

Good afternoon,

My name is Sarah Terry. My family and I reside in Ashtabula County, Ohio. My daughter Alice, who is now 7 years old, has a diagnosis of bilateral moderate-severe sensorineural hearing loss, which is permanent and possibly progressive.

Here is her story:

While pregnant I took pre-natal vitamins as advised, had a non-invasive pre-natal test, glucose oral glucose tolerance test, and ultrasounds, all of which were normal. Alice was born at full-term and failed the newborn hearing screening twice. Little did we know this was only the beginning of lengthy hearing loss diagnosis journey.

Multiple hearing screenings and audiologist consults, ENT (ear, nose and throat) consult, bloodwork, EKG (electrocardiogram), genetic consult and testing (more bloodwork), ophthalmology consult, and an MRI (mind you, awake, not sedated), completed all before the age of 4, and all covered by insurance. Once a diagnosis of sensorineural hearing loss was established, per recommendation of another provider, we began the hearing aid process. This is when we learned that insurance does not cover these particular medical devices, some companies even defining them as “cosmetic.”

As you can imagine being a parent whose child has hearing loss and went through all this extensive testing, and then to learn the treatment for the diagnosis is not covered, was shocking, and quite frankly infuriating. We were lucky enough that we qualified for an assistance program specifically for children’s first pair of hearing aids that paid all, but \$20 worth of the \$5,000 cost. To think we may not have been able to get them due to cost is unimaginable. Hearing is a crucial part of a child’s development and safety and I could not understand why anyone would want to deprive a child of this necessary treatment.

Difficulty understanding others, delayed speech and language skills, learning difficulties in school, such as with learning to read, sounds/letter associations, negative feelings about oneself, self-isolation, confusion, irritability, fatigue more rapidly due to greater listening effort, slower processing of auditory information, are just some of the many issues hearing impaired children will face. Studies show that early interventions for children who are hearing impaired gives them the best chance for their language to develop properly. Without this aid, the majority of conversation and instruction is missed, affecting the overall well-being, and safety of the child.

Up until Alice was 4 years old, she was able to remain at home with family, which I truly believe is why she was not as delayed in speech and language as your typical hearing impaired child. In Spring of 2021, we had to unexpectedly transition to daycare. Alice was always very happy and social, and we thought she would love daycare, and make so many friends, but to our surprise, it was the exact opposite. She cried every single day, even when she would come home, the crying continued until bedtime. She was a ball of anxiety the entire time she was at daycare and was isolating herself from other children, preferring to interact with the teachers instead, who found this behavior concerning. It broke my heart because I know my child and I knew this was not her.

Two weeks after Alice got her hearing aids, I got a message from her teacher that read as follows:

“Alice had an awesome day, interacting with her peers more than ever. I tried to snap a photo of her playing with a friend, but they finished playing before I could grab my phone. She loves being able to communicate with her peers, and her friends have been telling her in the morning that they love her, and she says, ‘I love you too.’ It’s adorable! She is much less anxious, and really coming out of her shell.”

While attending daycare, Alice was evaluated, and it was determined speech therapy was needed. With early intervention and hard work, Alice graduated from Speech Therapy in the middle of her Kindergarten year, and continues to thrive in school (she is now a 2nd grader), excelling particularly in mathematics. I am excited to see what the future holds for our sweet girl. I know God has a great plan for her.

Thank you for your time and consideration.

Respectfully,

The Terry Family