



# Hearing with the Brain and the Brainstem—Jessica's Unique Dual Implants

BY BARBARA LISS CHERTOK

An interview with Jessica Toews, one of the world's first recipients of both a cochlear implant and an auditory brainstem implant.

It began in 2009 with a pain on the left side of Jessica's head. An MRI revealed two brain tumors, one on each auditory nerve. The tumor on the left side was large and life threatening, pressing on her brainstem.

Later that year, Jessica Toews was diagnosed with neurofibromatosis type 2 (NF2), a genetic disorder causing tumors to form on nerve tissue. These tumors can develop anywhere in the nervous system, including the brain, spinal cord and nerves. Jessica's NF2 was characterized by bilateral acoustic neuromas.

Several doctors considered the surgery on her left side as too risky. Further research led her to Derald E. Brackmann, M.D., at the House Research Institute in Los Angeles. After reviewing her MRI, he explained that by removing the tumor, Jessica would lose all hearing in that ear, and since she would not be a candidate for a cochlear implant (CI), she could receive an auditory brainstem implant (ABI) at the same time.

In November 2009, one hour before the surgery was to take place, Jessica found out that her insurance company denied the implant because she still had

hearing in her right ear, making the ABI not "medically necessary." Dr. Brackmann subsequently removed only the tumor but did not implant the device.

As the tumor on her right side grew larger, her hearing in that ear declined. Jessica was referred to Dr. Ravi N. Samy at the University of Cincinnati, and she began chemotherapy treatment to shrink the tumor. After it shrunk considerably, in February 2017 she received a CI on her right side. Later that year, in August, Jessica received an ABI on the left side as it was now covered by insurance. Both implant surgeries were performed by Dr. Samy.

Jessica was the fourth person to have ABI surgery at University of Cincinnati and one of the first in the world to have the unique combination of both a cochlear implant and an auditory brainstem implant.

## The Surgeon

Dr. Ravi N. Samy received an M.D. degree from Duke University Medical School, completed his residency at Stanford University Medical Center and a Fellowship



Jess has worn fun socks every day for almost five years. They help her focus on what's really important in life and remind her how much she has been through and survived.



Jess with her husband Tim, son Marley (front left) and daughter Nadia (front right) at the 2017 Kentucky Walk4Hearing where they walked on the Cochlear team.



Jess teaching a lesson in the children's ministry at Grace Baptist Church. She has been a leader with the children in her church for 17 years.

at the University of Iowa Hospitals and Clinics. He has been a neurotologist at the University of Cincinnati Gardner Neuroscience Institute and program director of the Neurotology Fellowship at the University's College of Medicine since 2005. He is director of the Adult Cochlear and Auditory Brainstem Implantation Program at the University, and associate professor of Otolaryngology at the College. He is also chief of the Division of Otology/Neurotology.

Dr. Samy's research interests include cochlear and auditory brainstem implantation as well as acoustic neuromas, neurofibromatosis type 2, facial nerve tumors, cholesteatomas, and other diseases and disorders of the lateral skull base. Dr. Samy has performed seven ABI surgeries.

### Cochlear Implant (CI)

A cochlear implant is a small, surgically implanted electronic device and provides a sense of sound to a person who is deaf or severely hard of hearing. The implant consists of an external portion that sits behind the ear and an internal portion that is surgically placed under the scalp. The CI bypasses the nonfunctioning hair cells of the auditory system and transmits sound directly to the auditory nerve, which the brain processes as speech.

Babies can receive a CI as young as one year of age, some even younger. According to the National Institute on Deafness and Other Communication Disorders (NIDCD), children with profound hearing loss who receive cochlear implants before 18 months of age "develop language skills at a rate comparable to children with normal hearing."

### Auditory Brainstem Implant (ABI)

An auditory brainstem implant is a small, surgically implanted electronic device and provides a sense of sound to a person who is deaf due to retrocochlear hearing loss. The ABI is connected to the brainstem of recipients with severe auditory nerve damage or profound sensorineural hearing loss that results in an absence of any hearing ability, meaning the cochlea cannot relay sound information to the brainstem and the rest of the brain. As a result, hearing aids or cochlear implants are unable to help individuals with severe auditory nerve damage. Babies can receive an ABI between two to three years of age at the earliest.

### Neurofibromatosis Type 2 (NF2)

An auditory brainstem implant may be used when a person has neurofibromatosis type 2 (NF2), a genetic disease where a non-cancerous tumor or tumors develop in the nervous system. They are most commonly located along the auditory nerve. Often in the process of removing an NF2 tumor, the auditory nerve is severed, resulting in the complete loss of hearing in the affected ear. As this condition is rare and the surgery required very delicate and precise, an ABI is often the only viable hearing technology option for this small group of people.

This implant is similar in design and operation to cochlear implants. They have a receiver and an electrode surgically implanted along with a magnetic headpiece and a sound processor worn behind the ear. Unlike cochlear implants, the electrode is placed on the surface of the brainstem rather than being inserted into the cochlea. A person with an ABI usually cannot distinguish between

different sounds but instead has an ability to know when sound is present or absent, which can be assisted with lipreading and safety.

## An Interview with Jessica Toews

*(BC) You have a love of crazy socks. How did that start?*

(JT) I have worn crazy, fun-patterned socks every day for almost five years. In my opinion, you can't have a bad day when you're wearing fun socks. They help me to focus on what's really important in life and remind me that I have been through many trials and survived. For me the socks are just a visual [clue] that I can do hard things.

*During your eight years of deafness, what coping mechanisms did you use?*

I learned to lipread pretty well and I learned a little sign language. Texting and writing things down were also very helpful.

*When and at what age did you receive your CI and your ABI? Why did you wait eight years to be implanted?*

I was 36 years old when I received my CI on the right side in February 2017 and my ABI on the left side in August of the same year. I was told the ABI was an option, but my insurance wouldn't approve it. I wasn't a candidate for a CI because I have NF2. It's a genetic condition that causes tumors to grow on the nerve cells throughout the body. The tumors are located mainly

in the brain and spine. The main indicator of NF2 is bilateral acoustic neuromas. These tumors are located on the hearing nerves.

*What did you first hear when your implants were activated?*

With the CI, the first actual words were the sounds of my daughter saying, "I love you, mommy." With the ABI, I heard just beeps and buzzes.

*What can you hear now and how does it differ on each side? Did you do any specific rehab after activation?*

My CI is amazing! I can hear pretty much anything and everything. In noisy places, it's still hard to focus on a conversation, but with lipreading and the CI, I don't feel like I miss out on anything. The ABI is more for environmental sounds right now. I can't understand speech at this point with just the ABI. No one can predict what I will hear with it later on. It's different for each person\*.

For rehab, I listened to lots of audiobooks. I'd visit the public library and check out both the audiobook and the paper version. By listening and reading the words, I felt it helped me to understand and be able to make the CI work better for me. I did the same thing with TV shows and movies. I'd watch and read the captions at the same time.

*You were the first patient in the U.S. to receive the Cochlear Nucleus 7 sound processor to use with your ABI. This device allows implant recipients to wirelessly stream sound directly from any Apple-compatible device. Can you explain how this works for you?*

Originally, the Nucleus 7 processor was placed on my ABI side and the Nucleus 6 on the CI side. After two months, my audiologist switched the processors because I was hearing only beeps and buzzes on the ABI side, and the technology of the Nucleus 7 would be more useful on the CI side.

The Nucleus 7 is amazing! It has allowed me to enjoy music again. There is no need for extra streamers, phone clips, etc. Any sounds that come from the phone can be streamed directly to the implant. I can use FaceTime, listen to music, watch YouTube and Netflix all without headphones. It's definitely a life-changing device.

*How clearly can you hear speech and are you able to enjoy music with your CI?*

At my last hearing test, my word recognition score for sentences with my CI was 98 percent. I'm pretty pleased with that!



Jess on her ABI activation day in September 2017. With her are (from left) her husband Tim, Dr. Ravi Samy (her surgeon), University of Cincinnati health audiologist Lisa Wenstrup and Cochlear audiologist Laural Olson.

I have trouble listening to new songs. I find hearing the words with the background music very difficult. When I want to hear new music, I'll look up the lyrics to the song and read [them] while I listen. It seems to help with the understanding. After a few times listening while reading the lyrics, I can distinguish the words from the music.

### **Have your implants affected your speech in any way?**

My husband has said that my speech is much clearer and my volume is more appropriate than it was before the implants.

### **Were your surgeries and devices covered by medical insurance?**

Both the CI and ABI were covered by my medical insurance. We were responsible only to pay for the out-of-pocket portion. Every insurance is different, so this amount would be different for each patient.

### **In 2011, you and your husband became foster parents of two children, whom you later adopted. How old are they and can you understand them easily?**

Nadia is ten and Marley is nine. When we're riding in the car and they're talking behind me, sometimes it's difficult to understand them. Otherwise, I don't have much of a problem understanding them.

### **What is the best thing you've heard with your implants?**

The laughter of children is the absolute best sound ever.

### **How does your husband feel about your newfound hearing?**

Tim loves that I can hear again. Without hearing, it was difficult to communicate with each other, and honestly, became exhausting sometimes. Driving in the car, we couldn't communicate. He couldn't look at me while he was driving, so I couldn't lipread. Having the ability to hear again has definitely changed our relationship for the better.

### **Are you a stay-at-home mom or do you work outside the home?**

My husband and I have served in the children's ministry at our church for 17 years. I worked in the banking industry for 12 years. After a bank merger, I was left without a job and decided that maybe it was time to just be a mom. For the past three years, I have volunteered in the local public schools. It's such an honor to work with kids. It has given me the opportunity to educate children about hearing loss. I also encourage them not to give up just because things get hard.

### **You call yourself a "cheerleader" for others. How so?**

I have been very open to discussing my hearing journey with anyone and everyone. I have given Dr. Samy permission to give my contact information to anyone he believes could use my help. Dr. Samy can tell a patient all about the medical part of a CI and an ABI, but having never experienced it himself, there are things he doesn't know. He doesn't know what it sounds like or what it feels like to walk around with a device on your head. Most patients want to talk to a person who has been in their shoes. I've made it to the other side and I'm not afraid to share what getting there was like. So Dr. Samy, my audiologist, and Cochlear (the manufacturer of my CI) have shared my information with patients and I have been able to answer questions, share my experiences, and just be a cheerleader for others.

### **What would you say to others who, like you, lose their hearing from NF2?**

It's not going to be easy. You will cry. You will get mad. You will feel useless. Allow yourself time to experience those feelings, but don't dwell there.

I started writing down three specific things every day that I was thankful for. Things that were good. For example, "I'm thankful that I didn't hear that horrible storm last night." Train your brain to find the good and it will change your attitude and outlook on life. We're here on earth only for a short time, make every day count.

Jessica always ends her emails with "Life SOUNDS good." **HL**

*\* See the March/April 2010 issue of Hearing Loss Magazine and Barbara Chertok's interview with penetrating auditory brainstem implant (PABI) recipient Karen Lichtefeld: "Hearing with Our Brain: Karen's Journey Back to the World of Sound."*



*Barbara Liss Chertok lost her hearing suddenly at age 21 from Cogan's Syndrome, an autoimmune disease. She is a bilateral cochlear implant recipient and founded two cochlear implant support groups in Florida. A freelance writer and a former lipreading teacher, she advocates for the rights of people with hearing loss through mentoring, lecturing and writing. Barbara joined HLAA in 1979 and is active in the HLAA Sarasota/Manatee Chapter. She serves on the National Advisory Board of the American Hearing Research Foundation. Barbara can be reached at [barbchert@gmail.com](mailto:barbchert@gmail.com).*