COCHLEAR IMPLANT INTERNATIONAL COMMUNITY OF ACTION. AISBL
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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!**