

NEWBORN HEARING SCREENING MONTHLY

AN OFFICIAL
PUBLICATION OF
COLORADO EHDI



Why Stories Matter

For many families of babies who do not pass their newborn hearing screening, the medical world is foreign and filled with the strange new language of medical terminology. In our busy days as newborn hearing screening coordinators, newborn hearing screeners, audiologists, and midwives, it is sometimes easy to forget the wild new journey that families are embarking upon in the moments after sharing the newborn hearing screening results.

Family stories serve as an important reminder of our mission, our purpose, our WHY: Ensuring every baby born with hearing loss receives access to hearing screening by 1 month of age. This issue focuses on one family's story and the power of family stories in reminding and restoring in us a shared sense of purpose and passion for the work we do.

IN THIS ISSUE

Why Stories Matter

Maggie's Story

**Upcoming Family
Support Events**

**CLICK HERE TO ACCESS
THE AUGUST HIDS
MONTHLY BULLETIN**



Maggie's Story

By Elizabeth Cadkin

I noticed my daughter Maggie's facial differences as soon as I held her for the first time. When the nurse took Maggie to weigh and measure, I asked, "What's going on with her ear?" The nurse quickly responded, "Oh, just some skin tags, no big deal." Uh huh.

Maggie's left ear was shaped like a cup with the tiniest canal and a couple of ear tags, she had a lateral cleft lip, and her jaw was smaller on the left side.

I hovered during the newborn hearing screening. The technician screened her right ear (the ear with no visible difference) and she passed! However, the technician did not test the left ear. She said that the results may not be reliable, so she would not test.

We spent the following weeks getting to know Maggie. I would say her name from across the room and she would turn to look at me. My husband and I agree...her hearing was perfect!

One month after Maggie was born, we met with the Craniofacial Team at Children's Hospital Colorado. The team diagnosed

Maggie with Goldenhar Syndrome, a rare disease that can impact a child's eyes, ears, jaw, spine, kidneys, and heart. The diagnosis was just a starting point. There would be many specialist appointments in the coming months to determine how the syndrome uniquely influenced Maggie's development. However, I insisted on getting her hearing tested as soon as possible.

The very next day we were able to get Maggie her first ABR. Our audiologist told us she had moderate conductive hearing loss in BOTH ears. We cried. This was so unexpected. We went into the appointment optimistic and left defeated. We tested again 2 weeks later and the right ear tested normal, but the hearing loss in the left ear was confirmed. It was such a roller coaster, but we were so happy to have this bit of good news. On New Year's Eve, at three-months-old, Maggie was fitted with her Ponto [a bone conduction hearing aid] on a soft-band headband and she has worn it ever since!

Upcoming Family Support Events

Want to hear more family stories like this or help connect families of infants with hearing loss to other family supports? Check out this link to [Colorado Hands & Voices virtual family support events for 2021](#).

Here To Help

For technical questions about hearing screening, please contact:

Hannah Glick, AuD, PhD, CCC-A
 EHDI Consultant
hannah.glick@colorado.edu
 303-518-2053

For HIDS system access questions, please contact:

Leanne Glenn
 Newborn Hearing Screening Coordinator
Leanne.Glenn@state.co.us
 303-692-2603