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.

Jennifer Durgin has been a senior writer at Dartmouth Medicine since June 2004. Her other recent features for the magazine include “All Together Now,” about a collaboration between DMS and Dartmouth’s Thayer School of Engineering that is the nation’s most advanced effort to develop effective alternatives to mammography (see dartmed.dartmouth.edu/winter07/html/together.php), and “Compound Interest,” about two promising chemopreventatives that were developed at Dartmouth and are now in clinical trials (see dartmed.dartmouth.edu/winter06/html/compound_interest.php).

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 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 jargon. “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
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. 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 hear 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.

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 cochleas, 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.

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.

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 less like a big unknown. 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.

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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.
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 call or the purr of a cat. In fact, we were thrilled when a freight train passed not more than 50 feet behind her, blowing its horn, and she remained oblivious. 

I’d accepted and began to celebrate Geneva’s deafness rather quickly, thanks in large part to our parent advisor who was assigned to us by the Vermont Center for 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 Trouvel, 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 what they were capable of. Then we didn’t know for sure if 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. 

If 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 impulses 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 funnels to the internal receiver (the electrode array). It’s not a cure-all. The first experimental cochlear implants were tried in adults in the 1950s, ’60s, and ’70s. Parents of children with hearing loss may not be candidates for an implant 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 sign language 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 use even animated facial expressions. Now, looking back, I realize that what I interpreted as the medical profession’s lack of encour
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.

O 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 sign language user. 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.

Byron is fine and I was overly concerned. 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 my 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’s back, asked him to look up the signs for “I love you” and “mommy.” 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 stuck to the bulletin board in my office. Byron’s ABR confirmed profound bilateral sensorineural hearing loss.

At 18 months, early intervention began. When the intervention began to our home, I knew she had no speech 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 lining up and down, so I looked up the sign for “butterfly.” I tried to follow the picture and its arrows and awkwardly signed “butterfly” to Byron.

He immediately signed back an approximation of “butterfly.” I Francisco 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.

Iow, 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. That is to say, after years of having a hearing loss, 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
Fall all the way into the operating room. Here, pediatric perioperative nurse David Szczesiul, left, having When Geneva had her cochlear implant surgery at DHMC, her mom, right, was able to stay with her a period of several years. Vermont babies born over only two profoundly deaf 1,000 in the U.S. are born with some hearing loss; even deaf. Geneva was one of the 34 Being deaf is quite unusual. I mostly sat under a table in the front room of 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. Wenger ever 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 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 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 happening in longing to end an era. 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 over her outer ear. “She can just take off the external parts if she wants to hear,” I say. All that is true, but deep inside I know that tomorrow she will be transformed. We’ll be 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. 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.

“In all people,” he writes, “I should have had the least difficulty believing that these kids could hear, because I had the same confusion burning in my head as they did. And yet I found it almost impossibly hard to accept. I spoke to them, their processors pumped a morgibit 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, hearing loss was an intensely conscious act. But they were just doing it. I knew, in theory, what was going on inside their little heads—spatial representations and differentiation of dirstries as their brains developed explosively in adaptation to the input. The technology was molding them in its own image.

“Me to 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.”

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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 be 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.

**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 cloudy 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 remembered 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 said...
At first, she’d cry, scream, 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 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. “Dah, dah, dah. 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’ducker her lips and make a faint “oooo” 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 sticker with its blades flipping 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 speak 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 recognize it as a signal to respond to. She can hear how soft or distant. She can say “hi,” “bye,” “mama,” “daddy,” “yeah,” “kitty,” “grandma,” “mill,” “cheese,” “yoo” for “shoes,” “vrum-vrum” for motorcycle, “eree”—as in “where”—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 signing, 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.

All of the measures of progress, the one that lifts my spirits higher than any others Geneva’s new auditory system allows her to hear, is her comprehension of spoken language. Geneva now is able to take in all the little drawings that I spent so much time fretting over after her diagnosis, looks full of potential. I understand now more than ever before what the author of Rebel 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 at the opening of human potential, at the destruction of barriers, at the flowering of lives that might have been limited and shattered,” 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.