

GEORGIA

Caregiver Name: Ekaterine
Age at Implantation: 18

Child: Tatia
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.