

# Parent-to-Parent Support

### Meet the family:

Mom: Robin, hearing  
Dad: Patrick, hard of hearing  
Children: Steven, 7, hearing  
Natalie, 9, deaf, profound  
Adam, 14, hearing  
Spencer, 15, hearing  
Communication Method:  
Pidgin Signing  
Newborn Screening:  
Yes, with follow-up  
every 6 months  
Age at Diagnosis: 18 months

### Dear Parent:

Life sometimes tosses you a challenge. And, that is what we have in common. My child lost her hearing around age 18 months due to ototoxic drugs.

Our first hurdle to jump was to understand her primary diagnosis of Goldenhar Syndrome. This means that the left side of her face did not develop the same as her right side.

This introduces you to my daughter Natalie who is 9 and has a profound hearing loss with a medical diagnosis of Goldenhar Syndrome. Natalie's three brothers love having her in the family and have learned to chat (or fight) in sign.

At the time of discovering the hearing loss we lived in outstate Minnesota. On top of dealing with the medical issues of Goldenhar Syndrome, we had to decide which language approach to take with Natalie. It was overwhelming at times. In the end, we did choose sign with first trying to use SEE (Signing Exact English). In the beginning, it was fun to learn the basic vocabulary and have a little child give you back the word in sign. As we continued learning signs, another piece of Natalie's personality came out. My daughter loves to draw people—especially me, complete with facial expressions from the different moments of being a mom.

Now, at home we use a pidgin sign, which is a combination of SEE and American Sign Language (ASL) with the hope of turning to a more ASL model. We have made some wonderful friends in the Deaf community, and they have enjoyed teaching us ASL.

Natalie, who is in 2nd grade at Metro Deaf School, uses ASL at school. Although learning can be a challenge for her, she loves people and at school is a social butterfly. She is having a ball!

The journey has been long and hard, but oh, so worth it.

Life with a child who is deaf has many challenges. But, there is such a wealth of information out there for newly diagnosed children. I hope that in the future you will call the Family Support Connection, where you can talk to parents who also have children who are deaf.

Blessings on your adventure that life has tossed you.

**Robin**

*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](mailto:fsc@lifetrackresources.org).*