ODYSSEY
2014 EXTRA

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Reading Above Grade Level—We'd Expect Nothing Less

By Cynthia L. Antaya

In 2007, our son Brady was born. The day after his birth, he was diagnosed with CHARGE syndrome, a rare genetic condition named for the combination of physical characteristics that are evident during infancy and childhood. The geneticists who made the diagnosis told us that Brady would never be a normal child. For Brady, learning to eat, walk, and talk would be incredibly difficult—if any of this even happened at all.

Like so many parents, we had been planning for Brady since before his conception. Our dreams were made sharper perhaps because Brady's birth was the culmination of two difficult pregnancies, and his older twin sisters had not survived their birth. Further the day after a hard delivery, the geneticists informed us that Brady had second generation CHARGE syndrome. Though I had never been diagnosed, I learned I also had CHARGE syndrome.

I had grown up as an oral deaf child who learned to read and loved reading, and I excelled at school. While I had a host of medical issues, including the respiratory difficulties and severe-to-profound hearing loss which Brady now shared, none of these interfered with my graduating with a post specialist degree in school psychology from Gallaudet University or working as a school psychologist in a large school system in northern Virginia.

On one hand, I was relieved to have this diagnosis that explained so much of what I had experienced. On the other hand, the geneticist's words about Brady, uttered with such certainty, contradicted everything I had accomplished, everything I believed in, everything I stood for. How could he look at me and articulate such a grim prognosis? My husband and I were shocked, distraught, and confused. However, my husband—a teacher for children with severe disabilities—knew that with access to the right intervention and medical services, Brady could be much more successful than the geneticists had indicated.

Photos courtesy of Cynthia L. Antaya

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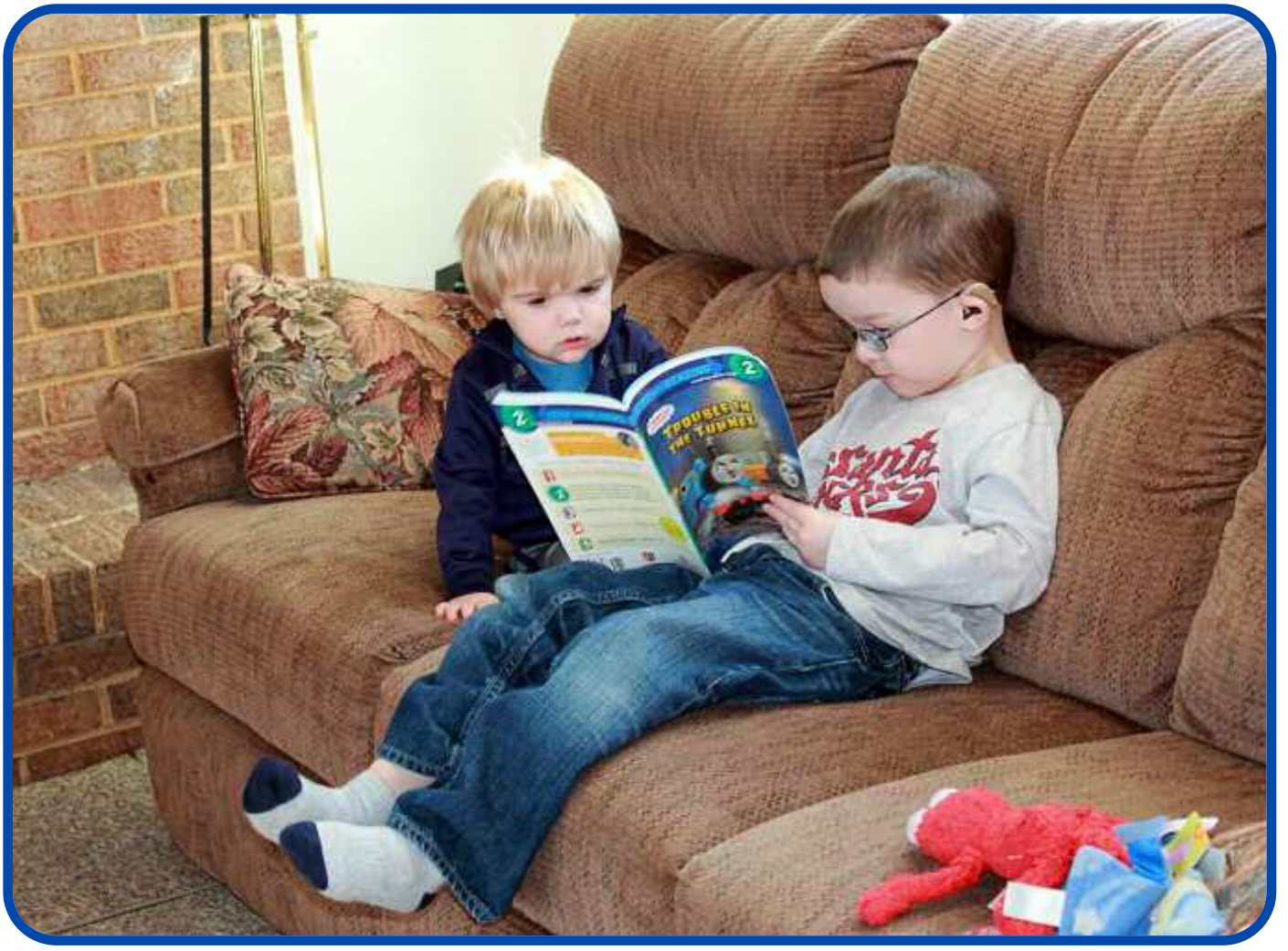
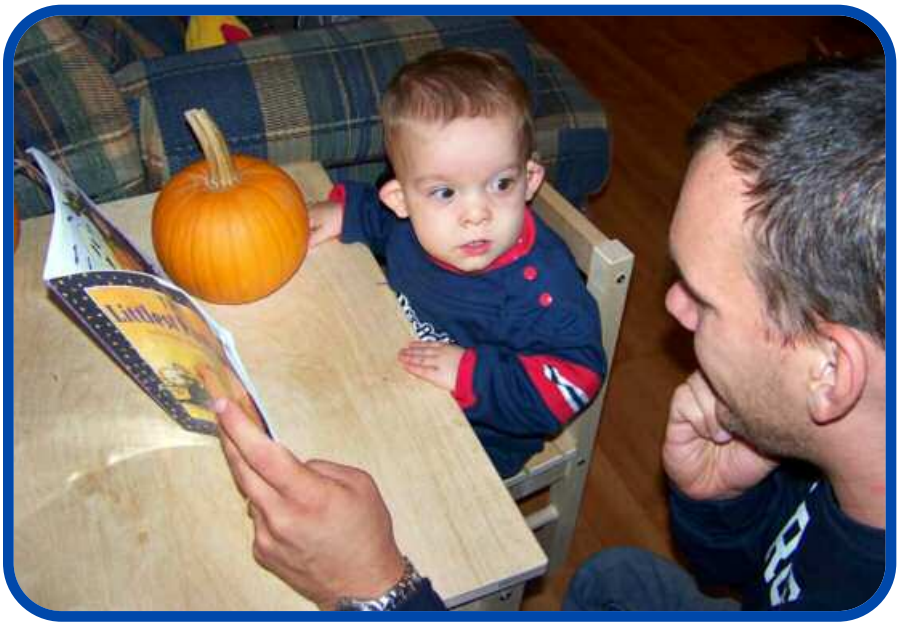


After eight weeks we brought Brady home from the Neonatal Intensive Care Unit, and we began to handle his numerous significant medical conditions and his hearing loss. He failed two newborn hearing screenings; an Auditory Brainstem Response test administered while he was under general anesthesia for his second surgery gave us the details we expected: a bilateral severe-to-profound sensorineural hearing loss.

Anxious to communicate with our son from the beginning, we used both sign language and spoken language. At 4 months old, Brady received his first set of hearing aids. We entered early intervention, using these aids as much as possible, and every week we saw a speech therapist, a teacher of the deaf, and a physical therapist. We read with Brady daily, sometimes multiple times.

When Brady was 2 years old, we became involved with the Parent-Infant Program at Kendall Demonstration Elementary School on the campus of Gallaudet University. We were determined, driving continually through hours of traffic in the northern Virginia/Washington, D.C., area to get to the preschool. In addition, we welcomed therapists into our home.

In 2009, Brady entered his first year of preschool in Prince William County Public Schools in Virginia with a teacher of the deaf in a classroom for deaf students. We pressed on, trying to communicate with our speech as well as our signing and reading, but we could see communication was slow to come for Brady. It seemed that a general developmental delay impacted his language development. Vestibular dysfunction due to small, semicircular ear canals—typical with children who have CHARGE syndrome—affected his balance and meant he did not walk until he was 19 months old. Additionally, Brady's hands have fine motor difficulties, and his left hand has significantly less muscle tone than his right. Forming signs was difficult for him. Still we kept trying despite frustrations, sadness, and fears that perhaps the doctors were right. We



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were as visual as we could be. We always ensured that Brady was surrounded by a strong educational team.

In 2010, we relocated to Massachusetts and explored many programs and schools there. We found a school system that put him in an integrated preschool program with a teacher who had experience working with deaf children. She incorporated signs into her lessons and could communicate with Brady both orally and in sign language.

In the fall of 2010, Brady began his second year of preschool and suddenly his oral language skills took off. Then, before he entered kindergarten, Brady began reading to us. His favorite books were the *Step into Reading* stories about "Thomas the Tank Engine," who chugs his way through many adventures, and Disney's *Cars*. We saw such growth that we were amazed. Brady was communicating with adults and peers alike. He formed friendships. He was invited to birthday parties and playdates.

When Brady entered kindergarten in a different school, we pushed for him to continue with the same teacher of the deaf as he had in preschool. The district honored our request. Kindergarten was different as much of the curriculum is language-based, and Brady struggled with math because manipulatives were not always a part of the lesson. However, his reading remained spectacular. When he left kindergarten, he was reading at the beginning of first grade level. At the end of first grade, he was reading at a mid-second grade level.

This fall, having faced many issues, Brady began second grade. In addition to the diagnosis of deaf/blindness—which comes as part of CHARGE syndrome but which has not significantly affected his learning—he has poor muscle stability in one of his eyes that necessitated glasses. Further, he has a significant respiratory condition and immune deficiency, and he has undergone 14 surgeries.

We no longer sign when we read to him. In fact, mostly now he reads to us—and reading out loud to his parents is required when the reading is school assigned. Thanks to speech therapy, his speech is understandable. He continues to read above grade level and to have close friends in school.

Often we glance back at those conversations we had with the geneticists in the first days of Brady's life and we just shake our heads. All of his teachers have been impressed by Brady's abilities, and my husband and I constantly attribute his continuing achievement to our determined involvement in Brady's early language development. We ignored the negative statistics, and we maintained high expectations. We were able to work with our son and to work with his teachers. With the right support, students can achieve their goals. Looking to the future, we see success.

Note: The precise words that yield the acronym CHARGE are: ***C****oloboma of the eye,* ***H****eart defects,* ***A****tresia of the choanae,* ***R****etardation of growth and/or development,* ***G****enital and/or urinary abnormalities, and* ***E****ar abnormalities and deafness. Although this is no longer considered the best way to define the condition, which varies from person to person and has a genetic origin, a decision has been made to retain the name.*