Teresa: Curious and Fun Loving—A Family's Journey

By Kristi Arsenault

Trying to imagine our journey without the support of family, friends, educators, therapists, and doctors is impossible.

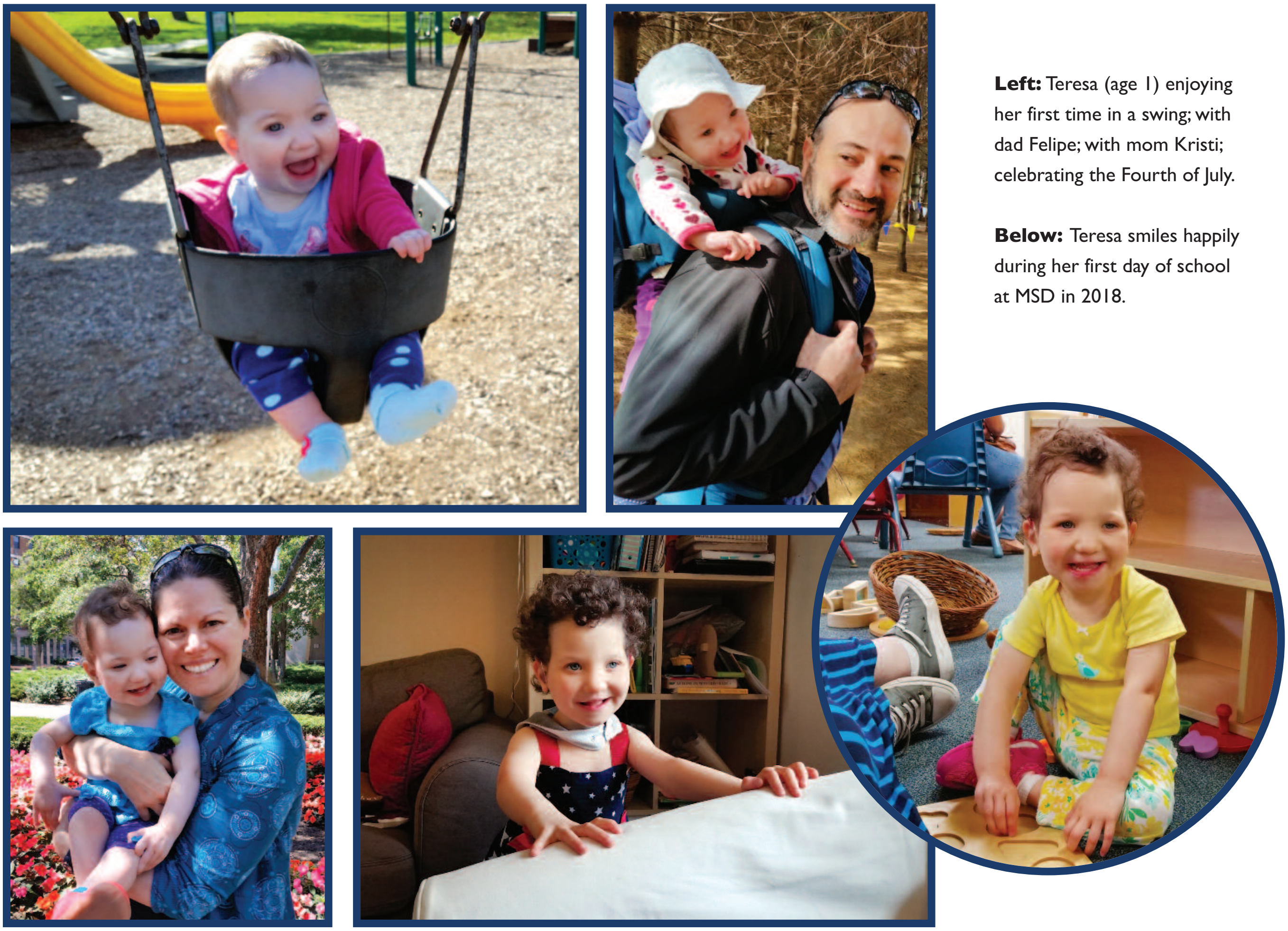
Our daughter Teresa entered our lives having been diagnosed with a mild-to-moderate hearing loss in her left ear and a condition known as hypotonia. Hypotonia relates to poor muscle tone and is a symptom of an undiagnosed condition, but as we did not have a medical background, we were really at a loss as to what that meant. My pregnancy had been pretty smooth, and Teresa was one of the few children actually born on her due date. Thus, whatever was causing her moderate-to-severe hypotonia and hearing loss was a mystery. However, her birth was just the beginning; as she grew older, there were more diagnoses to come.

Feeding issues (possibly related to her hypotonia) meant that we would spend the next five months in three hospitals, making every effort to get our daughter home. Teresa had about 10 different auditory brainstem response (ABR) tests during this time. However, the audiologists were never totally sure what her hearing loss was since she would sometimes wake up or would not remain still during the testing. After she was finally discharged, we faced a major challenge in finding an audiology team willing to perform an ABR while Teresa was under anesthesia so we could get an accurate hearing status.

Teresa was almost 12 months old before we finally received a call from a hospital in the Baltimore area that would perform the ABR. When the results came, we were shocked. Teresa now had a status of moderate loss in both ears. We were stumped as to what could cause such quick and progressive hearing loss. Some audiologists and geneticists pointed to a possible genetic anomaly, while others speculated about a range of possibilities, including a potentially ototoxic antibiotic Teresa had been given during her first year of life. We were put in touch with our county audiologist, who immediately informed us that we needed to get to an ear, nose, and throat specialist and see about possible fluid in the middle ear. *Could that be causing Teresa's hearing loss? Or was it possible structural issues with the bones? Or …?* So many questions, and so

Photos courtesy of Kristi Arsenault

Kristi Arsenault, PhD, received a bachelor's degree in geography from Arizona State University, a master's degree in atmospheric sciences from The Ohio State University, and a doctoral degree in climate dynamics from George Mason University. By day, Arsenault is a research scientist, and by night she's a dedicated mom and "semi-therapist" to her curious and fun-loving little girl, Teresa. She is married to a marvelous husband, Felipe Hall, who helps with so much—and she is busy all the time. Arsenault welcomes questions and comments about this article at *kristira@gmail.com*.



Left: Teresa (age 1) enjoying her first time in a swing; with dad Felipe; with mom Kristi; celebrating the Fourth of July.

Below: Teresa smiles happily during her first day of school at MSD in 2018.

few answers.

Around the time Teresa was 18 months old, she had another ABR with air and bone conduction tests performed while she was under anesthesia, and tubes were placed in both of her ears. She had very little fluid in her ears and this time received what would become the final diagnosis related to her hearing: severe sensorineural hearing loss. It was overwhelming. My husband Felipe and I did not know where to turn. Teresa was finally aided with hearing aids at 19 months old, and we were receiving some of our first instruction in American Sign Language (ASL) from a teacher in the county in which we live. We tried to learn from different online resources and from hand-outs that were provided to us. Then we learned about a family education program at the Maryland School for the Deaf (MSD). We contacted the school to learn more; everyone was welcoming and invited us to come for a visit.

Teresa was just 2 years old when we made our first visit to MSD. We met staff members and families. We were excited to meet other parents; it was wonderful to know others who were raising a deaf child with little to no experience or prior family history of deafness. That day, a new world opened up to us—part of our journey not just as parents but as parents of a child who is deaf. For more than a year, Teresa would enjoy a fully inclusive learning environment at MSD. She was immersed in ASL and had strong support from the staff and her peers. Teresa could barely sit up on her own when she turned 2 years old, but within two months of being in the program she began to crawl and was motivated to get to objects and people she found interesting. We were floored by how her abilities started taking off, and we noticed that she became more attentive to ASL, a visual language that she found immediately accessible. The other children saw Teresa as another deaf child, and they did not seem to mind that she did not quite sign as they did, walk or run, or even color like they did. They simply saw another child and accepted her for who she was.

We continued to take ASL classes provided by the MSD family program and other online resources. We attended conferences, going to meetings of the American Society for Deaf Children and ASL workshops to help us sign more and support our daughter at home. We were learning so much and signing as much as we could, but we noticed that Teresa still did not express herself much in sign. We wondered if we were doing something wrong. Why was learning so different for her? Soon we would gain insight into not only understanding how Teresa was unable to access the world around her, but also how her brain was developing in terms of language.

We had had two prior genetic tests that ruled out any genetic cause for Teresa's hearing loss and hypotonia. With our third and final genetic test, however, Teresa was diagnosed with a rare disorder that impacts both cognitive and language development, which included a possible expressive disorder.

Right and below: Teresa and a teacher work together on a craft at the Easterseals Child Development Center; Teresa enjoys finger-painting at the Center.

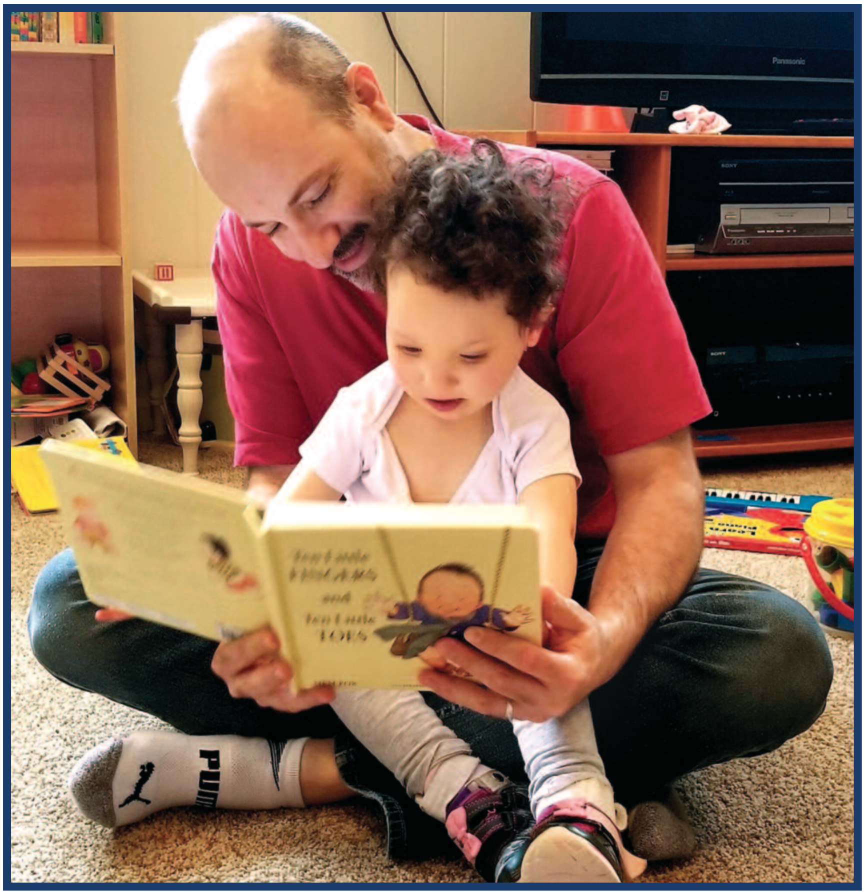
It also provided an explanation for Teresa's hypotonia. Again, shock could not begin to describe what we felt. Teresa was such a happy, full of life, and loving child; it was so hard to imagine that something could hinder her brain from developing normally. It was hard to believe that our child would not naturally acquire language—something many of us take for granted. We knew about the incredible ability of the brain to learn and adapt. Did Teresa's brain not have that ability as well?

Teresa's teachers at MSD had noticed that she looked at the world in a slightly different way than her peers did, and they called for assistance from an organization known as Connections Beyond Sight and Sound (CBSS), the deaf-blind project in Maryland. Teresa had a unique way of noticing the edges of things. Over a year's time, the CBSS team discovered hints and then made confirmation of a condition known as cerebral or cortical vision impairment (CVI), a brain-related vision impairment. Learning about CVI shed light on what had kept us in the proverbial dark for so long. Teresa was missing incidental visual information. She was now considered deaf-blind. This set us on a new course and proved to be a major turning point.

A New Journey
Help for Our Deaf-Blind Daughter

We had hoped that Teresa could attend MSD full time, but her needs outgrew what the school could support. Where does a child with deaf-blindness go? We were given names of schools in Maryland that have programs that support children with deaf-blindness; it seemed the most logical school was the Maryland School for the Blind. There was just one dilemma: it was far away. To get to the school, we would have to move.

It was a difficult time. While exploring other possible school options, we were still in need of a daycare. We looked into different daycare and child



Right: Teresa loves to read with her parents.

development centers in our area, but we were often told that our daughter's needs were too great and could not be supported. The Maryland Family Network (*www.marylandfamilynetwork.org*) has an online resource to help families locate schools to support children with special needs. One option popped up about 20 minutes from where we lived. It was a child development center run by Easterseals, which has a local office in the D.C. area. We called the center, and they were quite enthusiastic to have us come for a visit. Shortly after, Teresa was enrolled. She was placed in a preschool program with 19 children who were her peers in age, all of them typically developing. We were quite nervous about this next adventure, but before we even started we grew hopeful. The children in the class knew Teresa's name and warmly welcomed her. They were all so curious, asking many questions: *What are those things in her ears? What is that thing* [g-tube] *in her belly? Why don't I have one? How do I get one?* When Teresa joined circle time, the teachers and children signed the alphabet with her and they even learned new signs, like colors and weather-related words, based on some resources provided by teachers from MSD who visited Teresa in her classroom. Their fingerspelling became quite impressive—probably better than mine! The children at the center seemed to enjoy Teresa as part of their world and, in turn, Teresa had not just three adult teachers in her classroom but 19 children who also became her teachers.

We should never forget that a young child's journey, no matter his or her abilities, is best supported by helping that child reach his or her full potential.

We should never forget that a young child's journey, no matter his or her abilities, is best supported by helping that child reach his or her full potential. One way that potential is supported is through inclusive environments, which have opened up a new world to children like Teresa. Typically developing children benefit from these environments, too. They come to see the beauty and joy these differently-abled children bring to the world. In getting to know my daughter, her typically developing classmates do not see only her disabilities; they also see another child who shares their joys and fears.

We are grateful for Teresa's growth and all that we have learned while at MSD and the Easterseals Child Development Center. We are also grateful for the opportunities for our daughter to be in such inclusive environments. Helen Keller offered many beautiful sayings, but there is one that has especially hit home: "When one door of happiness closes, another opens; but often we look so long at the closed one that we do not see the one which has been opened for us." Doors have opened for us and for our daughter. As we venture on to find her next school, we grow ever more grateful to all those who have helped throughout our journey and excited about what's behind the next door.