HEARING HEALTH

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The *Seniors & Veterans* Issue

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Hearing Is *Believing*

A sudden hearing loss as a young adult inspires a life's work as a volunteer, mentor, and advocate for speechreading, oral interpretation, and technology. ***By Barbara Liss Chertok***

Top: Barbara Chertok speaks often as an advocate for those with hearing loss.

Above: In 2014, Barbara Chertok appeared on a Lifetime TV show about baby boomers, hosted by TV personality Morgan Fairchild.

I lost my hearing suddenly and in both ears at age 21. It was May 1957. I was on lunch break with friends and heading back to the Boston ad agency where we worked. Suddenly I pitched forward, losing my balance. The hearing in my left ear disappeared. Days later, my right ear lost nearly all hearing too.

My parents, who immigrated from Russia, took my sudden hearing loss harder than I did. I didn't worry because a respected neurologist told me I would regain all my hearing in six to eight weeks. At the same time, I discovered I was skilled at lipreading (speechreading), even the Yiddish we spoke at home. Yiddish was my first language but it was hard to lipread, especially my father's speech after a stroke left it impaired.

My hearing did not return as the neurologist predicted, so after seven months I received a hearing aid for my right ear to make use of a small amount of residual hearing. The hearing aid allowed me to hear a little bit of my own voice, helping me retain my voice quality. But I couldn't use the telephone to maintain my busy social life. My mother had to arrange everything, including my dates!

Decades later when I was investigating cochlear implants, I met with the cochlear implant pioneer John Niparko, M.D., at Johns Hopkins University. (The late surgeon was an Emerging Research Grants scientist in the 1980s and 1990s.) It was Dr. Niparko who—35 years after I lost my hearing—diagnosed the cause of my hearing loss as Cogan's syndrome, an autoimmune disorder.

Family Pitches In

My husband Benson Chertok and I met on a blind date—or was it a deaf date? We married in 1961, and he became a physics professor at American University in Washington, D.C. We welcomed a daughter, Victoria, and then a son, Maxwell.

Raising two children without the ability to hear compelled me to be creative. I put the playpen near the doorway to the kitchen to keep an eye on them while I was cooking. After a feeding, I made sure the baby faced me, so I could watch for burps. Our home was rigged with lights that flashed to alert me to the telephone, doorbell, and even when the baby cried.

The telephone continued to present a dilemma. Out of necessity, when Victoria was just a toddler I trained her to help me with calls. (See "A Lesson in Resilience," next page.) Victoria eventually became my oral interpreter. I'd read her lips as she interpreted group conversations or people who were hard to understand.

Likewise, my husband and son also helped with communication, and they always made sure they got my attention before speaking, faced me as they spoke, and did not speak rapidly. At the movies, Benson would silently repeat

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what was going on, and—in the dark and from the side—I read his lips and followed along.

I never lost my love of music, especially opera, passed on to me by my father. As a teen I took piano lessons and studied operatic voice at the Boston and New England Conservatories of Music. After I lost my hearing, I would sit in front of the television watching the Boston Symphony Orchestra perform, trying to remember how each instrument sounded. I continued to attend operatic vocal competitions, picking the winners with my eyes—and I was usually right!

Once after driving four hours to pick up my son at college, I passed the time singing nonstop, and arrived with a bad case of laryngitis. I still go to concerts frequently and engage musicians for the Sarasota Music Club in Sarasota, Florida, where I now live.

Volunteer Service

When my children were in school full-time, I began volunteering and advocating for the rights of people with hearing loss. This would become my life's work.

For 15 years, I volunteered with the Alexander Graham Bell Association for the Deaf and Hard of Hearing in Washington, D.C., serving on several committees and becoming certified as a reverse oral interpreter. This allows me to go to a hospital to read the lips of a patient who can move their lips but not produce sound, due to a tracheotomy or some other reason, for the benefit of a doctor or family member.

In 1971, living in California while Benson did a sabbatical at Stanford University, we bought our first two TDDs (telecommunication devices for the deaf, or teletype phones, TTYs) from Bob Weitbrecht. A physicist who was deaf, Weitbrecht invented the acoustic coupler that worked with the telephone and a teletype machine. But while I could now communicate with Benson by typing messages over telephone lines, I still could not

Starting as soon as she could talk, Victoria helped her mother Barbara as an oral interpreter.

A Lesson in Resilience

By Victoria Chertok

One of my earliest memories is answering the telephone for my mother. She taught me to do this when I was only 2 1/2 years old. I'd say to the caller, "Take a message for Mommy?" Then I repeated what the caller said, my mother responded, and we handed the phone back and forth as the conversation went along.

I didn't realize that my mother was different from other mothers until I was at a friend's home. I was 6 years old and my friend called downstairs to her mother—and her mother answered her. She didn't have to go downstairs, tap her mother on the shoulder, and then face her so her mother could read her lips. I was astounded!

Over the years, I learned a tremendous amount from my mother about hearing loss. I remember many dinner table conversations when she would explain how she was reach others who did not have the device.

To help solve the problem, I started selling TDDs for a local distributor—and sold them to my doctor, dentist, car dealer, insurance agent, financial adviser, and even to the White House (to an oral deaf lawyer I knew through A.G. Bell). When state relays came into being, I quit selling TDDs. Now I use a CapTel captioned telephone for my landline and an InnoCaption app on my iPhone. It was a treat when Morgan Fairchild asked me to demonstrate the app on a 2014 episode of her Lifetime television show, "Baby Boomers in America."

Rocky Stone founded the group Self Help for Hard of Hearing People in Maryland in 1979. I joined then and remain an active member of what is now the Hearing Loss Association of America. I volunteered at the national office and still write for its Hearing Life magazine. I have also been invited to share my experiences with speechreading and oral interpretation at conferences here and abroad.

In 1982 I served as the first juror with a hearing loss in Maryland. It felt wonderful to fulfill my civic duty, especially since 30 others with hearing loss had been denied the opportunity. I remember sitting in the jury pool of 55 people waiting for the 12 jurors to be announced. When the person next to me tapped my arm and said: "That's you, number nine, Barbara Chertok," I felt as if I was suddenly in the Miss America Pageant!

The media called me "a trailblazer," the first person ever to use an oral interpreter in a courtroom. My interpreter sat in the jury box with me while I read his lips for four days of testimony. A television cameraman was allowed in the courtroom to film us (another first). I was thrilled to appear on that evening's news and, the following day, in the Washington Post and other newspapers. In an article in Maryland's Montgomery Journal, the defendant's attorney said about me: "She probably knew more about what was going on in the courtroom than anyone else except for the judge."

Barbara Chertok and John Ball, the president of the National Captioning Institute, hold a TV caption decoder in 1990.

Hearing Music Again

After that initial meeting with Dr. Niparko, I received my first cochlear implant (CI) in my "better" right ear at age 62 in 1997, over four decades after losing my hearing. Loren Bartels, M.D., the director of the Tampa Bay Hearing and Balance Center, did the surgery. It was activated one month later. The first thing I did after arriving home was to listen to a recording of Nat King Cole's "Unforgettable." To be able to hear

determined to remain in the mainstream using her speechreading skills, a hearing aid, and any assistive devices available at the time, such as a vibrating alarm clock. Even now, at age 84, she is passionate and continues to mentor people with hearing loss. I honestly think she has touched thousands of lives.

I studied the harp from ages 5 to 21 and performed regularly. It was heartbreaking that my mother couldn't hear me play, even though she watched closely and felt some of the vibrations. A huge supporter of my music, she drove me for years to harp lessons and orchestra rehearsals.

Since my father had a demanding career as a physics professor, traveling extensively, and then after he died from cancer at age 46, leaving her with two young teens to raise, my mother leaned on me to be her oral interpreter. I helped her understand what others were saying at dinner parties, school visits, shopping expeditions, doctor's appointments, and movie theaters, just to name a few. I never minded helping her (and didn't know any differently), but I have to admit it did take up an incredible amount of time and effort to interpret.

My mother showed me how to overcome enormous obstacles while keeping a positive attitude. Her strength of spirit, drive to succeed, and advocacy for those with hearing loss continue to inspire.

Victoria Chertok is a teacher and photojournalist in Vermont. She has two adult sons and still enjoys playing the harp.

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music again brought tears to my eyes, and I was thrilled his voice sounded as I remembered it.

I received a second CI in 2008, in my left ear—which had not heard for half a century. After activation, I was amazed I could understand the audiologist without reading her lips. In a quiet setting, I can now carry on a conversation without needing to look at the person speaking to me.

To share my experience with CIs, I founded two support groups in Florida. It pleases me to advise others that infants with a profound hearing loss can receive bilateral CIs, at age 1 or even younger, allowing them to develop spoken language and attend mainstream schools.

In the U.S. there are 48 million people with hearing loss. Research tells us that untreated hearing loss can lead to cognitive decline, isolation, and falls. Hearing aids are now smaller and better, yet people wait an average of seven years before treating their hearing loss, such as with a hearing aid. People seem to think that because hearing loss is an invisible disability, wearing a hearing aid will make them look old. I remind them their hearing loss is more noticeable than any hearing aid.

The stigma associated with hearing aids can be more of a deterrent than their significant out-of-pocket cost. But now that people wear all sorts of devices in or on their ears, and less expensive over-the-counter hearing devices are becoming available, perhaps hearing aids will finally be no different than eyeglasses.

A Letter to the White House

Speechreading saved my life and helped me stay in the mainstream. To improve my skills, I took private lessons with Enid Lofchie, a professor of audiology at Emerson College in Boston. Enid was an exceptional teacher and, like me, had a significant hearing loss. My association with her inspired me to teach speechreading, which I did for 10 years at Montgomery College in Maryland, at community centers, and privately in my home. I'm happy that some of my students continued to practice together, even after I moved away.

During his presidential campaign, George H.W. Bush promised: "Read my lips: No new taxes." After he became President, I wrote him a letter saying, "I have been reading your lips and everyone else's ever since I lost my hearing suddenly." I asked if he and his wife Barbara could join me in promoting lipreading as a valuable communication tool for people with hearing loss.

I added a postscript to my letter: "A reminder: Your signature on the ADA [Americans with Disabilities Act] bill will help ensure that people with disabilities can be a part of the mainstream of society."

President Bush replied that "while longstanding White House policy prohibits us from endorsing individual, nongovernmental projects, we encourage you to continue your efforts to enhance the lives of the hearing impaired." A few weeks later, in July 1990, he signed the ADA into law. Thirty years on, I still like to think my postscript made a difference.

Barbara Liss Chertok lives in Florida. A mentor, advocate, writer, and speaker, she serves on the American Hearing Research Foundation board. Email her at barbchert@gmail.com.

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