

Sound & Silence

By Jennifer Durgin

The emotion of learning that your baby was born profoundly deaf.

The challenge of learning sign language so you can communicate with her.

The angst of deciding whether or not to have a device to help her hear implanted in her head.

A Dartmouth Medicine staff member shares the twists and turns in an unexpected parental journey.

At first, after we found out Geneva was deaf, I couldn't help feeling angry. I'd sit there and stare at her perfect-looking little ears as she nursed and think to myself, *How dare you not work?* But that's when I was still focused on all that we had lost—or that I thought we would lose. Geneva, then six weeks old, had, for example, never heard my voice.

It took two rounds of screening tests at the small community hospital where Geneva was born in January 2007, plus a couple of hours of diagnostic tests at DHMC in March, to determine that Geneva was deaf.

"I'm seeing a pattern consistent with profound sensorineural hearing loss," I remember the audiologist telling my husband and me. *What?* I thought. When I go to the doctor, I usually can comprehend



Geneva Durgin was born into a totally silent world; she was six weeks old when she was diagnosed as profoundly deaf.

whatever medical jargon is thrown my way. After all, as a member of this magazine's staff, I read and write about medicine every day at my job. But this time I had to make sense of an unfamiliar term while I was trying to contain the emotions welling up inside me.

"So is that like what you'd call deaf?" I asked. As the words popped out of my mouth, I suddenly wondered if the word "deaf" was politically incorrect and that's why the audiologist had used doctor lingo. "Yes," she answered. I think my next question was "Are you sure?" She was very sure.

Things became clearer for my husband, Christian, and me when the audiologist pulled out a graphic representation of sound. This chart, known as an audiogram, had volume (measured in decibels) on one axis and frequency (measured in cycles per second, or hertz) on the other axis. It showed the volumes and frequencies for everyday sounds—such as a bird chirping, a dog barking, a phone ringing, a person talking. It also showed where different speech sounds in the English language are found—between 20 and 60 decibels and 200 and 8,000 hertz. The audiologist explained that she had tested Geneva's hearing up to 100 decibels and 4,000 hertz but had seen no brain response at all. That meant Geneva could be right

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Since Geneva couldn't hear, her parents began learning sign language so they could communicate with her. Here, her mother signs "panda" as Geneva looks at a book.



Last fall, as Geneva was starting to babble, above, her parents were weighing treatment options, including a cochlear implant. Today, below, with an implant, her hearing is close to the normal range.

“Loss” was the perfect word for what I felt over the next couple of weeks. “She’ll never know the sound of her mother’s voice,” I remember saying to my husband one night, as tears fell from my eyes onto my pillow.



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next to a running lawnmower or a helicopter taking off and hear absolutely nothing. I felt something sink inside me.

So I understood that my daughter was deaf. But I still had lots of questions. “What does sensorineural hearing loss mean?” I asked. *And does it mean she has brain damage?* I was wondering to myself.

There are three regions of the ear, the audiologist explained—the outer ear, the middle ear, and the inner ear—and different hearing tests can help pinpoint which part of the ear may not be working. Judging from the tests she’d had, Geneva’s outer ear and middle ear were just fine. The problem seemed to be in her inner ear, where sound waves travel

into the snail-shaped cochlea, and tiny hair cells convert those waves into electrical impulses. The impulses then travel along the auditory nerve to the brain. Damaged, dysfunctional, or missing hair cells were most likely the cause of Geneva’s hearing loss.

The “sensorineural” part began to make sense to me, but I still had trouble with the “hearing loss” part. How could Geneva, who was only six weeks old, have lost something that she never had?

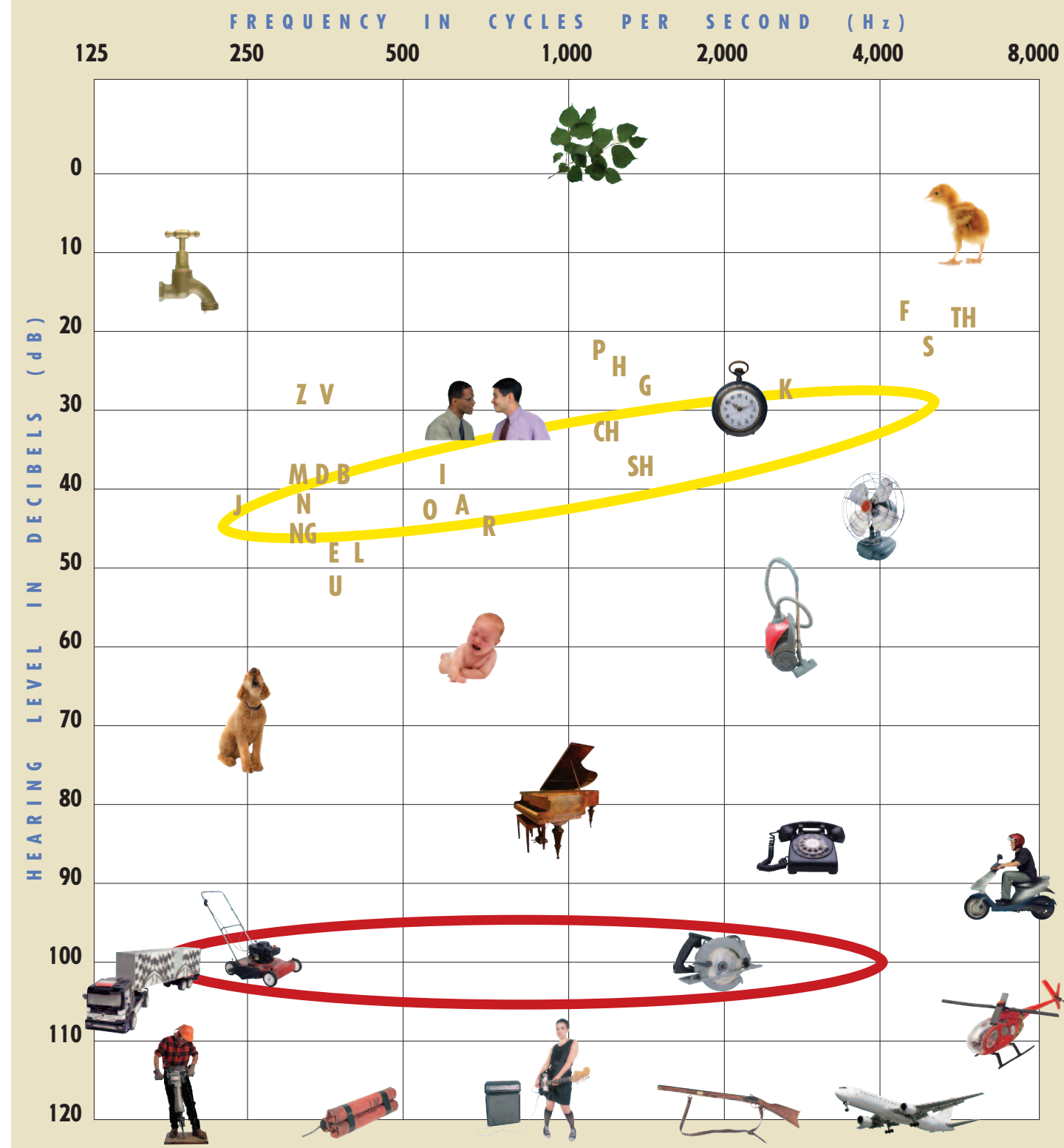
But “loss” was the perfect word for what I felt over the next couple of weeks. “She’ll never know the sound of her mother’s voice,” I remember saying to my husband one night, as tears fell from my eyes onto my pillow. And all those Beatles and Bob Dylan songs he had been singing her since she was born—she had never heard a single note.

I took the news harder than my husband, perhaps because I’d had more experience with babies and young children. I could imagine my daughter running toward the road and not hearing that a car was coming. I could picture Geneva as a toddler, reaching for something hot, and my not being able to call out “Careful!” from across the room. I think I also took the news harder because I would bear more of the load of making sure that Geneva did not fall behind developmentally, since I’d be spending more time with her. I love my job as a writer for DARTMOUTH MEDICINE magazine and had planned to return to work full-time after my maternity leave. But when we learned about Geneva’s deafness, I knew she needed lots of one-on-one attention from me more than I needed to work and more than my husband and I needed the money. Happily, however, the magazine’s editor agreed to let me work part-time, so I didn’t have to give up working entirely. To make up the difference in our income, we would find ways to lower our expenses.

Besides feeling a sense of loss over Geneva’s deafness and my inability to work full-time, we fretted over some big unknowns. Within a week or two after her diagnosis, we learned about all sorts of disabilities and syndromes that can accompany deafness. Syndromes that hit me in my gut and made my stomach turn. Syndromes that cause blindness, kidney failure, heart attacks. “If Geneva gets diagnosed with one of those syndromes, that’s when I’ll stop getting out of bed in the morning,” I’d say, only half joking. My husband and I worried for some time that there might be another, far worse diagnosis lurking in the shadows.

But as the weeks and months passed, and as all the scary syndromes could finally be ruled out thanks to genetic testing, three EKGs, and an eye exam at DHMC, Geneva’s being deaf felt less and

An Audiogram



An audiogram is a pictorial representation of sounds—from the rustle of leaves to the roar of a jet engine. When Geneva had her first audiogram, about a month after she was born, she showed no response at all to sounds in the area of the red oval; the testing equipment doesn’t even produce sounds beyond 100 decibels. On her most recent audiogram—in early May of this year, three months after the activation of her cochlear implant—she showed a response to sounds in the area of the yellow oval. Her hearing would likely be even better now, according to her audiologist, because she has had four more months of experience using the implant.



JON GILBERT FOX

While Geneva holds a wooden lion, her mom makes the sign for “lion.” By the time she got her cochlear implant at 13 months, Geneva knew at least 60 signs and could sign almost 30 herself.

I’d hit emotional lows when I’d notice some small piece of life that I assumed would not be available to my daughter—like the sound of a bird call or the purr of a cat. But my grief was short-lived. I accepted and began to celebrate Geneva’s deafness rather quickly, thanks in large part to our parent advisor from a state agency.

less like a big deal. In fact, we were thrilled when a clinician from DHMC called to tell us that Geneva had a Connexin-26 genetic mutation. Connexin-26 is the most common cause of nonsyndromic deafness in Caucasians. It meant that Geneva would likely have no other related health problems. We were giddy with relief and smothered our “little mutant” (as we jokingly called her) with hugs and kisses. Sure, other people would still refer to her deafness as “devastating,” but I had spent enough time at DHMC and seen enough sick kids to know what devastating is.

During the five months between Geneva’s initial diagnosis and that phone call from the genetic consultant at DHMC, I had a few minor breakdowns. I’d feel pangs of jealousy when I’d see other babies turn to the sound of their mother’s voice. I’d hit emotional lows when I’d notice some small piece of life that I assumed would not be available to my daughter—like the sound of a bird call or the purr of a cat. But my grief was short-lived. I accepted and began to celebrate Geneva’s deafness rather quickly, thanks in large part to the parent advisor who was assigned to us by the Vermont Center for the Deaf and Hard of Hearing, a state agency.

Geneva was diagnosed on a Tuesday in early

March. Just three days later, that Friday, our parent advisor, Tami Trowell, drove to our house to meet with us. Her warmth came through immediately as she told us about her own son, who was born deaf in 1984. Later during that first visit, when I lost the firm grip I’d had on my emotions, her eyes welled up, too. She hugged me and told me everything was going to be okay. I realized then that Tami was the answer to a plea I hadn’t yet uttered. She became my guide, my mentor, in this unexpected journey mothering a deaf child.

For a couple of hours every week, Tami helped answer my questions about deafness: Will Geneva speak? Maybe, if she has some access to sound. Can hearing aids help someone with her degree of deafness? Maybe, but probably not. Geneva received hearing aids about a month and a half after being diagnosed, and my husband and I did our best to keep them on her floppy little ears. But we suspected that the aids weren’t doing much for her, except maybe offering some stimulation to her auditory nerve. That suspicion was confirmed when a freight train passed not more than 50 feet behind her, blowing its horn, and she remained oblivious.

Of all the questions we wrestled with in the months following Geneva’s diagnosis, the biggest one was whether to pursue a cochlear implant. A cochlear implant is a device that tries to do what damaged, dysfunctional, or missing hair cells cannot. It translates sound into electrical impulses that stimulate the auditory nerve, which in turn sends those signals to the brain. Its internal parts, which must be surgically implanted, consist of a receiver and a wire-like electrode array that is threaded into the cochlea. The external parts consist of a microphone that picks up sound, a processor (or mini computer) that digitizes the sound, a transmitter that fastens to the internal receiver with a magnet, and a battery to power the whole thing. The first experimental cochlear implants were tried in adults in the 1950s, ’60s, and ’70s. But the technology didn’t really mature and become popular for deaf children until the last 15 years. It’s still controversial among many deaf people, who don’t see their deafness as a defect or something that needs to be fixed. (More on that later.)

The possibility of a cochlear implant for Geneva seeped slowly into our consciousness. At first we didn’t really know what the device was or what it was capable of. Then we didn’t know for sure if Geneva was a good candidate for one. People with Connexin-26 usually do well with cochlear implants, but if for some reason Geneva’s cochlea was malformed or if, as happens on rare occasion, she was missing an auditory nerve, she might not be

able to get one. In the early days of cochlear implants, surgeons would often discover such anomalies in the operating room. Today, sophisticated imaging techniques give doctors a clear preop look at a child’s auditory anatomy. But we would need to wait until late October 2007, when Geneva was nine months old and her inner ear was more developed, for those tests. And according to FDA guidelines, she wouldn’t be eligible for the surgery until she was 12 months old. (Children with less severe hearing loss may not be a candidate for an implant until they’re even older. In only a very few circumstances are implants permitted before a child turns one.) In the meantime, we had a lively, growing baby girl with whom we desperately wanted to communicate.

It was Tami’s job to introduce Christian and me to all the ways of communicating with deaf children. Some methods depend heavily on any hearing a child does have, plus or minus lipreading. Others depend on sign language, either American Sign Language (or ASL, an entire language with its own grammar), signed English (which uses many ASL signs but English grammar and word order), or cued speech (which uses hand shapes to represent phonetic sounds). Given Geneva’s degree of hearing loss, and the futility of hearing aids, we all agreed that some form of sign language would make the most sense—at least in the short-term when Geneva had no access to sound. We chose to pursue ASL, the official language of Deaf culture (the capitalization of “Deaf,” we learned, was a way to signal the sense of community among deaf people who use ASL). With that decision, a new, exciting—albeit daunting—challenge lay ahead: the task of learning a new language as soon as possible. Again, Tami was our guide.

I don’t know if Tami said it, or if I picked it up elsewhere, but the concept of “bathing Geneva in language” was one that I kept foremost in my mind. I’d repeat it to myself silently throughout the day and use my limited signing vocabulary to narrate anything and everything. “Look, I’m washing dishes with my yellow gloves,” I’d sign. Folding laundry was a chance to practice color and clothing signs. Grocery shopping was a chance to practice food and people signs. “See that tall man. Look at his red hat,” I’d sign. Everything was a language opportunity, a chance for both of us to practice this new language. My favorite times were when it was just us—Geneva and me, or Christian, Geneva, and me—or when we were with someone else who knew ASL. Those were the times when I felt like everything was going to be okay.

As a new mom, part of me craved socialization



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Geneva’s mom has just signed to her, “Where’s the doll?” and Geneva—here almost exactly one year old, just a few weeks before her cochlear implant surgery—is responding by pointing to the doll.

with other moms and female friends, but part of me also dreaded those interactions because most of the time I’d be worried about how little I was signing while I was talking with my hearing companions, and thus how little information Geneva was taking in. To talk with other adults, and even other children, without simultaneously signing was to ignore my daughter; but with my limited skills in ASL, I found it hard to both sign to Geneva and carry on a real conversation. Once again, Tami filled another role in my life. She became a close female friend, not just because we shared common interests but because we could socialize and still sign.

At the time, Tami was also the only professional we dealt with, medical or educational, who emphasized the importance of exposing Geneva to language immediately and in any way that we could. I found the lack of support from all other quarters frustrating and perplexing. The extent of the encouragement that we got from the rest of the medical world regarding signing seemed to be “Oh, that’s nice.” And I couldn’t help feeling irritated when people who knew she was deaf—medical professionals or not—would make no effort to sign, gesture, or even use animated facial expressions.

Now, looking back, I realize that what I interpreted as the medical profession’s lack of encour-

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Above, Geneva's mom, right, and Vermont Center for the Deaf educator Tami Trowell, left, sign "eat" for Geneva. The early exposure to language has made her a curious and social toddler, below.

Research shows that hearing children of hearing parents and deaf children of deaf parents have comparable language skills. But deaf children of hearing parents, on average, have much more limited language skills.



agement about signing may have been an effort to be unbiased. To sign or not sign is almost as controversial as whether to have a cochlear implant.

American Sign Language was developed in the early 1800s and became widely used as more and more schools for the deaf opened. For the first time in American history, deaf children learned and socialized together and were surrounded by a language

they could understand and access. American Deaf culture grew out of this rich and insular environment. As described in the book *Through Deaf Eyes*, by Douglas Baynton et al., "American Deaf culture over time generated the creative outpouring typical of human communities everywhere—folklore, poetry, storytelling, theater, and oratory; as well as games, jokes, naming customs, rituals of romance, and rules of etiquette and proper conduct—all enacted in a language of gesture and suited to a visual people."

However, not all deaf educators embraced the growth of ASL and Deaf culture. Again, from *Through Deaf Eyes*: "In the decades following the Civil War, educational reformers waged a campaign to eliminate *manualism*—the use of sign language in the classroom—and to replace it with *oralism*, the exclusive use of lipreading and speech." It's estimated that by 1920, 80 percent of deaf students were taught without sign language. Among the most influential oralists was Alexander Graham Bell, the inventor of the telephone. Bell even warned of the "formation of a Deaf variety of the human race" if deaf people continued to marry and Deaf culture continued to flourish.

But Bell and other oralists failed to eliminate sign language. ASL persisted, and the civil rights movement infused new energy into Deaf culture and its language. Today, sign language and oralism exist more as peers—each recognized as having different strengths. However, the rise in popularity of cochlear implants means that fewer and fewer deaf children are learning how to sign and are being exposed to Deaf culture. Cochlear implants—whether people like to admit it or not—are making ASL an increasingly rare language and may well once again redefine Deaf culture.

So what are hearing parents of a deaf child to do? I love languages, and learning new ones comes easily to me. Yet I knew it would take me at least a few years to become a fluent signer. The learning curve would be steeper and longer for my husband, since he has continued to work full-time and languages don't come as easily to him. Even Tami, a great lover of ASL, admits that it took her about seven years to feel fluent. I knew Geneva would be starved for language if we depended only on signing. Research shows that hearing children of hearing parents and deaf children of deaf parents have comparable language skills. But deaf children of hearing parents, on average, have much more limited language development and fall behind their peers as early as 18 months. I wanted (and still want) for Geneva and me to be fluent in ASL, but I knew that my best shot at offering her a rich and

Another chance By Tami Trowell

On July 9, 1984, I gave birth to my first child, Byron. He was beautiful and I was filled with excitement about being the mom I had always dreamed of being. I felt confident, but then as my baby grew I began to suspect something was amiss. I didn't know exactly what that something was, but by the time he was three months old, I questioned our pediatrician. She reassured me that Byron was fine and I was overly concerned.

Still, something nagged at me. I would quietly tiptoe into his room and call his name to see if he would turn. Sometimes he turned and I would let go of worrying for a little while, but then I would find myself trying to find other ways to test him.

An experienced mom told me to be noisy while your children are sleeping so they can sleep through anything. So I was noisy; I could even vacuum under his crib while he slept! I was proud of how well he'd sleep and bragged about it to my friends. Then Byron slept through the Fourth of July fireworks a few days before his first birthday, and the uneasiness crept back into my mind.

One day I'd be reassured when he'd vocalize in ways that seemed normal to me. I even wrote in his baby book that he said "mama." But right around the time he turned one, he became silent. My emotions were like a yo-yo. I'd be convinced there were reasons for concern and then reassured that everything was fine.

Finally, when Byron was 16 months old, I took him to a retired teacher's home for a few hours of child care. When I came back, she very bluntly told me she didn't think Byron could hear. That was all it took—I knew beyond a shadow of a doubt that she was right. All the denial I had been experiencing suddenly vanished, and I had a feeling of complete helplessness. I made an appointment immediately with our pediatrician. She clapped her hands behind Byron while he sat on my lap: no reaction. She wrote a referral for an auditory brainstem response (ABR) test, which measures brain-wave activity in response to sound. The diagnosis: my son couldn't hear. I still have the referral form tacked to the bulletin board in my office. Byron's ABR confirmed profound bilateral sensorineural hearing loss.

At 18 months, early intervention began. When the interventionist came to our home, she admitted that she had no training and had never worked with children with hearing loss. Byron would be her first and we would learn together. She did not know about the controversial communication methodology decisions that face parents of children with hearing loss. I had never met a deaf person in my life, but I knew "they" used American Sign Language (ASL). I went to the library, checked out an ASL book, and brought it home. Byron had a butterfly mobile that he loved lying under, so I looked up the sign for "butterfly." I tried to follow the picture and its arrows and awkwardly signed "butterfly" to Byron.

Trowell is coordinator of the Family Sign Language Program and a parent advisor in the Parent-Infant Program of the Vermont Center for the Deaf and Hard of Hearing. She has worked with the Durgins since three days after Geneva's diagnosis.



Tami Trowell, perusing a picture book with Geneva in May 2007, encouraged the Durgins to start reading with her early, even though she couldn't hear.

He immediately signed back an approximation of "butterfly." I frantically looked up the signs for "I love you" and "mommy." I couldn't learn signs fast enough. Even so, the impact of complete language deprivation for the first 18 months of Byron's life, and of my halting attempts to learn to sign all on my own, made it very difficult for Byron to learn.

Now, all these years later, I have a chance to walk that same path again—not as a parent, but as a parent advisor for the Vermont Center for the Deaf and Hard of Hearing. I have encountered many children with hearing loss over the years, but Geneva is the first infant I have worked with who was born as profoundly deaf as my son was. Erma Bombeck's poem "If I Had My Life to Live Over" reminds me vividly of the experience I am now having with Geneva and her family—but this time the odds are stacked in our favor. Thanks to universal screening of infants' hearing, Geneva's hearing loss was identified early and her family was provided with intervention immediately.

My son taught me to cherish the uniqueness in all of us, and to appreciate how essential communication is as the basis for the way we love and learn. Now I have the privilege of sharing this gift with Geneva and her family. Nothing could be more rewarding.



JON GILBERT FOX

When Geneva had her cochlear implant surgery at DHMC, her mom, right, was able to stay with her all the way into the operating room. Here, pediatric perioperative nurse David Szczesiul, left, having just taken Geneva's vitals, also takes a minute to play with her so she's at ease in the medical setting.

Being deaf is quite unusual. About 2 to 3 babies out of 1,000 in the U.S. are born with some hearing loss; even fewer are born profoundly deaf. Geneva was one of only two profoundly deaf Vermont babies born over a period of several years.

complete facility with language was through a cochlear implant. So we decided Geneva would get the implant.

But it wasn't until we met a preteen with a cochlear implant that I really began to imagine Geneva with an implant. Meeting Kaily, who lived in a nearby town, was like setting down a new anchor. Our wonderful, caring primary-care doctor had put us in touch with Kaily and her mom. My husband and I showed up at her house one muggy afternoon in late spring. When we got out of the car, we heard a voice call down to us from high up in a thick, old evergreen tree. "My mom's in the house," I remember the voice saying. We didn't find out until later in our visit that that voice belonged to Kaily.

She was very curious about Geneva. Almost immediately, she took her from my arms, asking permission as an afterthought.

Her speech was nearly perfect, she used no sign language, and she seemed to communicate effortlessly with her hearing sister and some visiting friends. She did say "What?" frequently, but she responded easily to the questions we asked her. "Do kids make fun of you?" we asked. Sometimes kids said things about her, she responded. But not because of her hearing loss, a friend piped in. Kaily laughed at that. She's aware of her tendency to be aloof and sometimes bossy with her peers.

Meeting Kaily was inspiring, but even so we ap-

proached the implant decision cautiously. Tami had been careful to educate us about the variety of opinions on cochlear implants.

It took most of the summer and fall for me to cobble together a good understanding of implants. I read books and articles. I watched promotional videos from the cochlear implant companies. I subscribed to cochlear implant e-mail listservs for parents. And I met several teenagers and adolescents with cochlear implants through a New Hampshire-Vermont group called DEAF (Deaf and hard of hearing Empowerment and Advocacy for Families).

I did my best to learn about Deaf culture, too—which is not easy in a rural area with few deaf adults. Being deaf is quite unusual. About 2 to 3 babies out of 1,000 in the U.S. are born with some hearing loss; even fewer are born profoundly deaf. Geneva was one of only two profoundly deaf Vermont babies born over a period of several years. My education about Deaf culture came primarily through Tami, a PBS documentary about deaf history and culture, and a conference I attended about deaf education. Another link to Deaf culture for me was Geneva's primary caregiver, Krista Harris, at the DHMC Child-Care Center, where Geneva goes two days a week. Krista's father is deaf, so she grew up signing and surrounded by deaf adults. At first Krista was hesitant to tell me what a negative impression she had gotten about cochlear implants from the deaf people she knew. But I welcomed her insight, and we educated each other from our different perspectives.

Whenever I doubted our decision to get a cochlear implant for Geneva, I'd think about Kaily and the other young people we'd met. I'd also refer to two books I'd read, both by deaf authors. In *The Unheard: A Memoir of Deafness and Africa*, Josh Swiller explains how the struggles of growing up deaf eventually drove him to Africa, where he hoped his deafness wouldn't matter. "I got my first hearing aids when I was four years old," he writes. "To that point, I was slow to pick up language, slow to show an interest in the world at large. I wasn't very social or curious. I mostly sat under a table in the front room of my family's big apartment on Manhattan's Upper West Side and stared at the corner."

When I compare Swiller's early years with Geneva's life so far, my heart aches for Swiller and so many deaf adults who had similar childhoods. Geneva is as social and curious as can be and always has been. We knew about her hearing loss before the absence of communication could shape her personality. For that I'll be forever grateful.

The other book I often referred to was *Rebuilt*:

How Becoming Part Computer Made Me More Human, by Michael Chorost. Chorost grew up hard of hearing, went completely deaf in his thirties, and then decided to get a cochlear implant. After his surgery, Chorost visits a preschool for the deaf that he attended when he was little, where about half the children now have cochlear implants.

"Of all people," he writes, "I should have had the least difficulty believing that these kids could hear, because I had the same circuitry buzzing in my head as they did. And yet I found it almost impossibly hard to accept. I spoke to them, their processors pumped a megabit of data per second into their heads, and they said something reasonable back. It staggered me. I kept testing them in little ways, verifying over and over again that they really were hearing me. For me, learning to hear again was an intensely conscious act. But they were just *doing* it. I knew, in theory, what was going on inside their little heads: vast spidery afferentiations and differentiations of dendrites as their brains developed explosively in adaptation to the input. The technology was molding them in its own image. . . ."

"To me the implant was an alien imposition made in adult life, grafted onto an underdeveloped auditory cortex formed in response to 1960s-era hearing aids. But the implant was all they had ever known, and their brains, still young, still hyperplastic, would make more use of its data stream than mine ever would."

Chorost's descriptions were at once comforting and disturbing. I took comfort from knowing that Geneva's brain was still young and could thus make maximum use of the technology. I couldn't help but feel uneasy, however, with the device "molding [her] in its own image." I couldn't help but feel disturbed by her becoming part machine.

As the date of Geneva's surgery drew closer, I also felt that something very special was coming to an end. Geneva would not remember a time when she didn't know what sound was. (Even today, six months postsurgery, that still makes me sad.) On the night before the operation, I jotted down my thoughts:

In some ways, I want to get the surgery over and done with. But mostly, I'm just weary that the point of no return has come. Tomorrow I will surrender my perfect child to the kind folks at CHaD [the Children's Hospital at Dartmouth]. I'll hand her over like I'm presenting her for some tribal ritual. I'll voluntarily allow her head to be cut into, drilled into, and allow a foreign device to be threaded into her tiny inner ear. What a strange feeling that is.

She will not remember a time when she didn't know what sound is. She will still be deaf. Yes, I know this.



JON GILBERT FOX

Above, Jen Durgin, right rear, and anesthesiology resident Matthew Muffly, left rear, are gowned to go into the operating room with Geneva, while surgeon Daniel Morrison, left, shares a few final words with Christian Durgin, right, Geneva's dad. Below, Geneva's incision two days after the operation.



I took comfort from knowing that Geneva's brain was still young and could thus make maximum use of the technology. I couldn't help but feel uneasy, however, with the device "molding [her] in its own image." I couldn't help but feel disturbed by her becoming part machine.

This is what I have been told, and this is what I tell others. "She can just take off the external parts if she doesn't want to hear," I say. All that is true, but deep inside I know that tomorrow she will be transformed. We'll leave a piece of her deafness behind.

My husband, a scientist through and through (he teaches middle-school science), saw the cochlear implant in more pragmatic terms. Geneva can't hear; she has a disability, like poor eyesight



After her implant was activated in February, Geneva kept pulling off her external processor—until her mom got some caps like the one below. But by the summer, she wore her processor happily, above.

At first, she'd cry, squirm, and go limp every time I tried to put on her implant's external gear. Finally, with finesse and determination, I was able to get the ear gear hooked up and quickly slide a cap on and tie it down.

For a **WEB EXTRA** with video clips of Geneva during the activation of her implant and during a hearing test, see dartmed.dartmouth.edu/fall08/html/sound_we.php.



or a missing limb; and there is a technology that can fix the problem, he reasoned. Don't get me wrong—Christian was nervous about the surgery, too, but not because of any philosophical uncertainty about Geneva's deaf identity. He was nervous about all the usual risks inherent in any surgery, such as a bad reaction to anesthesia. So when Geneva's surgeon, Dr. Dan Morrison, brought us the good news that the surgery was over and

everything had gone well, Christian left many of his worries behind. He began looking forward to the activation, in one month, when Geneva would hear sound for the first time.

"I'm so excited for you to hear!" he kept saying to her. "It's going to be amazing! In a month you're going to hear!"

Just as with the surgery, I saw the activation as another point of no return. The activation would mark a transition from sign language to oral language. Geneva and I would continue learning and using ASL, but I knew it would take a back seat to spoken English once she could hear. We had made such progress with sign language. By the time she was 13 months old, Geneva clearly understood at least 60 signs and had herself signed close to 30. I didn't want to see that progress slow.

But for all my consternation, the activation turned out not to be very dramatic after all. Geneva exhibited little reaction when the audiologists attached the external parts of the device and switched it on. She just kept trying to knock the microphone and processor off her ear. The drama came later when we took her new equipment home.

Suddenly my easygoing 13-month-old discovered toddler-style tantrums. She'd cry, squirm, and go limp like a nonviolent protester every time I tried to put on her new ear gear—which involved clipping the battery and controller to her clothing, hanging the microphone and processor on her right ear, and finding the sweet spot on her head where the magnet on the external coil connected with the internal magnet. For four days, Christian and I tried. Tami tried. Amy Bove, the teacher of the deaf who would be helping us with speech therapy, tried. But we all failed. Each time I failed, I felt more and more despair. Eventually I began to wonder if the device was somehow hurting her.

Day care answered that question. I picked her up one afternoon and learned that she had worn the equipment there with no problem. So it was just a mommy thing. If mom was around, she was not going to wear it.

I knew I had to walk a fine line between making Geneva wear her processor and keeping the experience positive and laid-back. I felt terrible about forcing the equipment on her. Here I was, the hearing mom, trying to force sound on her daughter. "Keep trying" was the only advice that most people offered, but that wasn't getting me anywhere. Success finally struck when two cotton pilot caps, as they are called, arrived in the mail. I had ordered the caps, made by the high-end children's clothing designer Hanna Andersson, after reading online

about other parents who had used such caps to keep their children's hearing aids and cochlear implant equipment on. With finesse and determination, I was able to get Geneva's ear gear hooked up and quickly slide the cap on and tie it down. Gradually her tantrums became shorter and fewer, until after a week or two I could easily put the equipment on her while she sat in my lap.

With the stress and emotion of the first two post-activation weeks behind us, Christian and I waited and watched for the magic of the implant to take hold. It didn't take long. "Duh, duh, duh. Noy, noy, noy." Those were the first magical sounds we heard. Geneva had always been very vocal, but she had never babbled with consonants and with such variety. And she began mimicking our mouth shapes, too. "A cow says 'mooooo,'" I'd both sign and say to her, and she'd pucker her lips and make a faint "ooooo" sound. Almost one month post-activation, she turned and looked up at the DHMC helicopter, which regularly flies over her day-care center. A child who once couldn't hear a chopper with its blades thumping just a few feet away was now pointing up at one flying overhead. Surely that was close to magic.

Before her second month of hearing was over, Geneva began saying "hi" and, most importantly, "mama," which she used to her advantage. What hearing mother of a deaf child wouldn't stop whatever she was doing to pick up a child who'd just called out "ma, ma, ma"? Geneva was responding to environmental sounds, too—a car driving by, a fan turning on, a door slamming, people's voices.

Now, five months after her activation, at age 18 months, Geneva turns to her name and seems to respond to all sorts of sounds, no matter how soft or distant. She can say "hi," "bye," "mama," "daddy," "yeah," "kitty," "grandma," "milk," "diaper," "apple," "cheese," "ooo" for "shoes," "vrum-vrum" for motorcycle, "eeee"—as in "whee"—for swing, and lots of animal sounds. And her comprehension of spoken language is taking off, too. "It's time to brush your teeth," I'll say, without signing, and she'll head to the bathroom to get her toothbrush. "I see a dog. Do you see a dog?" I'll say, again without signs, and she'll point to a picture of a dog. And, to my great relief, I can call her name when she's about to do something dangerous, like stand on a chair or touch something sharp, and she'll turn to my voice.

Of all the measures of progress, the one that lifts my spirits higher than any other is Geneva's new audiogram. When the audiologist showed me the results of testing we did in a sound booth just two months post-activation, I felt for the first time pure



When she was born, Geneva couldn't hear a helicopter at full throttle a few feet away. Today, above, with her implant, she points to a plane she hears flying overhead as her mom signs "airplane."

and unrestrained joy for what the implant could do. Geneva's hearing—which will likely improve still more—is already comparable to that of someone with only mild to moderate hearing loss. Suddenly the audiogram, with all the little drawings that I spent so much time fretting over after her diagnosis, looks so full of potential.

I understand now more than ever before what the author of *Rebuilt* felt when he walked the halls of his old nursery school with watery eyes and a lump in his throat. "What I felt was joy: joy at the opening of human potential, at the destruction of barriers, at the flowering of lives that might have been limited and shuttered," he wrote. And while I might take issue with the presumption that being deaf and having no access to sound would lead to a limited life, I take no issue with his statement that "for profound deafness to be rendered ultimately a nuisance—surely that was occasion for tears of pride and gratitude."

I began this journey grieving for all that was lost, or that I thought would be lost, because of Geneva's deafness. Now I am filled only with gratitude, with a desire to give thanks to all who have traveled the journey of deafness before us, and to all who have sought to make that journey easier. Geneva will bear the fruits of their labor. ■

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