

One Family, Four Cochlear Implants

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By Janet McKenna

A Rochester, New York, family of four all received cochlear implants during one week in 2004. As “Deaf community” members, how do their experiences compare with those of other cochlear implant users? The Matchetts tell their story.

Strong Memorial Hospital in Rochester, New York, hit the jackpot when Douglas and Mary Karol Matchett and both their children, Kara and Scott, all received cochlear implants over one week in March 2004. Kara was nine and Scott 11 when they received their implants.

The Matchetts consider themselves a Deaf family whose primary language is American Sign Language (ASL). Recently Mary Karol was inspired to establish a unique cochlear implant support group for Deaf implantees. The Rochester Chapter of SHHH invited the foursome as speakers a year post-implant. Afterward, chapter members compiled questions to be answered in more detail by Mary Karol and Doug.

Hearing Aids Not Power Enough

Q: What motivated you to have cochlear implants (CIs)?

Doug/Mary Karol: It took us about six years before deciding to get cochlear implants. We had sought much more powerful hearing aids (because of the profundity of our deafness) but there weren't any on the market. Also feedback was a real problem when we turned up to the maximum volume. Cochlear implants were the only option for the power we need.

Q: What was it like for you growing up deaf in a hearing family?

Doug/Mary Karol: We were raised as normally as any other family members, although we're pretty sure that we missed out a lot in conversation especially at the dinner table.

Q: Did your experiences as children and young adults in a hearing family enter into why you felt so strongly that you wanted a CI for yourselves and especially for your children?

Doug/Mary Karol: No, this has nothing to do with hearing families. We did it solely to enhance hearing new sounds with the new technology available, ultimately with no feedback. Mary Karol adds that auditory rehabilitation enhanced her awareness of the benefits of cochlear implants “as it's so different from hearing aids.”

Quadruple Surgeries in One Week

Q: When were your surgeries performed?

Doug/Mary Karol: Mary Karol went first on Thursday, March 17, 2004. Both kids had their surgeries on Monday, March 21, and then Doug on Thursday, March 24. We believe we are the first and only Deaf family having CI surgeries in one week and hopefully, we'll be in the Guinness Book of World Records!

Q: Do you see yourselves as being deaf, hard of hearing, or something else?

Doug/Mary Karol: We see ourselves as a Deaf family, still the same Deaf family before or after the CI.

Q: How much can you understand from others without an interpreter?

Doug/Mary Karol: We still rely on speechreading, which has become much easier with the cochlear implants. Cochlear implants have enabled us to depend on our listening skills more than lip/speechreading, reducing eyestrain. But in a large group of people we still depend on an interpreter.

Q: Has the CI affected the way you communicate among yourselves?

Mary Karol: When communicating with deaf people, we use ASL but with hearing people, we speak. There is a significant change in our speech when wearing the CI and our voices become more natural and clearer. The implant doesn't negatively affect the way we communicate, but it allows us the opportunity to use a different mode of communication without a struggle. It's important to stress that when speaking to hearing people, we rely on our implants a lot to "hear" our voice as well as theirs.

Our children use their voices more often when interacting with hearing peers or adults. It's much easier to respond to our names being called since we can recognize the differences between consonants, vowels and the length of the sounds of each.

Speech Becomes More "Natural"

Q: Has your own speech changed since your implants?

Mary Karol: As soon as we were hooked up, right away, our speech became more natural and clearer. We hear the difference in our children, who finish their sentences clearly when talking. Within two months after our initial programming, more than several people mentioned that my voice had adjusted to the level where it's not so soft or low. I was amazed as it wasn't my intention to raise my voice. It's clearly possible that the CI sends a message to my brain, letting me know at what level I am comfortable in hearing myself talking.

Doug and I and the kids are able to enunciate more clearly. We were told that our speech has improved in emphasizing certain sounds more naturally and finishing the last consonants like "T" or "S" of a word.

Q: How does using an FM system in school with CI's compare to using one with hearing aids?

Doug/Mary Karol: The CI is much clearer than the hearing aids. It brings the whole variety of sounds up almost to the hearing level. Scott was able to pinpoint the annoying sound of the microphone rubbing against his clothing; it's been corrected. Kara can hear voices in the halls while she's in the classroom. In the past with the hearing aids she wouldn't detect them immediately.

Q: How have the children's friends and classmates reacted to their CI's?

Doug/Mary Karol: Everyone was very supportive and happy to hear the news. Some were curious and asked questions, enabling Kara and Scott to describe what the CI does for them. Communication has become much easier for them as they recognize who is speaking and can follow more closely than with the hearing aids.

She Hears Squishing Sneakers

Q: Mary Karol, do you find the CI helps in your work at NTID (National Technical Institute for the Deaf at Rochester Institute of Technology)?

Mary Karol: The implant has helped me a great deal in recognizing environmental noises and sounds. I have become more aware of what's going on around me without having to guess so much or asking others what the noise is. I hear my students coming in about 10 to 25 feet away by their rattling keys and squishing sneakers. Also, I can hear several of my colleagues laughing or sneezing in their offices with the door shut.

During one-to-one meetings, it's neat to hear the person's voice and how the sound fluctuates, especially the deaf oral people. I can follow their speech as typically they talk more slowly and enunciate more clearly than hearing people. It's so easy to practice listening while they talk. Sometimes, I look away and try to listen to hear how much I can pick up.

Q: Have you had speech therapy and auditory training?

Mary Karol: Both Scott and Kara have speech and audiology services three times a week at their school. I received speech and auditory exercises/training at the National Technical Institute for the Deaf where I work. I was fortunate to have several audiologists who are very knowledgeable about CIs.

Doug didn't get any speech/audiology sessions, but he was involved with experimenting and figuring out how to maximize his CI. I often bring home resources and ideas of what he could use for himself. We both plan to use several programs from the Internet to practice our listening skills. During our regular family activities we always question the kids about what they hear. This allows us to know if we do hear similar sounds, noises or any new sounds.

I know Kara and Scott are benefiting from the speech/auditory training, as it's a lifetime learning tool. Just two months ago, Scott mentioned to me while we were bike riding in the woods that he heard a helicopter. I didn't believe him, but after looking up and listening for about 15 to 20 seconds, I saw the helicopter flying over us. I was dumbfounded, and he gave me a mischievous look, saying, "I told you!"

Kara borrowed her cousin's cell phone recently to try to talk to her aunt. To our surprise, they had a successful conversation.

Their teachers have seen big changes in them. Once Kara was taking a test in class when she heard a boy whimpering in the hallway. She told the teacher about it. Her teacher was shocked that Kara could pick up that sound and even know that it was a boy.

Q: Are you able to enjoy music more?

Doug/Mary Karol: We can hear different sounds and recognize more than several instruments being played in the background. Kara has improved in playing the violin along with others and not falling behind or being off tune.

Local Deaf Community and Cochlear Implants

Q: How did getting a CI impact on your relations with the very large, strong "Deaf community" in Rochester?

Doug/Mary Karol: It's our decision regardless of how or what the Deaf community thinks or feels about it. Surprisingly, many have come forward, supporting us and admitting that they did think about having surgery but weren't sure if the Deaf community would support them. We were told that we have helped them to accept that it's okay to do what they feel is right. Others who aren't interested in getting CI have asked many questions to clear up the myths.

Q: Would you recommend a CI to deaf friends?

Doug/Mary Karol: We talk about how the CI benefits us. We tell them it's their decision, not ours, since so many factors must be discussed. We highly recommend consulting an audiologist. We mention that it's already proven that most people who lost their hearing at a later age do benefit from CI just like deaf babies who get CIs benefiting more than deaf adults who are implanted at a later age.

Support Group for Deaf CI Users

Q: Almost all the CI users I know either are late deafened or are oralists (they do not use ASL). Please comment on your support group for Deaf culture CI users. Why was it felt that such a group was needed? What progress has been made so far?

Mary Karol: More deaf adults like ourselves (who have been deaf since birth or become deaf at very young ages due to illness) have obtained cochlear implants. There wasn't a support group for those who rely on ASL or total communication with an interpreter available for others who do not know sign language and/or have vision loss.

Thirty-two people attended our first meeting in May 2005. Of them, 12 were CI users, and ten were in the process of getting a CI. Seven came to learn more about the benefits of cochlear implants.

There were 27 people at the second meeting. Half of them had attended the first gathering, but the other half was new. The new people were there to meet other CI users. They wanted to feel “belonging” and companionship with fellow CI Deaf adults. Four of those who attended both meetings have announced that they are scheduled for surgery.

Out-of-State Interest

We keep in touch with several people beyond New York who have asked for a support group like this and advice on how to establish one. They want to make it happen without creating any conflicts with the Deaf community. One woman from Nevada who saw our advertisement in Deaf Times shared her frustration with lack of support where she lives. Most implant wearers there are late deafened and do not use sign language. Interestingly, in her area, many insurers reject requests for reimbursement for CI surgeries for deaf children and adults.

I can see how hungry deaf CI users are for a group where signing is the preferred communication mode. We were told many times they wish for such a support and information group.

Q: Do you anticipate that sign language will remain the primary method of communication for your family?

Doug/Mary Karol: Yes, sign language will always be our primary method of communication, as it's our first language. We do use voices as well. Learning to listen is like anyone learning a new language.

Q: Is there anything you would like to add?

Doug/Mary Karol: We all are happy with our CIs and have no regrets.

Meet the Matchett Family

Happy cochlear implantees Douglas and Mary Karol Matchett and their children, Kara and Scott, live in a suburb of Rochester.

Doug is a full-time parent and has worked as a contractor with New York Relay Services and Sprint Relay. He officiates during swim meets, coordinates Deaf Boys of Rochester events for children aged six to twelve, and enjoys skiing, camping, kayaking, and traveling. He received a bachelor's degree in civil technology from Rochester Institute of Technology.

Mary Karol has been an academic advisor at National Technical Institute for the Deaf at Rochester Institute of Technology for more than 11 years. She has chaired the Mark Seven Deaf Foundation Board of Trustees and founded Deaf Girls of Rochester. Her hobbies are reading, cooking, tennis, golf, and traveling. She has a bachelor's degree in social work from Rochester Institute of Technology and a master's degree in social work from Syracuse University.

Both children are mainstreamed. Scott, a 13-year-old middle school student, was implanted at age 11. A competitive swimmer for three years, he also plays basketball, fishes, and collects balloons.

Sixth-grader Kara was implanted as a nine-year-old. She also swims. Her hobbies include reading, movies, and sports. She is now 11.

Janet McKenna is a member of the Rochester SHHH Chapter and lives in Grand Island, New York. Chapter members contributed the questions that Doug and Mary Karol answered and Janet McKenna edited and prepared the interview for publication.