



Michael, after surgery, with his dad.

January 1997

Growing up Cochlear

BY KEVIN WILLMANN

“

I've spoken to many families and I try to help them understand that there's a success story out there," Michael says. "That if parents are willing to do the work that is necessary, their child can live a complete life in the hearing world."

By all appearances, Michael Lefkowitz of Miami, FL, is a normal 12 (going on 13)-year-old boy.

He's an honor student who excels at academics and plays multiple sports including football, golf, tennis, and basketball. His favorite subjects are history and language. In addition to reading and chanting Hebrew, he also studies Latin and Spanish. He recently won three awards in a Latin competition, where his school was the sole middle school participant competing against high school students. In May, he celebrated his bar mitzvah, the coming-of-age milestone in which a young man in the Jewish faith takes on the responsibilities of an adult.

Yet Michael hears with the aid of a cochlear implant, which he received at 17 months old, after being diagnosed as deaf when he was just over three months. (Since the age of 10, he has also worn a hearing aid on his other ear.)

"He functions like a hearing child," says his mother, Sherilyn. "Each year when we meet with his teachers, it's a dilemma for us about how to approach Michael's hearing loss with them.

We want their expectations for him to be the same as for a hearing student and yet we don't want them to forget that he's not. After all, it's much more demanding for him to do what we, as typically hearing people, do."

At the time Michael was born in Miami in 1995, there was no such thing as mandatory newborn hearing screening, which could have immediately alerted Michael's parents to his deafness. Although Michael has two older cousins who are profoundly deaf, Sherilyn says that no one suggested that Michael's hearing should be tested at birth.

"The family had been told, 'Don't worry about it, their hearing loss is not genetic,' which is ludicrous," she says.

Newborn hearing screening did not become mandatory in the State of Florida until a bill requiring it was signed into law by then-Governor Jeb Bush in 2000. Before that time, most children were not diagnosed with hearing loss until around age two. Michael's family was active in lobbying for mandatory newborn screening. However, Sherilyn says, even though we now have newborn identification, there is still much more that needs to be done.

"The newborn screening gives parents a diagnosis, but now the problem is that there is no consistent follow-up, support, or appropriate referral," she says. "Pediatricians need to be notified immediately and be willing to work alongside audiologists on an ongoing basis to manage the hearing loss. Deafness is not an uncommon diagnosis. Unfortunately, there's no central location where people can be helped to understand all of the available and wide-ranging options for intervention with hearing loss. Ninety-five percent of deaf babies are born to hearing parents. Most of these new parents have no idea what to do with a deaf infant. We were unusual in that regard since we had already had a history of hearing loss in the family."

Michael's hearing loss was discovered on a Tuesday evening after he had just turned three months old. Sherilyn and her husband, Robert, noticed that Michael was not orienting to the sounds that they made. Concerned, they made a call at 11:00 pm that night to a friend who ran an early-intervention program. They were told to bring him in the next day to see an audiologist. By 9:30 am the next morning, they received the diagnosis that Michael had severe to profound bilateral sensorineural deafness. They were then told to call the next day to make an appointment to have him fitted for hearing aids. But for Sherilyn, time was of the essence.

"As a psychologist, I knew that every day mattered, so waiting to first schedule an appointment didn't work for me," Sherilyn said. "We insisted on coming back the next morning and immediately had him fitted for hearing aids." That same urgency in getting Michael fitted for the hearing aids also applied to receiving them once they were ordered. While they

were originally told that it would take three weeks to receive them, through parental persistence, Michael received his hearing aids in one.

Immediately upon receiving his diagnosis, Michael's parents began investigating the best ways to help him. In addition to the experience of having two deaf nephews, Sherilyn had previously worked with deaf children as part of her undergraduate work, so she was aware of the wide variety of options that existed for Michael. Through their research, Robert and Sherilyn learned of auditory verbal therapy (AVT), a type of therapy where children learned to listen and speak using their auditory capabilities. At that time, no one in Miami offered such a treatment. The nearest place that did was the Bolesta Center in Tampa.

Sherilyn contacted Ellen Rhoades from the Bolesta Center and had a 20-minute telephone conversation with her about AVT. Then, at the end of their conversation, Sherilyn learned that Rhoades herself was profoundly deaf.

"Immediately, I said to my husband, 'I don't know how this woman accomplished this, but this is what we need to do for our son,'" Sherilyn said.

They arranged for the Bolesta Center to fly a therapist from Tampa to the University of Miami on a weekly basis to work with Michael (and the other families from the surrounding counties who were interested in AVT for their deaf children).

Although the combination of AVT and hearing aids helped Michael achieve receptive and expressive language development equivalent to his chronological age, he required

more amplification as he grew. By the time he was 14 months old, Michael needed more powerful hearing aids, yet their increased power made him dizzy. Sherilyn and Robert learned that Michael was suffering from Tullio's phenomenon, in which the sound from the new hearing aids affected his vestibular system, impairing his balance. It was at that time that audiologists at the University of Miami made the recommendation that Michael receive a cochlear implant. It was explained that the implant would bypass the vestibular effects associated with wearing higher-powered hearing aids.

Jerry Schloffman, now a vice president of marketing at Advanced Bionics, was one of three staff audiologists at the University of Miami working with cochlear implants and he first met Michael when Michael was about four or five months old. Schloffman initially worked with Michael to confirm that his hearing aids were fitted correctly and then to regularly measure his progress using them. Schloffman was also the one who initially made the recommendation that Michael receive a cochlear implant, after concerns about the Tullio's phenomenon were identified.

"I remember thinking she (Sherilyn) was going to be upset that I might suggest we have to do a cochlear implant. Instead she responded, 'I knew you were going to say that,'" Schloffman recalled.

While Schloffman made the initial recommendation to Michael's parents, he explained that it had been a team decision among those in the University of Miami Cochlear Implant program to recommend that Michael receive an implant.

Dr. Thomas J. Balkany, the surgeon who performed Michael's surgery, performed his first implant in 1979 and has now implanted over 1,000 devices. Dr. Balkany has also worked with Michael since he was around four months old. He explained that, although Michael had made progress with speech and language utilizing hearing aids, it was not the type of progress that would lead to being successful as an aural person. Balkany was also involved in discussions with Michael's parents about the process of receiving a cochlear implant.

"If there is some residual hearing, we go through a trial of hearing aids and auditory verbal therapy. We try to evaluate how a child is progressing, and we compare that with how the child would do with a cochlear implant," Balkany said, adding that the final decision about whether or not to implant is left to the parents.

Sherilyn and her family had attended a cochlear implant conference before they thought that Michael would be an implant candidate in order to educate themselves about the device. Now that a cochlear implant was being recommended, they made the life-altering decision to have the surgery done. However, there were obstacles to overcome. Other treatment professionals who worked with



Michael were opposed to him receiving the implant. They felt he was progressing at an age-appropriate level using the combination of hearing aids and therapy. Schloffman recalled receiving a letter from one of Michael’s therapist, stating, “don’t implant.”

“It was a tumultuous decision, because at the time, if you were doing as well as Michael was with hearing aids, it wasn’t standard to do a cochlear implant,” Schloffman recalled. “Over time, our expectations with cochlear implant patients have gone up, but back then, it was a hard decision. Anytime you go against FDA guidelines and conventional wisdom, you wring your hands because the first rule of medicine is to do no harm. But we knew it was the right thing for Michael because of the experience we had with him.”

The warnings from treatment people not to get an implant were not the only opposition Sherilyn and Robert faced when pursuing the cochlear implant surgery for their son. Their insurance company denied the request to cover Michael’s cochlear implant, claiming that (at that time) the FDA-approved minimum age for children to receive the implant was two years. Sherilyn reported that they fought the insurance company “tooth and nail,” adding that, once again, there were significant neurodevelopmental consequences of waiting to have the procedure done.

Finally, the insurance company gave their approval and Dr. Balkany performed the surgery in January 1997, when



*Michael visits with Jerry Schloffman during one of his Miami visits.
2005*

Michael was 17 months old. One month later, on February 10, Schloffman and his team turned on the implant. Dr. Balkany explained that the one-month gap between installation and turn on of the implant was to allow the swelling from the operation to heal. Today, he says, patients only have to wait about two weeks from the time of

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47

implant until the initial stimulation. Balkany also reports that, currently, the target age for children to receive cochlear implants is nine months.

“It’s a balance between a child being big and strong enough to undergo surgery, the desire to provide hearing as early as possible to enhance language development, and the need to be absolutely certain that the child requires a cochlear implant,” Balkany said.

Michael’s implant regularly requires reprogramming by the University of Miami Cochlear Implant staff. “We follow these children very closely for the rest of their lives,” Balkany said. As they develop and experience different amounts and types of auditory challenges, “slight adjustments help the patient hear better.”

After receiving his cochlear implant, Michael continued to meet with the AV therapist, Tina LeVasseur, once a week until his third birthday, when he transitioned to every other week. One week before his fourth birthday, Michael officially graduated from AV therapy.

The impact on Michael’s life from the implant and AV therapy has been phenomenal. At 2½ years old, Michael was speaking in complex sentences of up to 12 to 14 words. He could understand speech in noisy environments like restaurants and airplanes without the aid of visual cues. Sherilyn said he was never in any special education classes; he was always integrated in classrooms with hearing children. Today, Michael reads at a college level and can converse easily over the phone, though he admits that he and his friends do text-messaging most of the time. Though he knows others who have cochlear implants, Michael says they are mostly acquaintances and that most of his friends hear normally.

“When I first meet people, I don’t necessarily tell them (about the cochlear implant), only if they need to know. When I do tell them, they’re like, ‘Oh wow!’” Michael said.

Michael says that he doesn’t have many limitations with his cochlear implant. As a young child, his main restriction was plastic slides, as the static from them could affect his implant. Today, he just has to take his implant off to participate in water activities. Other than that, he says he hasn’t yet experienced any real disability due to having a cochlear implant.

“Every night, I put it in a dry and store kit and every three to four days, I have to change the batteries,” he said. He looks forward to having his device retrofitted with a processor that is water resistant.

Both Michael and Sherilyn actively help other families who face the decision of getting a cochlear implant for their child. They understand the importance of early identification, appropriate amplification, and aggressive therapeutic intervention. They are strong supporters of AVT and work as volunteer advocates for Cochlear Corporation, the company that developed Michael’s device. They regularly address groups of medical, educational, and treatment professionals. It is their way of giving back to the community in gratitude



Michael with his AV therapist, Tina LeVasseur, on the day of his graduation from therapy. July 1999



Michael plays flute at his middle school’s winter concert. December 2006

for Michael’s ability to hear. Dr. Balkany noted that Michael spoke at a UM cochlear implant family picnic last year, saying he was “articulate and inspiring.”

Michael really enjoys meeting the children and speaking with their parents about what his life is like with a cochlear implant. Sherilyn noted that she and Michael have recently been involved with one family as the parents decided to get a cochlear implant for their infant daughter. “I can spend hours on the telephone trying to reassure parents, but I can put Michael on for two minutes and there’s no comparison,” Sherilyn says. “It really helps to give them a vision for their own child’s future.”

“I’ve spoken to many families and I try to help them understand that there’s a success story out there,” Michael says. “That if parents are willing to do the work that is necessary, their child can live a complete life in the hearing world.”

As part of becoming a bar mitzvah, Michael learned to read and chant Hebrew. His Torah portion had to do with our responsibility to protect the earth and to take care of one another. For his mitzvah project, completed as part of his bar mitzvah preparation, Michael and his family produced a homemade DVD titled “Growing up Cochlear,” detailing Michael’s experience. The DVD is used by the University of Miami when working with families considering an implant for their child.

“The main topic of my Torah portion was giving back to the earth and the community, the message being any way in which you give back makes the world better,” Michael said. As one example of how to preserve resources, Michael addressed the preservation of hearing by preventing noise-induced hearing loss. At the celebration following his religious service, Michael’s family requested that the DJ play the music at a lower volume, and they distributed earplugs to all those in attendance. Each guest received a black velvet pouch containing earplugs along with a note that read, “Hearing is a precious gift. Preserve yours!”

To further illustrate the message of hearing preservation, the Academy’s rap song, “Turn It To the Left” by Ben Jackson, was played at the reception (available at www.audiology.org). For Michael, who once played flute in his middle school band, the message of hearing preservation tied to music was very important. “I think it was pretty cool to incorporate information about hearing into a song,” Michael says. “Music is one of the things I enjoy in my life. To have a song about preserving hearing is great; it’s a catchy tune and I think it works.”

On the occasion of his becoming a bar mitzvah, many of the people who helped Michael with his “journey to hearing” were invited to share that special day with him and his family.

“It was an absolute honor to attend Michael’s bar mitzvah with my wife, to watch a child you’ve known as deaf





Michael, warming up at the range, before a round of golf.
July 2007



Michael, with his parents, Robert and Sherilyn.
April 2008

from 4 or 5 months old and to see him speak and translate Hebrew and English was truly spine-tingling,” Jerry Schloffman said. “Someday he’s going to graduate from college and I’m going to be just as proud. He is a leader amongst his peers, a popular kid, everyone looks to him, everyone wants to be around him.”

Most importantly, as Schloffman points out, the key to Michael’s success is a reflection of the perseverance and high expectations of his parents.

“It’s evidence that anything is possible. The expectations that Sherilyn and Robert had for Michael are expectations we should have for any child with hearing loss. Michael is a model, a best-case scenario of what we should hope for with every child. This success is why many of us got into the field of cochlear implants. Because this child received the necessary technology and therapeutic intervention, he was able to achieve things no one thought were possible.”

Dr. Balkany describes Michael “as an exceptional young man. He started out with a condition that, if not recognized and treated properly in a timely way, would have placed him at a tremendous disadvantage throughout his childhood and his life. But through his own natural abilities and the perseverance of his family, he was able to obtain treatment for his hearing loss and developed into an extremely bright, outgoing, and happy young man.”

As important as the sense of hearing is to people who hear normally, Michael says, it is as much, if not more, of a gift for those who have received a cochlear implant.

“If you do have an implant, you should cherish it and be grateful you can hear,” he says. **AT**

ABOUT THE AUTHOR

KEVIN WILLMANN is the editorial assistant for *Audiology Today*.



To view Michael’s DVD, “Growing up Cochlear,” visit www.audiology.org and click on Publications, then *Audiology Today*.