

ANGOLA

Caregiver Name: Edson
Age at Implantation: 1

Child: Alice Sophia
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.**