

Cochlear

Kids: Tracy, Casey

It's been 25 years since three patients under the age of 18 received the first pediatric cochlear implant (CI) – a single-channel auditory device developed by William House, M.D., at the House Ear Institute (HEI) and later approved for clinical trials by the FDA under new federal medical device regulations in 1982. Results with the first three “pediatric” patients led Dr. House to start a clinical trial of cochlear implants that also included younger, pre-school aged children.

In 1981, Tracy Husted became the first pre-school-aged child to receive the cochlear implant. Since the application of cochlear implant technology in very young children had not been attempted before Dr. House's clinical trial at HEI, Tracy was heralded as the “first cochlear implant child” and her progress was

well documented by news cameras over the years. Tracy's implant also caused some upheaval within the Deaf Community, and media coverage of the debate fueled controversy. Tracy received her cochlear implant at the age of three, after losing her hearing as a result of spinal meningitis. Her frustration and unhappiness at losing her connection to sound

motivated her parents to seek a cochlear implant for her, and Tracy's heartfelt and enthusiastic response to first hearing sound again with her CI was a rewarding moment for all involved.

In 1983, shortly before her third birthday, Kristen Corey received the single-channel implant as part of the ongoing clinical trial at HEI, with William House, M.D., and William Luxford, M.D., as her surgeons and treating physicians in the recently-established

Children's Auditory

Research and

Evaluation (CARE)

Center of the House

Ear Institute. Kristen's

hearing loss had

occurred as a result

of spinal meningitis,

just as she was

beginning to learn

language and enjoy

music. She began

working with a speech pathologist at the onset of her hearing loss, and with hard work and additional



and Kristen

Reflections on Growing Up **Cochlear**

help from other experts on the CARE team, she received good results with the cochlear implant. Upon entering school, Kristen was enrolled in a Deaf and Hard of Hearing (DHH) program and was gradually “mainstreamed” into regular classes by the time she reached junior high school. In 2003, she received the multi-channel cochlear implant in her other ear. Now 25 years old and a recent college graduate, Kristen continues to consult with Dr. Luxford in the House Clinic’s adult cochlear implant program.

In 1989, five-year-old Casey

Correia became the first child to receive the 22-channel (multi-channel) cochlear implant in the United States. Like Tracy and Kristen, Casey lost his hearing as a result of spinal meningitis. His profound hearing loss was diagnosed a few months after Casey returned home from the hospital, at which time he withdrew from everyone, and his speech started changing. After he was given very powerful hearing aids that provided him no benefit, Casey’s parents decided to try the cochlear implant. They also enrolled him in a

special oral-focused school program called Oralingua, before “mainstreaming” him into regular classes in public school.

While Tracy and Kristen were initially very happy to hear sounds through their cochlear implants and did well with the device, Casey was initially unhappy with his implant and frustrated with the challenges of rehabilitation and speech therapy. Now in their early twenties, these three remarkable individuals reflect on their experiences growing up with a cochlear implant.



Casey’s Story *In his own words...*

“I remember when I first got my implant that I didn’t really like it that much. It took a lot of

practice to get used to it. I had to go through a lot of speech therapy. I just remember it was

very hard and I had to work so hard to be able to hear again.

The greatest challenge I faced before the implant was trying to understand what was going on and why I was deaf. I was made to wear hearing aids that didn’t help me and everyone was trying to make me hear but nothing worked.

I remained deaf until I got

the cochlear implant, and then when I first got it, I thought it was horrible. I hated it. In fact, I wanted to take it off and throw it away. The biggest challenge was trying to get used to it. All the testing and speech therapy was a really big challenge. My low moments included not being able to figure out what a sound was or where it was

coming from. I couldn't even recognize my parent's voices. I had to face people when they were talking. I couldn't tell when a phone or a doorbell rang. Then, as time went by, every new sound became a high moment for me.

My first 'high moment' came at home when I was upstairs, and my mother was downstairs, and she called out my name and I responded, "Yes, Mom?" It was a shock to both of us that I could recognize her voice. Eventually, I could hear my parents even with my back to them, and soon, I could talk on the telephone. I was going to public school by then and I had my own friends. I also remember being able to order food from McDonald's for the first time.

My friends are all hearing kids. We can communicate just fine. We talk on the phone all the time. I'm in college and I enjoy it a lot. I either want to be a teacher for the deaf or maybe pursue a career as an architect.

I've had a couple of negative experiences with the Deaf Culture. Once I met a deaf person who asked me why I was wearing a cochlear implant. I told him it was so I could hear. He got very angry and offended and asked why I 'was made' to hear. He said that I shouldn't be wearing a CI. I asked him when he'd started making choices for me in my life. This made him mad and he left. Not all deaf people are this way.

Every once in a while I meet someone like that and I think, 'Why don't they want to hear?' Sound is the most beautiful thing.

I have the best of both worlds. I can communicate with the hearing and the deaf. I don't know why the Deaf Community is so prejudiced against people with cochlear implants. Why can't I be part of their world?

I think my life would be extremely different without my CI. I wouldn't be able to communicate with the hearing



world in the same way. I would only know sign language and would have interpreters help me. I probably wouldn't be able to communicate with my family unless they knew sign language.

If I had a child who was deaf, I would 100% choose the CI for him/her. I would also teach my child sign language, but give him/her the opportunity to hear. Once old enough, I'd let him/her choose if he'd like to continue to wear the CI or just sign. I would just want to know that I'd done everything I could to help my child communicate.

I thank my parents for the choice they made for me. I'm very grateful that they chose the cochlear implant for me. I didn't ask to be deaf, but I know I would make the choice (for myself) to hear with the CI."



Tracy's Story *In her own words...*

"My parents tell me that I was so unhappy after I lost my hearing because I loved sound so much. My Dad threw away all my toys that made sounds because he felt it wasn't fair to me to play with them when I couldn't hear the sounds they made.

I remember how thrilled I was when I got the cochlear implant and first heard a sound. The video that shows me hearing sound for the first time still gets me teary every time I watch it. A young child does not lie. In that video I look so overjoyed.

I liked the attention I got from adults and the doctors. They were so amazed that I could speak clearly and hear things that they

hadn't thought a deaf person could hear. I liked impressing them so I worked hard to do better. I think I was more comfortable with adults than kids, but they still saw me as a kid.

I used to feel like I had to start over with my speech [skills] every time I started working with a new speech therapist. My mom is the best speech therapist I ever had. She helped me through the

"It has been my dream to make cochlear implants accessible to more children to bring them the life-long gift of sound."

– William House, M.D.

whole cochlear implant experience. She is the one who helped me identify sounds. The first time I recognized a sound at home was when my mom turned the washing machine on. She showed me the source of the sound I was hearing, with the water swishing around. After that she took me all around the house to show me the different sounds. Even to this day, I am still learning to identify new sounds. My favorite moments are when I say a word the wrong way and I make my mom or friends laugh.

I used to feel torn inside because I couldn't decide which group I really wanted to belong to. I liked being around hearing kids because I didn't know many kids with cochlear

implants. I wanted to fit in with the rest of the group. This got harder as we got older. Some kids started tormenting me, while others treated me like a special case. Only two or three kids remained friends with me through the years and didn't think of me as being any different from them.

I went through about 15 different schools while I was growing up. When my parents were going through a divorce, I was "mainstreamed" into public schools with no assistance from interpreters. At one point, I went to a school at a shelter. Later, I attended schools with deaf program classes and got some help in regular classes from interpreters.

One of the best times of my

life was when I was in deaf program classes in mainstream schools. The best part was being able to communicate with the other deaf kids with such ease, which made me feel like I was not really a deaf person with a CI. I was just Tracy to them, and to me. We communicated using American Sign Language (ASL), a language I picked up with no problem. Another advantage to these programs was that the hearing kids at those schools often knew sign language. It gave me the opportunity to communicate not only with my deaf classmates, but with hearing classmates as well. This was very important to me and made a big difference in how I viewed myself.

There are some people who

20th Anniversary Celebration of Family Camp

June 2005 marks the 20th anniversary of the House Ear Institute's "Sharing is Caring" Family Camp – a weekend of fun and personal growth for deaf and hard-of-hearing children and their families. The mountains and beaches of North Malibu provide the backdrop for group activities and discussions about feelings and family experiences.

The Institute's camp is designed to ease the frustration and confusion frequently experienced by parents who are raising a deaf child. Counselors skilled in sign language, cued speech and oral communication guide the children through a fun-filled weekend of camp activities, while their parents attend panel discussions and educational workshops.

tell me to go put on [the external accessories for] my cochlear implant if they're trying to communicate with me and I don't understand them. I hate that. Talking with some people can be hard. Not a lot of people have patience, so most of the time I write down what I need to say to them.

There is so much more to me than my cochlear implant – that is just one part of me. I'm still learning things about myself every day. I'm still so young and awkward sometimes!

I've been answering questions about my cochlear implant for 24

years, and I find that people are still very curious about it. I'm happy to answer people's questions because I think it's helpful if they learn about the implant from someone who uses one. I only share my personal experience with the implant, though, and try to be as neutral as I can on the topic. My experience won't be the same as everyone else's.

People always ask what it is like to hear with a cochlear implant. This is hard to describe since I only vaguely remember the sounds I heard before going deaf. The sounds I hear with my

cochlear implant are natural to me but may sound mechanical or 'robotic' to others. It takes more effort for me to hear things than it does for most hearing people. For example, I prefer listening to classical music because I can identify and hear the difference between the instruments. Whereas with pop music, I have to really concentrate to follow the lyrics."



Kristen's Story *In her own words...*

"I was almost three years old when I received the single-channel cochlear implant, but I don't

accurately recall how I felt at first hearing sound again. My parents tell me I was excited, and continued to be the happy child that I was. Music was, and continues to be, my biggest pleasure and I wouldn't have been able to enjoy it if it weren't for the cochlear implant (CI).

I was one of Dr. Luxford's first pediatric patients at the Institute's CARE Center, and I worked steadily with the pediatric audiologists and speech pathologists there for my rehabilitation. I am still treated by Dr. Luxford as an adult CI patient, and currently work with audiologist Dawna Mills in the

House Clinic. You should see my medical file – it is thick with more than 20 years of tests and records!

When I first entered school with my cochlear implant there were some social challenges. Other children were very curious about my cochlear implant, and I was often teased on the playground. I figure everyone gets teased for one reason or another when they are growing up, right? Sometimes for comic effect I'd pretend to be a "bio-robotic" girl. I was a pretty happy-go-lucky child, so I didn't notice a lot of negativity against the cochlear implant itself – more about the fact that I was deaf. Nonetheless, I was an exceptional student, often praised by my teachers, and it showed in my grades. I attended the University of California at Santa Barbara for my bachelor's degree in Socio-cultural Anthropology

and used the special services they offered on campus, like real-time captioning and sign language interpreters, to maximize my learning experience. I'm currently working as an Accounts Payable Specialist and teach American Sign Language at a community college twice a week.

Growing up with a cochlear implant, one of the things I've learned to understand and accept is that I'm not fully hearing or fully deaf – I don't fall neatly into either category, so I do face some ignorance and prejudice from people in both the deaf and the hearing worlds. I get a variety of reactions to my cochlear implant, ranging from curiosity to bewilderment and suspicion. People ask a lot of questions, which I don't mind answering, and there seems to be a lot of confusion about how a cochlear implant differs from a hearing

aid. It is interesting that nowadays people mistake my implant for a behind-the-ear cell phone or a mini iPod (portable stereo).

When I think about what I'd do if I had a child who was deaf, it is difficult for me to decide if I would choose the cochlear implant for them or not, and I know this is a question that comes up often in the Deaf Community. On the one hand, I would not elect the cochlear implant for my child because I firmly believe that if one has never experienced sound, one cannot fully benefit from the cochlear implant. On the other hand, if my child lost hearing at a later age after being accustomed to sound, I would consider whether or not my child showed signs of distress upon losing sound. If he did, I might first consider powerful hearing aids, and if those didn't work, then I'd consider the cochlear implant as an option for him. I might



wait and let my child choose for himself. But then again, implantation at an earlier age is considered more beneficial. As you can see, I have mixed feelings on this issue, and I know these are the considerations parents of a deaf child face.

I'm glad my parents decided on the cochlear implant for me, not because it helps me communicate verbally with virtually everyone, but because it has allowed me to enjoy music. I must admit that sometimes I leave the accessories for my cochlear implant off just to enjoy the silence (for me, this is one of the few benefits of being deaf). If I had it to do all over again, I would probably not change a thing. I've had my ups and downs with the CI, but I believe I've fared very well. I'm so grateful for the support system I have in my parents, family and friends.

I would like to share this with parents raising a deaf or hard of hearing child. Be patient and allow your child to explore different methods of communication – be it oral language, total communication or sign language. I didn't pick up American Sign Language

Independent Films

Two new independent films featuring cochlear implant users are being viewed at film festivals this year.

Pilar, a film by Leda Maliga, follows the story of the filmmaker's sister, who lost most of her hearing as an infant and decided to get a cochlear implant as a young adult.

What's Bugging Seth, a film by cochlear implant user Eli Steele, tells the fictional tale of a young man living with hearing loss in a "hearing" world. Both filmmakers can be contacted for more information:

ledatanite@mac.com regarding *Pilar* or sunrami@aol.com regarding *What's Bugging Seth*.

(ASL) until my teens, but I was very glad I did. Your child will experience frustration, but it will allow him to grow stronger and be a positive role model for others. I feel that I've inspired both hearing and deaf individuals – not because I have a CI, but because I've used it as a device to grow and support myself through life". ❖

For additional information on cochlear implants and research for children with hearing loss, please contact the CARE Center at (213) 483-4431.