

Child Born Deaf Competes in the National Spelling Bee

Neil Maes is the real deal—a child born deaf who was early identified, early implanted with cochlear implants, and part of a family that worked hard at providing him with what he needed to develop spoken language. In May 2016, 11 year old Neil traveled from his home in South Carolina to compete in the Scripps National Spelling Bee in Washington, D.C. Neil was identified with a hearing loss through newborn hearing screening, fit with hearing aids early, and received his first cochlear implant at 11 months of age. His family worked with an auditory verbal therapist and utilized a parent-centered therapy approach emphasizing talking, listening, and play. He has two younger sisters; one is also a cochlear implant recipient. ACI Alliance staff spoke with Neil's mother, Christy Maes, about their family's experience with early intervention and their cochlear implant journey.

ACIA: What were you told by early intervention specialists when Neil was first identified with a hearing loss?

CM: We were lucky to work with a number of early intervention specialists who provided us with a lot of information about the different options available for children with hearing loss. We received information on spoken language, sign language, hearing aids and cochlear implants. We were given literature to read including a helpful booklet from the Alexander Graham Bell Association.

ACIA: Were you told about cochlear implants and Neil's possible candidacy? Who first told you about cochlear implants?

CM: I had a friend, prior to having children, who had a cochlear implant so I was familiar with the technology. Additionally, I'm a nurse and I had some exposure during nursing school. Our early intervention specialist at the SC School for the Deaf and Blind, as well as the audiologist who diagnosed Neil, both brought up Neil's possible candidacy.



Above, Christy Maes with her son, Neil, on at the Gaylord National Hotel at National Harbor



Left: Peter, Neil and Christy Maes on the Scripps National Spelling Bee stage

ACIA: Were you told that early implantation leads to better outcomes?

CM: Yes. Charles, our early intervention specialist at the SC School for the Deaf and Blind, mentioned the importance of early implantation.

ACIA: Were you directed to your cochlear implant center, Medical University of South Carolina (MUSC)? If not, how did you find out about the center?

CM: Our home in South Carolina is between two cochlear implant centers. I was given information by Charles on both centers and did research on my own. I contacted audiologists at both centers and collected information that helped us make our decision.

ACIA: What guidance did you receive from your pediatrician regarding Neil's hearing loss?

CM: Neil's pediatrician wasn't a big part of our hearing journey. We saw him regularly for well-baby checks and other health issues but our audiologist, the early intervention specialists, and the CI center staff were the ones who we interacted with on Neil's hearing loss.

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ACIA: Did you have any negative experiences with professionals? If so, how did you handle the situation?

CM: We worked with so many great individuals and those are the ones you really remember. However, there was one negative visit from an early intervention specialist at the beginning of our journey. She only focused on the difficulties Neil would encounter with a spoken language approach, none of the positives. She even told me he wouldn't be able to say his own name—that it would be too difficult. After she left the house, I called the early intervention office and requested that they send someone else next time. I felt it was important to focus on the positives. Parents are the best and first advocates for their child.

ACIA: Was there any information you would you have liked to receive from early intervention specialists before getting to your cochlear implant center at (MUSC)?

CM: Not that I recall. We worked with a number of great early intervention specialists. I was emailing and calling MUSC before we even had our first appointment. I felt like we were well prepared for our first visit.

ACIA: Did Neil wear hearing aids prior to the cochlear implant? How old was he when he received them?

CM: Yes, Neil was fit with hearing aids at about 3 months of age. My understanding, as part of the CI candidacy, was that he needed to wear them for around 6 months to determine if he was receiving meaningful benefit from the hearing aids.

ACIA: When did you start parent-centered therapy? Before Neil received his cochlear implant did he have exposure to language?

CM: We were learning some sign language before we learned that Neil was definitely a candidate for CIs. Once we knew he was a candidate we switched to all auditory-verbal therapy. He was about 6 months old when we started working with an Auditory Verbal Therapist (AVT). We followed the advice from our AVT who advised: "No TV and minimize background noise. Lots of talking and reading." We began this program even before the cochlear implant. I did a lot of research. I was determined for him to have speech and language. Early interventionists came to the house. We did goal directed play.

ACIA: Is there anything you would like to share about the support you received from MUSC?

How do you think MUSC provided support? What particularly helped your family?

CM: They are just such a great team. The audiologists, speech language pathologist and surgeons all work together. It is obvious they care a lot about the child's outcome. They knew time was of the essence and worked hard to not lose a moment in moving Neil forward. We were lucky that both of our children were perfect candidates. We've spent a lot of time at MUSC and they feel like family. They get genuinely excited about our progress and success, like Neil's competing in the Spelling Bee.

ACIA: Your six-year old daughter also has a hearing loss and uses CIs. Was your experience with early intervention as positive with your daughter?

CM: The same support system was available to us when our daughter was diagnosed. However, we didn't utilize the early intervention system as much because we already had therapists in place. We jumped right in with MUSC. My daughter had her first visit at two weeks of age with the surgeon who performed Neil's surgery. She is a pistol and picked up speech and language quickly. Both of them have done well, but hear differently with their CIs. All children learn differently.

ACIA: If you had one piece of advice for the early intervention system, what would it be? What is the most important thing that early intervention can do to help a child along this path?

CM: Don't assume that anybody knows anything. Offer as much information as possible and accommodate different learning styles. Some people need verbal while other people like written information. I tend to like written as I can go back and re-read and really process what I've been given. AG Bell is a great resource. Inform families of their options. Educate, educate, educate! Allow families to make a decision on what is best for their family. Many families find the diagnosis of hearing loss overwhelming and are in denial. They need help with their feelings that this is a negative diagnosis. Still, families need to know that time is of the essence.



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