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Hear Her Out
One girl’s adjustment to a cochlear implant
by Erica Rimlinger

At 2 years old, Elena Pearlstein wasn’t babbling. Instead, “she was screeching,” says her mom, Michele Pearlstein. “I was told: ‘Don’t worry. [Elena’s older sister] Isabella is probably speaking for her.’ I had a feeling it was more.”

At a speech and language evaluation at age 2, Elena was at the six-to-nine-month mark. “She was really behind,” Michele says. Nevertheless, Elena’s “hearing had been tested. Twice. We’d been told her hearing was perfect.”

Through the Harford County Infants and Toddlers program, Elena’s hearing was tested again. The result? “Hearing loss. I’d been told over and over: ‘Nothing is wrong. You’re worrying too much.’ Lo and behold, she has a hearing problem,” Michele remembers. “We were floored. In absolute shock. I picked up Elena and walked out to the car. I said, ‘Thank you,’ and I just walked out.”

The first test led to more tests. The hearing loss had to be confirmed and measured. At St. Agnes Hospital, Elena underwent sedation for an Audio Brainstem Response (ABR), a test that measures the brain’s reaction to sound waves, which confirmed the loss.

Elena “had the kind of hearing loss that gets worse over time. With her recurring inner-ear infections, it was difficult to tell what was going on. It started mild, then deteriorated. There was severe loss in her left ear, profound loss in her right ear. When she was 2 or 3, her hearing declined rapidly, then stabilized until recently,” Michele says.

The Pearlsteins were advised to have Elena use hearing aids. “There were many, many appointments,” Michele remembers. “Because the loss fluctuated, the hearing aids had to be adjusted constantly.”

At age 2, she wasn’t speaking. At age 3, she still wasn’t speaking.

Michele and her husband, Jon, decided to be proactive. The Pearlsteins found the Hearing and Speech Agency Preschool, which offered a program called Little Ears, Big Voices for auditory-oral development of language with some signing.

The school was an hour away from their house. Tuition was expensive. “We went into it thinking, ‘We can’t do this.’ We were so traumatized at this point,” Michele recalls. “And then we met the teacher, who said, ‘I can’t wait to work with her. She’s going to be just fine.’”

Michele and Jon enrolled Elena that day.

Six months later, Elena could speak in whole sentences. She spent her mornings at the HAS preschool and her afternoons in kindergarten at the private school, St. James Academy, where her older sister, Isabella, attended elementary school. At this point, Elena was younger than the other kids in kindergarten. Michele says, but starting Elena early allowed the family to test out kindergarten and see if it was going to work for Elena. It worked well enough.

In kindergarten, Elena’s teachers used a microphone system that linked with Elena’s hearing aids, but the aids often failed and the microphone amplified the wrong sounds. Often, Elena still couldn’t hear the teacher in front of her, although she heard all the ambient sound in the room.

At this point, because the hearing aids weren’t helping, the family consulted Elena’s audiology team to see if Elena could get a cochlear implant. She was, according to her doctors, not a candidate at this point. “We were, frankly, pretty relieved to hear it,” Michele says. Michele and Jon were worried because, once implanted, the cochlear implant would eliminate any residual hearing Elena might have.

By third grade, Elena was seriously struggling in school. “She complained a lot about the hearing aids. The (microphone) system didn’t work for her. We couldn’t figure out why. We had her equipment tested a lot.”

Even when the hearing aids were working, “hearing aids aren’t like glasses,” Michele says. “There were still so many sounds of speech Elena couldn’t hear at all.” In particular, Elena couldn’t hear the letter “s” and struggled to spell and
understand words that were plural. Spelling was her worst subject.

With an added diagnosis of ADHD and the amplification of the classroom sounds, the situation "was a recipe for failure," Michele says. With Elena "exhausted, grumpy and struggling," Michele says she and Jon took the suggestion of their audiologist to have Elena reassessed for the cochlear implant. Elena qualified. This time they were all ready and relieved.

The cochlear implant looks like a centipede, with sensors for the legs. The anatomy of Elena’s inner ear was unique: Surgeons were hopeful for a good outcome, but offered no guarantees. Elena might not get the full effect with her ear shape. Surgeons anticipated implanting 10 sensors and she underwent surgery at Greater Baltimore Medical Center in June 2017. The surgeons also inserted a magnet behind her right ear that worked with the device.

Elena spent the next two days recovering from the anesthesia with a cup strapped over her ear. Because of the surgery, she had no hearing whatsoever in the ear that was implanted — that would have to wait a month. Over the next few weeks, she says, the implant “felt weird and kind of hurt. I don’t feel it anymore, if I’m not touching it.”

When the implant was activated, Elena says, sounds were "high-pitched and muffled.

“If you activate the implant, you have to program it,” Michele explains. “You don’t get the full range of sounds right away. Essentially, you have to relearn how to hear. It digitizes sound. The audiologist told us Elena would hear sounds that were kind of like a robotic Duffy Duck. She had to relearn how to identify voices. She had to relearn the sound of my voice. She’d move away from sounds, flinching and saying, ‘What is that?’”

Jon says, “I expected when it finally turned on, I thought it would be instant. But there is such a learning curve in retraining your brain to interpret new sounds. They’re electrical signals and it’s a long process for her, having to learn the new sounds. It was slower than we anticipated. Nothing that she did was different [from most kids’ experiences.] That’s just how long it takes.”

Because Elena can now hear all the sounds of speech, including the "s,” this means no more speech therapy, which garners an enthusiastic fist pump and a “YESSSSSS!” from Elena.

“I think of all the things we worried about. We were so focused on the actual surgery and choosing the device, we didn’t fully understand the hard work it would take to get her using the device properly,” Michele says. But now, Elena has “made so much progress within a year. School is better. Everything’s better.”

Elena is now a fifth grader at St. James Academy. She plays piano and has been playing since she was in first grade. She writes her own music. With the cochlear implant, Elena says, “I can hear notes better. Sounds are a little clearer.” And it’s also helped minimize her ADHD symptoms, because there are fewer distractions.

This fall, Michele and Jon tell me, Elena got the best report card of her life: All A’s, except for one B. Her best school subject now? Spelling. BC