t do that. No, it’s not possible. No, it’s not allowed. Endless “no’s.” But I knew one thing with certainty: I was not going to accept “no” as the final answer.**

So, we widened our world. I travelled to Israel to attend an international congress on hearing loss. I sat in the front row, absorbing everything, asking questions, learning, and finally understanding what Chris needed: a cochlear implant. If Panama couldn’t offer it, then we would find a way elsewhere.

And we did. Chris was operated on in Colombia at 2 years and 11 months old, becoming the first patient there to be implanted with Mondini syndrome (absence of the cochlea). To make it happen, we brought

together a North American surgeon and a Colombian doctor, which at first seemed impossible due to country restrictions for medical practice with foreign professionals), but we didn't take no for an answer! What followed has been the never-ending task of educating family, neighbours, teachers, professionals, and even strangers who stared at Chris because of his implant. **Advocacy became part of our daily life, and it never really stopped.**

Today, Chris is 34 years old. The dream I had—to see him grow into a happy person—came true. He was fully mainstreamed, is bilingual, holds a degree in Marketing and Administration, works, and is happily married.

As for me, I now preside at an institution that works to promote early hearing screening and provide real solutions. Through this work, we have expanded our impact beyond Panama, collaborating with twelve allied countries across Latin America to share best practices, resources, and experiences in hearing health.

It has been 31 years since this extraordinary journey began. It has allowed me to encounter angels along the way and to turn around every NO into let´s make it happen. I truly believe the best is yet to come.

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Panama

Caregiver Name: Karina **Child: Kyan**
Age at Implantation: 3 **Age Today: 7**

The beginning of this journey was very difficult emotionally. Receiving the diagnosis meant facing, as a mother, a world full of technical words that I did not understand, creating fear and uncertainty. From one moment to the next, everything felt complex and overwhelming. **Understanding what that diagnosis really meant and how it would impact my son's life and our family was one of the first major challenges.**

The decision to move forward with a cochlear implant came with a lot of expectations. You hoped that the progress would be fast, almost immediate, but over time you learned that it doesn't work that way. The implant is not a magical solution, but the beginning of a long process that requires consistency, commitment and a lot of patience. **Learning to respect my son's own timing has also been one of the great challenges throughout this journey**. Another difficult aspect was the cost. Everything related to the implant, therapies and follow-up care is extremely expensive, and as parents you are constantly worried about how to cover everything without taking away what your child needs in order to move forward.

When we migrated to Panama, new challenges were added. The healthcare system changed and we had to continue therapy virtually for a period of time. In addition, something that may seem small but has a big impact on language development was adapting to a different everyday vocabulary. Words that are used one way in Colombia are said differently here. For a child who is developing language, an extra effort has to be made.

Throughout this journey, support has been essential. **The professionals and foundations that have accompanied us have made a huge difference**. Being in face-to-face therapy has been valuable, and the therapists are characterized by their empathy, patience and commitment to both the children and their families.

Emotional support within our family has also been crucial. I remember very clearly the day the implant was activated. It was a deeply emotional moment. I looked at my son's father and without needing words, we understood everything through our eyes. We hugged tightly and he said to me 'this is where everything begins'. That moment marked the true beginning of this process for us.

Today, my son's achievements are immense. **His language development, social interaction, school performance and independence are milestones we celebrate every day.** As a mother, there are moments that fill me with pride, such as when I speak to him in Spanish and he replies to me in English, showing that he can differentiate between languages and contexts. These achievements go far beyond hearing; they are about communicating, expression and being a part of his environment.

From our experience, I have tried to contribute by raising awareness and sharing our journey with other families. Talking about the importance of timely therapies, recommending foundations and guiding parents, especially those of newborns, about the importance of hearing screenings has been one way to help. **Hearing**

loss is not always visible when children are very young, but detecting it early can positively change the child's future. The journey has not been easy, but it has been full of learning, growth and hope.

PANAMA

Caregiver Name: Ana Victoria
Age at Implantation: 8 **Age Today: 8**

Becoming parents to a child who survived cancer changes you profoundly. It reshapes long-held beliefs and teaches you to live with perspective and gratitude, but also with constant awareness: knowing that some battles do not end when treatment does.

Our oldest son was diagnosed with hepatoblastoma as an infant. He received multiple rounds of chemotherapy, including cisplatin; a drug that at the time meant survival, but that gradually left a measurable consequence in the hearing tests conducted alongside his treatment: a mild to moderate sensorineural hearing loss in the high frequencies.

At that time, our priority was his survival. He went through the entire oncological treatment, hospitalizations, surgeries, and medications while supported by love. He moved forward. We celebrated remission and felt that the worst was behind us.

From his first year of life, he used hearing aids with regular monitoring and adjustments. For several years, they seemed to meet his needs. It was only last year, at age seven, that more noticeable changes emerged, first observed by his piano teacher. It became clear that sound discrimination was becoming more difficult, background noise was increasingly disruptive, and following conversations in noisy environments was growing more challenging.

New evaluations, repeated several times in the hope that there had been an error, confirmed what we feared; his hearing loss had progressed in the high frequencies, showing a pronounced slope on the audiogram. The damage had become profound and affected both ears. The medical explanation was clear: in some cases, cisplatin-related ototoxicity can progress over time, even when hearing levels appear stable for a period.

The greatest challenge was not only medical but understanding how to best support our son beyond his medical history. The decisions we had made were not easy, but they have been intentional and aligned with his needs.

It was during this process that something helped us see more clearly. In an art therapy session, our son was asked to create a bilateral drawing on a board. When he stepped back and looked at it, he pointed to the center and said, “these are my ears.” Then he pointed to the shapes on each side and added, “these are my hearing aids.” After a brief pause, he said, “they’re like erupting volcanoes; they hurt my ears.”

At that moment, we understood that this was no longer only about test results or percentages, but about how he was experiencing sound in his everyday life. That word ‘hurt’ revealed something we could no longer overlook. It helped us re-center the decision around him and moved forward from that place.
Our support has come from a combination of people and convictions: dedicated physicians, close family and friends, attentive teachers, and therapists who believe in his potential, and the belief that communication is one of the most essential ways to belong in the world.

Our son's achievements are not measured by his ability to discriminate sounds or pronounce words. They are reflected in his resilience, his curiosity, and his desire to participate and learn. Every step forward and every adaptation has been a meaningful victory.

When cochlear implantation entered the medical conversation, uncertainty followed. There was time for research, questions, and long conversations. Today, we have made a decision and see it as an opportunity to strengthen his communication, participation, and sense of belonging. This year, we have decided to proceed with cochlear implantation in one ear.

To other parents, we would say this: trust your intuition and the knowledge you build about your children. **Do not minimize symptoms or late effects**. **Ask questions, document, and seek allies. Early intervention and access to appropriate technology can change a child's trajectory**.

This story centers on one of our children, but it is upheld by our family of five, who have learned to support one another, adapt, grow in sensitivity, and move forward together. Our son's journey is what it is: difficult, beautiful and complex. It has been transformative and healing, and it has shaped how we understand growth, resilience, and care. **Difficulties leave a mark but also sharpens our ability to recognize what matters**. It is a reminder of how children grow and endure and how the world around them must continue learning how to support them.


PARAGUAY

BE0798.221.710

Paraguay

Caregiver Names: Oscar and Rina Child: Agustina

We are Oscar and Rina, parents of a child with a cochlear implant. We would like to begin our story by saying that early detection is the most important factor. In our case, our daughter was diagnosed with profound bilateral hearing loss. As parents we were completely devastated by the diagnosis. However, at the same time, we found support and strength within our family circle, which helped us begin to face this reality and explore every possible option.

Our journey began in early 2003. At that time, in our country, Paraguay, this diagnosis was very much unknown. There was only one specialized medical professional that preformed this type of surgery, and he was working in South Africa. On top of that, **the cost of surgery and the cochlear implant itself made it extremely difficult for us to even consider it as a possibility.**

Through a member of a volunteer service organization in our country, beneficial connections were made with their colleagues in Brazil. **With this support, we were able to access the technology and surgery in the city of Bauru, in the state of São Paulo.**

Once this major step was accomplished, we fully committed ourselves to our daughter's therapy. She began her rehabilitation process here in Asunción, while we also traveled to Brazil once or twice a year for evaluations and updates on her implant. The road was long and full of sacrifices, but today we can say with absolute certainty that every effort was worth it.

Our daughter proved that despite her hearing loss, she was able to overcome countless obstacles. **Today, with immense pride and joy, we can say that she has become the first hearing-impaired graduate in Speech Therapy in Paraguay, working with children who have conditions similar to her.**

Our final message to parents who are facing this diagnosis is simple but heartfelt: do not give up and do not lose hope. Exhaust every option, knock on doors and be persistent. All of this is worth it. Improving our children's quality of life and allowing them to live fully and independent brings us immeasurable happiness.

Today, as parents, we are deeply proud of her. Despite discrimination and many challenges that not even the most advanced societies have managed to eliminate, she moved forward. As a family, we raised the flags of perseverance and resilience and today we can confidently say that we have fulfilled our mission as parents and as a family.

PARAGUAY

Caregiver Name: Ruth **Child: Benjamin**
Age at Implantation: 4 **Age Today: 12**

Benjamín was born with Down syndrome, along with everything that comes with that condition. During his early years, he was a very healthy child, with no major difficulties. However, when he was around a year and a half old, we began to suspect that he was not hearing properly.

We carried out all the necessary audiological tests, and he was diagnosed with profound bilateral sensorineural hearing loss. That was when we first heard about cochlear implants and their cost. My husband and I looked at each other and thought it was impossible—we didn't see how we could achieve that goal in such a short amount of time.

We began to educate ourselves. We met people, joined parent support groups with children who had hearing disabilities, started reading, learning, and discovering a completely new world for us. After that, we made the decision to ask for help from different institutions and organizations to cover the cost of the implant since the support from the government was very limited.

Another major challenge was finding professionals who were able to work with two disabilities at the same time. It was not very common to find specialists experienced in both intellectual disability and hearing loss, and it took a great deal of effort to find professionals willing to take on that challenge and believe in Benjamín's potential. At one point, we even considered moving to another country in search of additional support. We were told that we would have to give up our Paraguayan nationality to become citizens elsewhere and gain access to the implant. After much reflection, my husband and I decided to stay in Paraguay and continue seeking help here.

This entire journey lasted until Benjamín was almost four years old. Finally, we received a donation from an organization that covered the cost of the device. Benjamín was four years and nine months old when he underwent the surgery, and we were overjoyed. The activation of the implant was one of the most emotional moments of our lives. **I remember speaking to him and saying, "Benja, Mommy is talking to you," and he turned around to look at me. That moment is one we will always treasure.**

After that, we faced yet another challenge: finding a speech therapist who could accompany him throughout his rehabilitation process. Once again, this was one of the most difficult parts due to the limited experience available for working with both conditions together.

Today, Benjamín is very happy with his implant. While he can hear, verbal expression remains challenging because of his Down Syndrome. However, he understands, he comprehends, he enjoys life and the moments he lives. He communicates in different ways, and that is extremely important to us. We truly believe that the implant has helped improve his quality of life. Perhaps not in the

same way as it would for a child without an intellectual disability, but we clearly see progress and positive changes, and that fills us with satisfaction.

Our message to other parents is to never give up. The earlier you seek help, explore options, and knock on doors, the better. Do not lose heart. Cochlear implants can be incredibly beneficial. Even if you feel tired, take a breath and keep going with renewed strength. All this effort becomes the driving force to give our children a better quality of life. We encourage all parents to always seek the best for their children, never give up, and remember that the work done within the family is the most important and fundamental part of a child's journey with a cochlear implant.

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PARAGUAY

Caregiver name: Mario
Child: Dulce Valentina
Age at Implantation: 2
Age Today: 5

My name is Mario and my little girl is Valentina. She is five and a half years old today. When Valentina was born, everything seemed normal. However, when she was about eight months old, we began to notice that she was barely responding to sounds. After a series of audiological tests, we were finally told that she had bilateral profound hearing loss.

Here in Paraguay, where the healthcare system often falls short, we found ourselves completely overwhelmed. We had no prior experience with this situation, nor did we know anyone who had gone through something similar. Emotionally and mentally, we felt crushed. It was an incredibly difficult moment for our family.

Then, something happened that we can only describe as destiny—or perhaps a miracle. **During one of the audiology appointments, we met a woman whose name we never learned, something I still regret to this day. That woman told my wife about a hearing loss organization in Paraguay and about an extraordinary speech therapist.**

We reached out to her, and in less than three months, we already gotten approval for a cochlear implant in Valentina's right ear. It truly felt like a miracle. **The surgery was performed, the processor was activated, and Valentina began to hear. She really began to hear.**

However, despite consistent speech therapy and our constant efforts, Valentina has not yet been able to form sentences or speak fluently. Because of this, we began pursuing the possibility of a second cochlear implant through a legal protection order. We won the court ruling, but to this day, we have received no response.

To make matters more difficult, the implant Valentina currently uses is now outdated. Technology continues to advance rapidly, and there will come a time when this device will no longer function properly. Unfortunately, we do not have the means to maintain or replace it on our own in the long term.

That is why we are currently organizing activities and seeking support to obtain a newer cochlear implant processor—one that can truly serve her for many years to come. In the meantime, we continue with her speech therapy sessions without missing a single appointment. At home, my wife, my other daughter, and I all do everything we possibly can. While they focus on her daily support and stimulation, I do my best to keep moving forward financially in order to find a solution for our daughter.

This is our story with Valentina. She is pure love—a beautiful little girl who has stolen the hearts of everyone who meets her. Many people

see her as a symbol of sacrifice, perseverance, and strength in the fight against deafness. She carries it all with remarkable grace.

Of course, what we want most is for her to have a life that is as close to normal as possible. We may not reach absolute normality, but we truly believe that we can—and that we will—give her the best life possible.

Thank you very much for reading our story.

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Paraguay

Caregiver Name: Clara **Child: Elías**
Age at Implantation: 2.5 **Age Today: 5**

Elías is a five-year-old boy from Paraguay who was born on November 6, 2020, at a local medical center, at 37 weeks of gestation. He required intensive care and was hospitalized for a total of 32 days. During that time, he suffered cardiac arrests and other serious complications. Those were very hard days, filled with uncertainty, but thankfully they had a happy ending.

At that time, basic hearing screenings were not routinely performed at the hospital. I began researching on my own and found a private institute where Elías underwent his first hearing test, otoacoustic emissions (OAE), which he did not pass. We were asked to repeat the test at six months, this time with auditory brainstem response testing (ABR). That was when we received the news: Elías had bilateral hearing loss—severe in his left ear and moderate in his right.

As a family, we went through a grieving process. It hurt deeply. As a mother, I cried, felt powerless, and was overwhelmed with doubts. We didn't know how to face this reality. Questions flooded our minds: How much would hearing loss aids cost? Are there speech therapists in our city? Will we be able to afford everything? At the same time, Elías was also diagnosed with non-progressive chronic encephalopathy, which required even more therapies and consultations with multiple specialists.
What helped us react quickly was his father's optimism. We purchased hearing aids and found a speech therapist—an angel who appeared at just the right time. She worked at a private institute and specialized in auditory-verbal therapy. Although she lived in a city near the capital, she traveled to our city, to provide therapy. **She became our greatest support, along with our determination as parents to learn and help our son.** We took online courses, received reading materials, practiced constantly, and learned to understand hearing loss better.

Through those courses, I learned about cochlear implants and the incredible benefits they offer. Unfortunately, due to their cost, they were not accessible to everyone. It was also through our speech therapist that we were introduced to a foundation. There, we met wonderful people with big hearts, deeply empathetic to our daily struggle.

After many therapy sessions and limited progress, our speech therapist recommended that Elías be evaluated as a candidate for a cochlear implant. This time, I did not cry—I felt joy. **I knew the biggest obstacle would be the cost. Both of us work as employees, and realistically, even a full year's salary would not have been enough.** Still, we saw examples of other families who succeeded, and we decided to pursue this dream.

Our fundraising campaign was called *"Elías Wants to Hear You."* **We organized raffles with donated prizes, distributed donation boxes, and friends hosted benefit events.** The support came not only from people in our city, but also from relatives in other cities and even other countries. Although I am naturally introverted, I overcame my fear and spoke to the media. Through all these efforts, we managed to raise 50% of the required amount.

I will be forever grateful to the foundation. They donated the remaining funds, covered the surgery, and continue to support us with audiological evaluations, implant programming, and therapy. Because implantation is only the beginning—it also requires constant monitoring, therapy, and daily practice to achieve results.

Today, Elías—despite his encephalopathy—crawled at two years old and began walking at four. He has been in physical therapy since he was seven months old and continues with multiple therapies, including speech therapy, psychology, physical therapy, early stimulation, and equine therapy. He attends preschool, received a cochlear implant in his left ear at two and a half years old, and continues to use a hearing aid in his right ear.

Although he does not yet speak clearly, we communicate with him by talking to him constantly. **He understands us, follows instructions, and responds in his own way.** We hope that the dream of hearing his words will come true very soon.

And as a piece of advice—one you didn't ask for, but I want to share—educate yourself as much as you can so you know how to help your child. Don't be afraid. The pain will pass. Do everything possible to provide the necessary devices and therapy and repeat at home everything you learn. Everything comes in its own time. Have faith, stay strong—it is possible.

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Paraguay

Caregiver Name: Ester **Child: Elías**

Age at Implantation: 3 **Age Today: 6**

We are from Paraguay, and we are the parents of Elías Benjamín. We would like to share a little of our story. We learned about our son's hearing loss when he was twelve months old. It was a very hard blow, especially because we did not know the world of hearing loss. We felt lost and uncertain, not knowing which direction to take. Through that process, we met professionals who guided us and introduced us to the foundation that provided us with tremendous emotional support and, above all, valuable information about cochlear implants, the advances in technology in recent years, and auditory-verbal therapy.

At that time, our greatest challenge was obtaining a cochlear implant. Thanks to God, the generosity of supportive people, and the help of the foundation, we were able to access a cochlear implant. And with that, our little boy gained access to the world of sound.

Our greatest support throughout this journey has been the foundation and the parents of other children with the same condition. Without them—without their life stories and shared experiences—we would not have been able to continue this path.

Our greatest achievement so far is that our son can hear us. Little by little, he is beginning to say some words, to connect with us and with other children. He goes to school and gradually overcomes each challenge that comes his way.

The advice we would give to other parents is this: allow yourself to grieve but then stand up and fight for your child. With determination and perseverance, many achievements are possible. Never stop equipping your child, taking them to therapy and regular programming sessions, because all of this will be worth it in the future.

Fully immerse yourself in the world of hearing loss. Learn about the tools and strategies that exist so that this change can truly happen. And keep going all the way to the end.

PARAGUAY

Caregiver Name: Mercedes **Child: José Carlos**
Age at Implantation: 2 **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.


SOUTH
AFRICA

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SOUTH AFRICA

Caregiver Name: Bibiche **Child: Bravery**
Age at Implantation: 2.5 **Age Today: 12**

Bravery was born in 2013, a healthy and happy baby. In 2015, my daughter was diagnosed with meningitis, which affected her hearing. I began to notice changes in my baby, she became very quiet and unhappy. There was no more singing, no calling her sisters by their names, and every word she had learned slowly disappeared.

The biggest challenge for Bravery was not being able to hear like her sisters. While they could laugh, talk, and respond to sounds naturally, Bravery lived in silence. This was very difficult for her and heartbreaking for me as a mother.

She suffered a profound hearing loss that could not be helped with hearing aids, as both cochleae had been damaged by meningitis. The only chance for Bravery to hear again was a cochlear implant. It was one of the hardest decisions I have ever had to make, but I decided to give my child the opportunity to hear.

In 2016, Bravery received a cochlear implant. From that moment on, my child has made incredible progress. She can hear, dance when music is playing, and she becomes very excited about every sound she hears.

One of Bravery's greatest achievements is that she is able to hear and respond well using only nine electrodes in her cochlear implant. Despite having fewer electrodes than some children who use hearing aids or cochlear implants, Bravery has shown remarkable hearing ability and progress.

Throughout this journey, I have had to put in a great deal of extra effort — supporting Bravery daily, patiently helping her learn, and constantly explaining her condition to friends and family so they could understand her journey and treat her with care and compassion. I would not have managed this journey alone.

My greatest support and help have come from my family and friends, the dedicated hospital support team, and my faith, which carried me through the most difficult moments and gave me strength and hope when the journey felt overwhelming. When I look at how far Bravery has come since the implantation, I am filled with gratitude and pride.

My child's journey inspires me every day. She is my very brave Bravery. **The advice I would give to anyone facing similar challenges is simple but powerful: "DO NOT GIVE UP!"**

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South Africa

Caregiver Name: She-Attel **Child: Kyana**
Age at Implantation: 11 months **Age Today: 7**

Kyana was born at 38 weeks. This was a normal pregnancy without any complications. There is no family history of hereditary diseases. At the age of 3 months, Kyana was admitted to the hospital with bacterial meningitis. Two months later she underwent a bilateral "refer" hearing test and was referred for a diagnostic audiological assessment a month later. That summer, we unexpectedly received the diagnosis that Kyana has a bilateral extreme sensorineural hearing loss. Kyana was only 6 months old when she was fitted with bilateral hearing aids and referred for intervention. She was also referred as a possible cochlear implant candidate. A month later, Kyana began rehabilitation at the Centre. Initially, they had weekly sessions (twice a week), and they also received tele-intervention during the Covid pandemic.

In February 2020, Kyana was fitted with a cochlear implant in her right ear. In September 2021, it was felt that Kyana needed more structure and daily intervention from the Centre, so in October 2021 **we packed a bag and moved to a residential home for weekly intervention sessions.**

I was facing lots of challenges physically, emotionally and financially. It was a whole new world that opened for us. It was a new challenge after receiving her cochlear implant. When she was diagnosed and was a candidate for an implant, it was the first time I heard of a cochlear implant and was scared at first. After seeing kids with them and hearing other people's stories, it motivated me knowing that she will have the ability to hear even if she's deaf.

It was a struggle financially knowing that the procedure is quite expensive and the cost of maintaining the cochlear implant is high. My greatest support was the people and parents I met at the Centre. People that know what it is like to be a parent of a child that has a cochlear implant. We share a great bond and support each other a lot.

When she was first switched on was the greatest day of my life. **Watching her when she really started hearing my voice and different sounds was an amazing moment.**

My advice to parents is to do what is best for their child and accept that what their child is going through will make the healing process better. Moving to be near her school where she can have better access was the best decision I made. Having her near and around children with cochlear implants and being in the best school where she learns and experiences a lot is great.

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South Africa

Caregiver Name: Carmelita **Child: Leah**
Age at Implantation: 1 **Age Today: 10**

This is my beautiful daughter Leah. She was born on July 7, 2015. She looked like a healthy, cute little baby. We did not expect that she would be born deaf. At the age of 9 months, it was confirmed that Leah had bilateral hearing loss. It felt like the world was crumbling down on me, but I quickly realized that I had to get out of that hole and accept her for who she is.

As a mother, I wanted my daughter to have a normal life, and being deaf felt far from normal at the time. I did not know that there was technology that could possibly change my daughter's life. All I could see was her using her hands to communicate and it broke my heart, my wish was for my only child to speak, and I knew that might not be possible.

After 2 months, I received a call saying that I needed to bring Leah to an early intervention centre where deaf children learn to speak. **In that moment as a mother, I knew I had to get my child there without even knowing where it is or how it would help us.** Then, I did some research about the centre and the first thing that popped up was 'did you know deaf children can speak?'. From then on, I knew we were in the best hands.

My biggest challenge as a mother was the cost of the cochlear implant, even though this was the only option for baby Leah, as parents we knew we couldn't afford to give out child the gift of hearing out of our pockets. We would lay awake at night thinking how we could do this to make it possible for our daughter to hear. This was one stressful part of our journey. We were blessed beyond our dreams when an audiologist answered our prayers that we had been crying for. They managed to get a sponsor so that Leah could have her cochlear implant. Without that, to this day, my husband and I would not be able to give her this gift.

Our greatest support was the interventionist and audiologist involved in Leah's journey. We were so lucky to receive these two diamonds on our path. It was hard work, but to know that we as a family were supported by these professionals made everything so much easier. They walked every step of this journey with me. We shared so many tears together but also made so many memories that will forever be a part of Leah's life. They encouraged me when I thought it would not work out, push us when they saw the potential in Leah and celebrate her achievements. **My family's support also played a big role; they supported us emotionally and helped us in any way possible even though finances were never possible for us as a low-income family.**

My child's greatest achievement is her ability to listen, follow instructions, speak, read and write. When I look at her today, sometimes I think about where my child would fit in this world without her cochlear implant. But she lives her life like a normal girl who is always ready to give her best.

My advice to parents starting this journey is to put in all of your effort and always have time available to ensure your child does not miss any appointments. Remember it is very important to always have eyes open and ears on, this way you get the best benefit from the cochlear implant. It is a lot of hard work in the beginning, but after time it becomes natural. As a parent, you need to put all of your dedication into your child. Each child is different, but all I ever wanted was for my child to understand me. I am so grateful for how far we have come.

When we started this journey, I had to leave my job because my daughter needed me more at the time. With the support from a centre here, we had access to cochlear implants and all of the necessary knowledge. We are truly grateful for this amazing team.

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South Africa

Caregiver Name: Singathwa **Child: Mbali**
Age at Implantation: 2 **Age Today: 13**

Mbali was born hearing, until she got sick when she was 3 months old with meningitis, to which she lost her hearing. We went to the hospital and were referred to a professional who told us about cochlear implants, and we decided this would be the best decision. She got the cochlear implant when she was 2 years old and at that time, she was not producing any speech. After the cochlear implant, she learned to hear and speak with the help of resources from a clinic.

My biggest challenge was the language. She had to go to an English school, but my family is Xhosa, so we also had to learn English. It was not easy because my mother-in-law also did not speak English, so it was difficult for us to communicate with her.

My greatest support has been from one of our hearing centres, when I was working long hours in the retail industry, they helped tremendously. My nanny did not know how to speak English to my child, so I asked for a cleaning job at the centre so that I could learn how to help my child hear and speak. The centre gave me the opportunity to be at Mbali's school to learn how to support her, also allowing us to go home early so we could spend more time practicing.

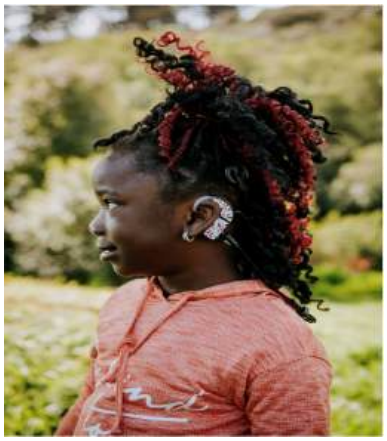
The greatest achievement my child has accomplished was her learning to hear and speak, especially in a school with hearing children. The cochlear implant brought her hearing back, allowing her to be in the same grade as her peers.

My advice to parents is never give up on your children. It does not matter where you come from, who you are, if you get opportunity for your child to get cochlear implant, grab that opportunity with both hands because that could change your child's life forever. I am a mother who is coming from a family with many disadvantages but that did not stop my child from getting the cochlear implant. Yes, it is expensive to maintain, and it is a lifelong commitment because once your child can hear, they will never want to go back.

Thank you, cochlear implant, for changing lives. I want to express my deepest gratitude for the cochlear implant that has transformed my child's life, enabling her to hear and communicate with the world. The impact is immeasurable, and I am committed to supporting her through every step of this journey, ensuring she gets the best care and opportunities to thrive with her new hearing ability.

South Africa

Caregiver Name: Mamie **Child: Peace Victoria**
Age at Implantation: 2 **Age Today: 8**



My name is Mamie and I'm Peace Victoria's mum who is a CI user. I'm originally from the Democratic Republic of Congo and have been a permanent resident in South Africa for 20 years now.

Peace is 8 years old now. Born on August 8th, 2017. At 10 months she had meningitis and was treated at a Children's hospital. Where we were then discharged after she completed the antibiotics and some more medication was given for her to take home.

While in the hospital hearing tests were done and she passed, we went again for a checkup 3 months later she passed and all was fine.

In March 2019 I noticed that she wasn't responding very well when you called or spoke to her. She was also delayed in her taking. I called the hospital to make a new appointment for her ears to be checked since I was worried. We went there on April 15th, 2019, and were told that she was struggling to pick up sound.

They sent us to another facility to do more tests since their room for these tests were not available. The next day we went for the tests, and they told me that she had lost both hearing permanently, and after that I was told, she would have to use hearing aids. It was 2 weeks later that she got the hearing aids, and I was told that they were not sure yet if she could hear - let's give her some time. After a month, tests were done, confirmed that she can't hear with the aids, a cochlear implant was suggested and this was the first time I heard about it...she had the surgery in June 2019 and got the cochlear implant on July 9th, 2019.

This was a big relief for me that my child could hear and speak again. **The biggest challenge that I had was to first accept that my daughter is deaf, the rejection from the family that did not support me enough and the blame that they put on me saying that I was not praying enough for such a thing to happen to my little girl.** I had to take her every week for speech therapy, work hard with her so that she could improve. A few months later I divorced their abusive father which left me as a single mum with 3 kids. This made my life very complicated since I had to deal with all the situation on my own.

Thank you to the CI Unit in the hospital for all the support and encouragement I always receive from them. Peace is in a special school for kids with hearing impaired, she progressed to the third grade now. The school has been a great pillar of support to both of us. Peace has settled well in school and has also developed a strong social confidence though she suffered from anxiety and went on medication for quite some time. She received a sound processor upgrade in March 2025, so she now wears a newer model. This was obtained through hospital funding.

Peace is a good technology user; her most recent hearing test shows good access to sound and she can discriminate soft speech 92% of words. This score reflects effective hearing through her cochlear implant.

My advice to other parents is that this is a hard and stressful journey sometimes. We first need to accept the condition of our kids so that you can have the strength to support and help your child.

Reach out to other parents in the same situation for emotional support. Ask for help where you feel stuck.

Also remember to start saving some money even a small amount that you can, this will help with repairs or replacement for spares parts when needed. To the parents with small kids, always pay good attention to the development of your kids and this can help with an early awareness.

Today, Peace has effective hearing through her Cochlear Implant. This is a life changer for us.

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SOUTH AFRICA

Caregiver Name: Thaakierah **Child: Zidan**
Age at Implantation: 2 **Age Today: 5**

I am the parent of a profoundly deaf little boy, and I am excited to be able to share my story and journey with you all. My son was born in 2020, and he came prematurely at 31 weeks. Little did we know, our son had to be in the hospital for just over 2 months, with several tests done, apneas, a hole in the heart, and even a blood transfusion. Almost 3 months later we brought him home!

He was developing well each day, but there were some delays. The doctor re-assured me that it's due to his prematurity, and he will catch up. Although he failed his hearing test in the hospital, doctors and audiologists re-assured me again that it could be due to his prematurity. My little superhero is nearly 2, and does not say "mama" or respond to loud noises. Finally, we had him tested. He failed. We took him to another hospital and had him tested again, but he failed. We were optimistic and pretty certain that ALL the doctors' tests were wrong. Eventually, after a plethora of tests, an ABR confirmed he is profoundly deaf (only started to hear at 85 decibels). At this point, I was full of fear for my son and this scary cruel world. We proceeded to have him fitted with hearing aids almost immediately. We had an amazing moment that brought us all to tears when he giggled so beautifully at the sound of our voices!

We were enrolled into an amazing support program at our local hospital, this team is Godsent. Everyone from the audiologists to speech therapists really knew exactly what to do. They were available to answer all the questions and ready with a tissue to wipe the tears. We were set! Happy that we got over this and that our son has hearing aids.

A few months into the program, we were informed that our son is not getting enough access to sound and he NEEDS the cochlear implant surgery, in both ears, now. If you know South Africa, you know that this surgery and devices are not affordable at all, and no average South African has this amount of funds laying around. My husband and I scratched our heads on how we would get this done, as the time was ticking and he needed to be implanted before the age of 2. The amazing audiology team stepped in and assisted us, wrote whatever letters needed to be written and submitted and we were set! HE GOT THE SURGERY!!!!

For me, the hardest part of getting here was the unknown, as we are a hearing family. It's been 3 years since my son has been implanted, and he is not speaking Fluently yet, but his understanding and hearing has improved so well! He can hear whispers, and he has become so dependent on his devices. As soon as he wakes up, he puts it on himself. He absolutely loves music and other days, he appreciates silence.

To be honest, more emphasis and awareness as well as education should be provided to parents in the hospital if babies fail their hearing test. There should be follow-ups and counselling. I am a firm believer that everything happens for a reason, but in my experience, I was in denial and it was presented as an option. I was uneducated in this regard and not aware of the negative impact my delay in handling this has.
I wish that cochlear implants and cochlear implant surgery was free at birth, it truly does provide our kids with better opportunities! **My son can communicate now. We can head to the mall and he can tell me whether he wants chicken or fish for lunch.** He can tell me what game he wants to play or when it's time to use the loo. We had 3 years of challenges and I'm sure there are many more ahead, but the accomplishments and little miracles are so much more rewarding. **Being able to communicate with my son, where I could not before, that is indescribable!**

South Africa

Caregiver Name: Naeema
Age at Implantation: 18 months **Age Today: 9**

I'm a mother of a 9-year-old energetic, strong-willed boy who was diagnosed with profound hearing loss just before he turned 2.

My biggest challenge I'm facing is financial costs of maintaining it, as it always requires unexpected maintenance. **My family and our support team were my greatest support throughout**. We have achieved so much to date where **he is now able to reach his full auditory, speech and language development.**

I would advise anyone considering getting cochlear implants to go ahead as it's the best decision one can make to live a normal life. It improves the ability to communicate to those around you and reduce feelings of social isolation**. I've given up a full-time job to give my son the support he requires** and I'm continuing doing so, so that he achieves the best access to cochlear implants.

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South Africa

Caregiver Name: Moereeda
Age at Implantation: 2 **Age Today: 22**

My boy was born profoundly deaf. He was implanted at twenty-two months old in 2005. He was bilaterally implanted a week before his third birthday. **The biggest challenge at the time was having a limited knowledge about deafness.** In my community, deaf meant you were unintelligent and would have a limited chance at living a successful life.

We knew we had to teach him speech to communicate effectively. He had to catch up 3+ years of lost sound. It was a scary time. The community was ignorant as to what the devices were on his head and what it was for. Most people thought they were fancy, upmarket headphones for listening to music. **We overcame this challenge by raising awareness and advocating.** The other challenge we had while he was growing up was bullying and misunderstanding from his peers. We had to teach him coping skills and give him practical strategies to handle this.

The biggest emotional support came from my husband, for both of us, this was foreign ground and we had to navigate it carefully and also preserve our relationship. My parents helped with logistics like transport, finance, childcare for our daughter and other support that was needed. **We received immense support from the kind professionals at a centre here in Cape Town.**

After attending a mainstream primary school, he went to a mainstream high school with minimal issues. He is 22 now and finished his third year of film school with a bursary he had won all by himself. When he graduates, he will be qualified to direct, produce, screen write, etc. any film project he works on. **I can truly say that where he is today is one of the biggest achievements of my life.**

My advice to other parents is to trust your instincts. Listen to the professionals and give your child and yourself the benefit of the doubt. Most of the time you will be pleasantly surprised at the results, the rest is just character building.

The discovery of our child's deafness changed the trajectory of our lives! We were going to move overseas for better opportunities, but it was not meant to be. We discovered his deafness at the same time we made plans to leave the country, but we couldn't because he needed to be implanted as well as begin intensive therapies. I am still working at the same centre 20 years later helping other parents in similar situations believe in themselves and their ability to help their child.


UGANDA

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Uganda

Caregiver Name: Sekamwa **Child: Kato**
Age at Implantation: 12 years **Age Today: 17**

Kato is our twin son, who was born before his due date. He had profound hearing loss from birth. Nobody initially understood how that would affect his future, only that it would influence everything. As parents, we were taught patience at a young age. We discovered how to watch, wait, and hope without certainty.

As parents, we saw that Kato was not reacting to sound the way his twin brother did at two years.
He got his first pair of hearing aids when he was three years old. He started wearing them regularly at the age of four. We thought these would be helpful, but it soon became apparent that this was not the case. Communication remained a daily struggle, and language did not develop as anticipated. Words arrived late. Some never showed up. Instead, Kato has had to work hard to learn by reading lips, reading faces, mimicking motions, and learning patterns. He has put forth more effort than most people realise. While other kids speak mindlessly, Kato considers each word before trying it.

We made the tough decision to have Kato implanted at the age of 12 after many years of serious consideration, advice, prayer and love. The doctors had been cautious with their words by that point. Instead of promises, they discussed possibilities.

We thought it would provide the best opportunity to access sound more meaningfully, but it was not an easy choice, particularly at a later age. Kato has improved since receiving the implant. Although his language skills are still limited in comparison to his peers, his speech and comprehension have both improved.

Kato follows the Accelerated Christian Education (ACE) curriculum in school. He is fond of order. He enjoys anticipating the next move. Teachers say he is intelligent, attentive, and ready to learn. He continues to demonstrate dedication and self-control in his academics. **He listens with a level of focus that is almost overwhelming, as though he doesn't want to miss anything.** Every victory, every new word, every longer statement, every time he decides to speak rather than back down is applauded.

Kato is learning, maybe slower, but he is learning. He is learning language the long way around.
As parents, we have realised that Kato's journey is not about catching up, but about moving forward, step by step, at his own pace.

Kato is seventeen years old today. He is developing into a young man and is no longer just a boy. He is still learning not just how to speak but how to belong, how to express himself, how to claim space in a world that often moves too fast, a world that demands fast, fluent, and effortless communication. His words may be limited, but his determination is not.

As parents, **our biggest worry is that Kato continues to struggle with expressive language and communication.** There are moments when he knows what he wants to say but is at a loss for words, and occasionally it has an impact on his self-esteem and academic achievement. However, we firmly think that **Kato's path is not yet complete, and that he may continue to grow and create a meaningful future with the correct understanding and support.**


UKRAINE

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UKRAINE

Caregiver name: Natasha **Child: Yegor**
Age at Implantation: 2 **Age Today: 10**

We are a family from Ukraine. Our youngest son, Yegor, is 10 years old. He was born at 25 weeks of pregnancy and spent a long time on artificial ventilation. As a result, he lost his hearing and was diagnosed with bilateral sensorineural deafness while still in the perinatal center.

Yegor received his first cochlear implant only at the age of 2 years and 7 months. Between 2015 and 2019, there was very limited state support for cochlear implantation for children in Ukraine, and very little public information about the procedure. **The government funded only one implant per child, and there was a waiting list of around 400 children. From the age of 11 months until his surgery, Yegor wore very powerful hearing aids, but unfortunately, they did not provide enough support for his hearing loss.**

Because there was so little information available, we had to search online ourselves to learn about the surgery, its risks, and the possible outcomes. When Yegor turned two, we went to the ENT Institute where children were placed on a waiting list for implantation of one ear. Yegor was number 374, and we were told we might have to wait years. We did not want to lose valuable time, so we decided to pay for the surgery ourselves. At that time, one implant cost about €30,000 — an impossible amount for an average Ukrainian family.

We started a fundraising campaign and contacted many Ukrainian charitable foundations, but unfortunately, we often received refusals because hearing loss was not considered a priority. Another mother of a child with a cochlear implant told us about a Foundation, and she helped us find a way to purchase an implant at about half the usual price. Following her advice, we also contacted another German foundation which granted us €6,000. The rest of the funds were raised within four months thanks to the generosity and support of many compassionate people.

In April 2018, we purchased a cochlear implant, and in May 2018 Yegor underwent surgery. His rehabilitation went very well — he learned to hear and speak successfully. At the age of six, he was enrolled in a mainstream primary school in Ukraine because of his good progress. Unfortunately, due to the outbreak of war, he was unable to start first grade there.

In 2022, our family moved to Germany, where Yegor entered a regular German primary school class. With only one implant, he experienced difficulties understanding speech in noisy environments, so in 2023 he received a second implant in Germany. With the support of hearing services, his classroom was equipped with microphones for teachers and students and an FM system.

Today, Yegor is in the 4th grade. He completes all assignments and takes tests at the same level as children with typical hearing. He still has some challenges, such as understanding word endings and speech in noisy situations, but overall, he communicates well, watches cartoons, listens to music, and is learning German and English.

Based on our experience, we strongly encourage parents of children who have indications for cochlear implantation not to lose valuable time and to consider implantation as early as possible. No modern hearing aid can provide a child with the same level of hearing access, speech development opportunities,

and chances for social integration as a cochlear implant. Consistent rehabilitation after implantation is also extremely important, as well as continuous development of listening and communication skills.

Unfortunately, even before the war there were serious challenges with funding cochlear implantation in Ukraine. During the war, the situation has become even more difficult, as many adults who lost their hearing now also require implants. In most cases, only one cochlear implant is funded, which limits opportunities for many children and adults who need bilateral implantation.

There is also another major challenge — the lack of state funding for external equipment and rehabilitation. If external components break after the warranty period, families must pay for their replacement themselves. All post-implantation therapy and rehabilitation sessions are also paid for privately. For most Ukrainian families, this represents a huge financial burden and creates a significant challenge in maintaining proper hearing development.

Despite all these challenges, we are grateful for the opportunities Yegor has today. He can communicate, learn, and participate fully in school and social life. His journey shows that with timely cochlear implantation, proper rehabilitation, and strong family support, children with hearing loss can achieve their potential and integrate successfully into mainstream education and society.

We hope that sharing our story will encourage other parents not to delay cochlear implantation when their child has a clear medical indication. Early intervention, ongoing rehabilitation, and support in school can make a life-changing difference. It is also our hope that funding and support for children and adults with hearing loss in Ukraine will improve, so that no family has to face these challenges alone.


VIETNAM

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VIETNAM

Caregiver: Thanh Hương **Child: Hong Anh**
Age at Implantation: 10 **Age Today: 19**

My daughter, Hong Anh, is a young girl with hearing loss. Looking back, our journey began when she was nearly two years old, when we first discovered her hearing impairment. Like many parents in similar situations, I was overwhelmed, frightened, and unsure of what the future would hold. However, we made an early decision that would later prove to be crucial: Hong Anh was fitted with hearing aids immediately after diagnosis.

At that time, I did not understand the importance of early intervention and was not properly instructed. Hong Anh started receiving intervention at around 3 years old, but it was not frequent. I still regret that she did not get the right early intervention method soon after her hearing impairment was identified.

For many years, Hong Anh used hearing aids and attended speech therapy, gradually developing listening and spoken language skills. However, when she was ten years old, her right ear experienced complete hearing loss. At that point, cochlear implantation became the only viable option to support her continued auditory and language development.

The decision to proceed with cochlear implantation was one of the most difficult for our family. In Vietnam, cochlear implantation is not covered by public health insurance, meaning that families must bear the full financial cost. This alone is a significant barrier for many parents. Yet **for us, the greatest challenge was not only financial, but also the emotional and medical impact**.

Hong Anh was born with a congenital allergic condition. As parents, we were deeply concerned that her body might reject the cochlear implant. The fear of possible complications, surgical risks, and long-term outcomes weighed heavily on our entire family. Reaching a consensus among family members required countless discussions, consultations, and moments of doubt. Ultimately, the question we asked ourselves was simple but profound: *What kind of future do we want for our child?*

My guiding motivation was always clear. I wanted my daughter to be able to hear and speak. To attend mainstream schools, and most importantly, to live independently as an adult. **This vision helped me remain steady when doubts arose**. I was fortunate to have friends who are professionals in audiology, rehabilitation, and education. Their expertise, honesty, and encouragement gave me the confidence to move forward.

Equally important was the strength I drew from the community of parents of children with hearing loss in Vietnam; a community that I founded in 2012 and continue to lead. Sharing experiences, fears, and hopes with other parents reminded me that we were not alone. This collective resilience became a powerful source of emotional support, not only for my family but also for many others walking similar paths.

Before making the final decision, we invested significant time in researching cochlear implant manufacturers, understanding the differences between electrode designs, and assessing suitability for Hong Anh's specific

condition. We worked closely with medical professionals to develop a clear auditory-verbal rehabilitation plan and realistic milestones to evaluate feasibility after implantation.

One principle I strongly believe in is respecting the child's voice. **I made sure Hong Anh was part of the decision-making process**. I explained the differences between hearing aids and cochlear implants in ways she could understand, answered her questions honestly, and even allowed her to choose the colour of her device. A small but meaningful choice that gave her a sense of ownership and confidence.

Now, after nearly ten years of implantation, Hong Anh is almost 20 years old and a first-year student at one of the most prestigious and competitive fine arts universities in Vietnam. **Her journey is not a story of "overcoming disability," but rather a testament to what is possible** when a child is loved, receives timely support, is included in the decision-making process, and has unwavering familial support.

Through my experience as both a mother and a community advocate, **my most important message to parents is this: *accompany your child***. Be their partner and their friend**. Stay committed to your goals, whether short-term, mid-term, or long-term, and do not give up when progress feels slow**. Learn continuously, seek reliable information, and create opportunities for your child to engage in diverse experiences that support language development, social understanding, and self-confidence.

Cochlear implantation is not a miracle solution; it is a tool. Its success depends on informed decisions, consistent rehabilitation, and above all, the belief that children with hearing loss deserve every opportunity to participate fully in society. **When parents walk alongside their children with patience, knowledge, and hope, the path toward sound and independence becomes possible.**

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Vietnam

Caregiver Name: Lien **Child: Minh Triet**
Age at Implantation: 3 **Age Today: 10**

My name is Lien, and I am the mother of a bright, energetic boy named Minh Triet. Our journey into the world of sound has been a path paved with both immense challenges and miraculous blessings. Today, I share our story to shed light on the realities of raising a child with cochlear implants (CI) in Vietnam, hoping it brings both inspiration and awareness to the global community.

The Hurdle of Sustainability

While receiving a cochlear implant is a medical miracle, the "happily ever after" requires constant vigilance. For our family, the most significant challenge is the long-term financial burden of maintaining the device. **We were blessed to receive the initial implant through the generosity of sponsors, but the ongoing costs of maintenance, specialized hygiene services, and expensive replacement parts weigh heavily on our daily lives.**

Minh Triet is an active boy who attends an inclusive school. He plays, runs, and explores like any other child. However, every accidental bump or technical malfunction is a moment of terror for us. For a family with limited means, the high cost of components means that a single broken part could silence our son's world indefinitely. The fear that we might one day be unable to afford a repair—returning him to a world of silence—is a shadow that never quite leaves us.

A Village of Support

We have not walked this path alone. **Our greatest support has undoubtedly been a Foundation.** They have not just been donors; they have been companions for years, recently helping us upgrade Minh Triet's device. This upgrade was life-changing, allowing him to hear more clearly and speak with newfound confidence.

Furthermore, we owe so much to the direct intervention by Vietnamese audiologists and therapists. Their professional guidance and love turned a daunting medical process into a successful reality. They taught us that a cochlear implant is not a "fix," but a tool that requires patient, skilful nurturing to truly bloom.

Miracles in the Classroom

Today, Minh Triet is a confident boy who can hear and speak clearly. If you asked me years ago what my dream was, it was simply to hear him call my name. He has far exceeded that. **His greatest achievement to date is his successful integration into a mainstream school alongside hearing peers.**

There is no greater joy than seeing him stand boldly in front of an audience, reading aloud from a book. Seeing him communicate fluently and laugh with his friends is a happiness we once only dared to dream of. He is living proof that with the right technology and support, the gap between silence and sound can be bridged.

Advice and Advocacy

To other parents starting this journey, my advice is simple yet difficult: be patient and stay calm. There are no shortcuts to language. I encourage you to let your child wear their device all day, talk to them constantly, and expose them to every sound the world has to offer. Your persistence in daily speech practice is the bridge that connects your child to society.

Since the day we discovered Minh Triet's hearing loss, we completely reorganized our lives. We adjusted our work schedules and transformed our home into a rich linguistic environment, accompanying him through every syllable.

As a final word, we are eternally grateful for the gift of sound. However, I urge global organizations to look beyond the surgery. Families in LMICs (Low- and Middle-Income Countries) need support for the ongoing costs of maintenance. No child should lose their connection to the world simply because a plastic part is too expensive to replace. Let us work together to ensure that the gift of hearing is a gift that lasts a lifetime.

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VIETNAM

Caregiver Name: Ngoc Hoa **Child: Nhat An**
Age at Implantation: 4 **Age Today: 7**

My name is Ngoc Hoa, and I am the mother of Nhat An. My child received a cochlear implant in 2023 and is currently studying at a special school in Trang Bom, Dong Nai, Vietnam. Today, I would like to share our family's small story, as the voice of a mother who has walked through tears and happiness during her child's cochlear implant journey.

The day I learned that my child had hearing loss, I felt as if I had fallen into an empty space. It was not because I did not love my child enough, but because I did not know where to begin. Hundreds of questions filled my mind: Would my child be able to speak? Would my child go to school like other children? What would my child's future be like?

Our family's biggest challenge was not only financial. The cost of cochlear implantation and rehabilitation was truly a heavy burden. Even more difficult was the emotional side. There were days when I was exhausted from caring for my child while learning how to enter my child's world. Then I realized something important: if I collapsed, my child would have no place to lean.

The greatest support our family received came from an international NGO, together with doctors, therapists, and especially the principal of my child's school. The NGO donated a cochlear implant. Our support team did not only provide technical guidance, but also gave me hope. I learned that a cochlear implant is not magic. It is only a door. The people who must guide a child through that door every day are the parents.

My child's greatest achievement today is not speaking clear or complete sentences, but truly connecting with the world around us. My child turns when called by name, recognizes familiar voices, responds to environmental sounds, and actively searches for sound sources. My child has begun to imitate speech, combine simple sounds, and use gestures together with words to express needs. The moment my child naturally called me "mom" deeply moved me. My child is more confident, plays with friends, understands simple instructions, and participates in daily family activities. For me, this is not only progress in language, but proof that my child has opened the door to sound and started building real connections with life.

If I could offer advice to other parents, I would say: believe in your child and believe in yourself. Do not compare your child with hearing children or with "fast success" stories. Every child develops at their own pace. Be consistent with early intervention, make sure your child wears the device every day, talk with your child as much as possible, and do not be afraid to seek help.

Now, when I see Nhat An running, playing, and gently practicing words, I know that choosing cochlear implantation was a major turning point in my child's life—and in mine as well. **I hope our family's small story can add one more voice, helping the community understand that behind every cochlear implant are countless quiet efforts by parents**. With stronger support from communities, healthcare systems, and education services, more children will have the opportunity to hear and succeed sooner.

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VIETNAM

Caregiver Name: Thi Hein
Age at Implantation: 2

Child: Quang Thái
Age Today: 9

My son was born on May 11, 2017, in Dien Bien Province, a heroic yet remote region of Vietnam where daily life remains challenging and access to advanced medical facilities and modern equipment is still limited. He came into our lives like any other child — healthy, cheerful, with bright eyes and a constant smile that filled our home with joy. No one in our family could have imagined that behind that innocent smile lay a long and arduous journey ahead.

The greatest challenge began when I slowly realized that my child did not respond to sound. He did not startle at loud noises, did not turn when called, and only reacted to vibrations or physical touch. At first, our family tried to reassure ourselves by believing that perhaps he was simply developing more slowly than other children. However, when he reached twelve months of age — an age when children usually begin to babble, speak, and interact more actively — he remained completely silent.

A mother's intuition told me that I could not wait any longer, and I decided to seek medical help. We first visited the provincial general hospital, then continued our journey to a pediatric hospital in Hanoi — the capital of Vietnam. There, doctors diagnosed him with congenital deafness and advised cochlear implantation as the only viable option. At that moment, my world seemed to collapse. My heart tightened, tears streamed down uncontrollably, and I held my smiling child in my arms while feeling an indescribable pain deep inside.

Beyond the emotional shock, another overwhelming challenge soon emerged — the financial burden and geographical distance. The cost of a cochlear implant alone was nearly 500 million VND, not including travel, accommodation, and long-term rehabilitation expenses. Our family consisted of farmers and low-income civil servants, and our home was 500 to 600 kilometers away from Hanoi. The figure and the distance felt almost impossible to overcome.

Fortunately, in our darkest moments, we were not alone. **Both sides of our family became our strongest support, with grandparents, relatives, and friends lending a helping hand, borrowing wherever possible so that our son could have a chance to hear. Alongside them were dedicated doctors and medical staff who not only treated my child but also gave us hope and confidence.**

I am especially grateful to the surgical team at the hospital, who performed the cochlear implant surgery when my son was just two years old and weighed less than nine kilograms. The operation lasted from early morning until noon, and fortunately, it was successful.

Recovery was not easy. I still remember the day his device was activated on June 21. The day my son heard the first sound in his life marked a milestone that I will never forget. From that moment, a new journey truly began.

For nearly a year, my child and I traveled hundreds of kilometers almost every week from Dien Bien to Hanoi for device mapping, auditory training, and speech therapy. When our financial resources were exhausted, we shifted to home-based practice and returned for adjustments every three months. Through perseverance, patience, and relentless effort, my son gradually learned to recognize sounds, speak more clearly, and engage more confidently with the world around him. Each day, he became more active, joyful, and self-assured.

To me, his greatest achievement is not merely the ability to hear and speak, but his radiant smile and his growing ability to integrate into life, connect with friends, and experience a world filled with sound. Throughout this journey, I myself changed profoundly from my mindset and lifestyle to the way I embraced motherhood.

I learned to accept reality, educated myself about hearing loss and cochlear implantation, reorganized my family life to prioritize my child's listening and speech development, and became his first teacher, patiently repeating sounds and words countless times.

More importantly, I learned to believe in my child and in myself, understanding that with enough love, persistence, and determination, he could walk his own path. The encouragement and companionship of various leaders and associations further strengthened my resolve and reminded me that we were part of a larger, caring community.

If I could offer one message to other parents of children with hearing impairment, it would be this: *never give up*. No matter how difficult the circumstances, remain resilient and steadfast in helping your child rediscover sound. Trust in your child's potential, trust in medicine, and trust in the power of love.

This journey may be long and exhausting, but its reward is an open future — a life rich in sound, color, joy, and meaning.

As a mother, my deepest wish is for my child to always be confident, love life, listen well, speak clearly, and grow up happy surrounded by the love of our family.

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VIETNAM

Caregiver: Thu Thuy **Child: Son**
Age at Implantation: 2 **Age Today: 10**

The day my child was diagnosed with hearing loss was the day my world quietly changed. When the doctor advised us to consider a cochlear implant, my family and I stepped onto a path filled with fear, uncertainty, and a faint glimmer of hope. We were afraid that we would not know how to walk alongside our child, unsure of how to teach them to listen, to speak, and to live in a world full of sound. Yet beneath that fear was a powerful belief that one day, my child would hear my voice, express their own thoughts, and have a bright future like any other child.

The journey to reclaim sound has not been easy. It has been the most difficult journey of our lives, but also the most meaningful one.

The greatest challenges our family faced were financial hardship and geographical distance. The cost of cochlear implant surgery was an enormous burden. After more than a year of careful consideration, research, and countless sleepless nights, we could only afford to implant one ear. We told ourselves that one ear was still better than none that even a small doorway to sound was a miracle worth fighting for.

However, the challenges did not end after the surgery. Long-term auditory and speech intervention requires significant financial resources, time, and professional support. In our country, most auditory and speech therapists are concentrated in major cities. For families living in remote areas like ours, accessing these services is almost impossible. There were times when I was overwhelmed with fear, afraid that even with a cochlear implant, my child would not be able to hear and speak well without proper intervention.

In the darkest moments of this journey, support came from a team of professionals. They provided not only knowledge, but also emotional strength. When I felt exhausted and lost, they encouraged me to keep moving forward. They helped connect me with suitable therapists and created opportunities for me to attend a short-term auditory and speech intervention training program designed specifically for parents. Through this experience, I realized that parents are not only caregivers but can also become active partners in their children's language development. I learned how to turn everyday moments into listening opportunities, how to speak with intention, and how to trust my child's abilities even when progress was slow.

My child's greatest achievement since the implant, is not simply the ability to hear, but the ability to integrate and live with confidence. Today, my child is 10 years old. Even with only one implanted ear, my child speaks quite clearly, listens well, and is studying in a mainstream school alongside hearing peers. My child communicates, learns, and plays just like any other child. Watching my child smile, tell stories, and express thoughts freely is the greatest reward for all the hardships we have endured.

If I could offer one piece of advice to other parents, it would be this: stay calm, stay strong, and remain persistent in walking alongside your child. A cochlear implant is not a miracle that happens overnight. It is a long journey that requires patience, perseverance, and faith. **There will be days filled with exhaustion and doubt, but please believe that every effort is meaningful**.

One of the biggest decisions I made was leaving my hometown to move to a major city, where my child could have better opportunities to learn listening and speaking skills. More importantly, I changed myself. **I chose action over waiting, learning over fear**. I believe **my child deserves the best possible opportunity to develop with a cochlear implant.**

I believe that if I can do it, you can too. The sentence that has accompanied me throughout this entire journey is: **"Be diligent and never stop believing - miracles will happen."**

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VIETNAM

Caregiver: Thị Mai **Child: Tùng Lâm**
Age at Implantation: 3 **Age Today: 10**

Tùng Lâm was born on January 21, 2016, carrying our immense hope for a bright and beautiful future. However, those dreams soon collided with a harsh reality when we discovered that our son was born with profound hearing loss.

That moment was a devastating shock that left us completely broken. But after the painful tears, my husband and I told ourselves: we must stand up and find sound for our child. We began the journey by purchasing hearing aids and tirelessly teaching him at home. Yet, this stage was incredibly gruelling. Tung Lam was uncooperative, his hearing remained limited, and speech therapy felt like a dead end. **Despite our efforts to have him mimic our lip movements for hours on end, progress was painfully slow, leaving us exhausted and heavy-hearted.**

The year 2018 marked a major turning point when we were introduced to an education centre for children with disabilities. Thanks to the guidance of their teachers and the auditory-verbal training courses, our path was no longer a shot in the dark. We gained the confidence to set appropriate goals, turning every playtime into a purposeful interaction. The results were sweet: Tung Lam made remarkable progress. The moment he uttered his first words, "Papa" and "Mama," our hearts truly overflowed with happiness.

Despite living nearly 30km away, we never missed a single auditory-verbal therapy session. We understood that to accompany our child, we, the parents, had to be the first students.

An even greater milestone arrived on Tung Lam's third birthday (January 21, 2019), when he underwent cochlear implant surgery. However, while the surgery opened the "door" to sound, it also signalled the start of a challenging rehabilitation journey. **At times, we felt overwhelmed by the complexity of post-surgical speech and language intervention.**

In those difficult times, the **support from all the professionals and teachers became the decisive key.** Their invaluable financial and technical assistance helped Tung Lam escape a world of silence. Without these compassionate hands, our son could not have achieved the progress he has made today. This is a priceless gift that strengthens our faith to continue this long journey.

Today, our greatest pride is not just Tung Lam's ability to hear and speak,

but his confidence in connecting with the world. Seeing him as a happy primary school student with excellent academic results is a testament to his resilience and the miracle of technology. Our family has completely transformed our lifestyle, dedicating ourselves to understanding hearing loss so we can best support him at home, hoping to close the gap between him and his peers.

To parents in similar circumstances: This journey is arduous, but you are not alone. Stay proactive, be patient, and cherish every tiny step forward. **Tung Lam's story is a profound expression of gratitude to our supporters and a firm affirmation: When families persevere and the community joins hands, every child with hearing loss has the chance to reach for a bright future.**