INDIA

Caregiver Name: Gaingampou **Child: Rachun**
Age at Implantation: 1.5 **Age Today: 12**

My son Rachun was diagnosed with congenital hearing loss, a condition that quietly entered our lives but changed everything; our dreams, perspectives and outlook. We did not recognize the signs immediately, and access to early diagnosis and guidance was limited. Everything seemed so normal until around six or seven months of age, when we began to doubt his inconsistency in responding to certain verbal cues. We took him to the child specialist and to ENT doctors, yet nothing was for sure confirmed that he had any deficiency. Having no family history of such, it was hard for me to ignore some of the incidents I observed during my son's gestation period and at the time of delivery that could have led to his condition. However, I knew nothing could reverse the situation at that point of time.

When my son turned 12 months, we consulted an ENT specialist about his delayed milestone in verbal development and not walking on his first birthday, unlike his other siblings. We were suggested to go for BERA test for his hearing. Without any delay, we booked the appointment and finally confirmed that he had a severe to profound hearing loss (about a 90% hearing loss). When we heard the report, I felt my ground slipped and my chest tightened, as if there was no more air left in the room. The audiometry room was calm and peaceful, but inside me, my thoughts were screaming. I could hear the audiologist saying something, but I didn't understand them anymore. With a lump rolling in my throat and teary vision, I turned to face my wife, and I saw her embracing my son tightly against her, nuzzling his cheek, not wanting to lose him. This marked the beginning of a long journey of fear, confusion, courage, and fierce love. We were determined to fight no matter how hard the road ahead would be.

The audiologist prescribed us a powerful hearing aid and suggested that we come there for rehabilitation. We went back to the ENT doctor to discuss the BERA report, to which she informed us that there is no cure for hearing loss so far, and advised us to be prepared to enrol him in school for deaf and mute. I felt annoyed because **I thought she lacked empathy and concern for what we were going through at that moment.**

The real challenge came when we had to meet the speech pathologist who was 200 km away or when we needed to consult the nearest ENT doctor which was 50 to 70 km away. Our hearts sank and we struggled to make ends meet. The financial needs and going for treatment which meant leaving behind two other young children at home. Besides this, the mental burden tripled by not seeing any immediate benefits from the rehabilitation.

I began to browse and started researching about hearing loss and every possible support for rehabilitation. I came across a successful cochlear implantation done in Southern India, so we decided to go there to consult and explore available treatments and possible intervention. It was a

life changing experience meeting the expert team and getting valuable information on the available technical supports. We were made to understand that cochlear implants were one of the best options for hearing loss, and that we could possibly get financial support from the government of India. Nevertheless, we first needed to convince ourselves that a cochlear implant was the right option for my son, considering the risk involved, the complexity of the procedure, and the high cost of both the device and its maintenance. I continued to gather more information about cochlear implants, different brands and their benefits. I also learned about the benefits of bilateral implants and the importance of follow up speech therapy.

My son finally got his implant, when he turned 20 months (1.5 year) old. While the surgery gave him access to sound, the real struggle began afterward. Rehabilitation services and regular speech therapy were scarce in our area. Reaching hospitals and therapy centres required long travel, financial strain, and constant adjustment, yet we continued with hope and determination. In the later part of 2017, **we met an audiologist at a clinic through a friend, and my wife decided to take leave without pay to stay with my son in a rental house to go to therapy in the same clinic**. We felt as if the clinic was established just in time for us, where we get the technical support, parental guidance and hearing solution. We became so attached with them. **With the support of the church, family and friends and the guidance of the clinic,** my son got the second implant done in August 2018, when he turned five.

Living with a cochlear implant means living with a quiet fear that never fully leaves us - the fear of accidental damage to the hearing device during routine childhood activities; playing, running around, cycling, crowded classroom, peer interaction etc... A loose wire, a short cable, a processor that suddenly stops—any small fault often disrupts not just sound, but communication, learning, and confidence for the entire day.

And then there is the deeper fear inside us—the worry about the internal device. What if something went wrong? What if we must go through another surgery for the implant? That thought alone is enough to make our heart race. Yet despite the fear, protecting a tiny piece of technology that carries a huge part of our child's world has become a part of our lives.

In school, communication became another challenge. Many teachers were unfamiliar with cochlear implants and the specific needs of children with hearing loss. Classrooms were often noisy, instructions unclear, and technical support for the implant was difficult to access. At times, misunderstandings replaced encouragement, and his potential was overlooked due to lack of awareness.

Despite these obstacles, my son showed remarkable resilience. **With patience, persistence and the support of the parents, teachers and the therapists, he continued to learn, adapt, and grow. Each word he spoke and each sound he recognized became a victory not just for him, but for our entire family.** In the future, I hope to see my child succeed in education, develop strong self-esteem, choose a career based on his passion, and be an inspiration for the people to understand and accept differences. I also pray that he will pick up meaningful hobbies such as playing badminton, cycling, reading, singing and playing musical instruments which we are introducing to him.

His life story is not only about hearing loss—it is about courage, parental struggle, and the urgent need for inclusive education, trained teachers, and accessible rehabilitation services for cochlear implant children, especially in rural communities.