

Parent-to-Parent Support

Meet the family:

Mom: Amy
Dad: Brian
Children: Matthew, 10;
moderate hearing loss
Casey, 8, hearing
Communication method: Voice
Newborn Screening:
Not available
Age at Diagnosis: 3.5 years
Wears hearing aids

Dear Parent:

Our journey with hearing loss began almost 7 years ago; after we had tubes put in Matthew's ears because he had chronic ear infections. Within a month of the follow up appointment after the tubes were inserted, Matthew's hearing had been tested at least three times, he had been diagnosed with a moderate sensorineural hearing loss, and he had new hearing aids.

I remember having questions. How did this happen? There was no family history, no in utero illnesses, no exposure to ototoxic medicines, and no reason at all for his loss. Did we do something to cause it? Why did it take so long to test him? And finally, what do we do now?

At first, the physicians appeared to want to shield us from the diagnosis. They didn't want to give us the results of the audiogram. His first hearing aids were recommended because they were the least expensive option, since hearing aids were generally not covered by insurance. And the recommended ear molds were made of clear silicon, so as not to be easily noticed by others. We didn't feel comfortable with these choices, and we went on a search for our own choices.

The first thing we did search the internet for organizations that could provide us with the unbiased education that we needed. We found that in Lifetrack Resources. We began taking sign language classes, and researching cued speech so that we would have a clue about different communication options. In the end, our son chose to be oral vs. signing or cueing, but we still use an occasional sign in difficult listening situations. In the end, it was our choice based on our families needs not what someone else desired for us.

As he was entering kindergarten, it was time for new hearing aids. This time, we knew that we were in charge of the decision. We did our research, went to the audiologist, and with her guidance chose digital programmable aids. Matthew picked out the camouflage-colored swirled ear molds himself, which he wore proudly as an expression of who he was.

As Matthew has gotten older, we continue to teach him to self advocate and to temper information he is given with his own good sense to make his own choices. Hearing loss is something that will always be a part of him and our lives. It is not a shameful condition, just an extra challenge in the auditory world we live in. A challenge that will ultimately make him a stronger individual and aware that he is in charge of what happens in his life and that he has options and choices.

Sincerely,

Brian and Amy

For information about how to connect with a family like this, please contact the Family Support Connection at 1-866-DHOH-KID, or 651-265-2435 in the Twin Cities. Or, you can email fsc@lifetrackresources.org.