

## Hear to Here

By Gabrielle Johnston, MPH | December 21, 2017

**A**round the end of 2009, Kristine Siwek began noticing she was unconsciously switching her cell phone from the left ear to the right. At age 29, she was in good health and pregnant. She thought the problem was likely her phone and service, but soon realized, "I was actually having a difficult time hearing."

Having worked in medical device sales, and given her age and seeming good health, Siwek recognized that this was not a symptom to be ignored and made an appointment with an ear, nose and throat (ENT) doctor. After a routine hearing exam, the ENT informed her that she was experiencing approximately two percent hearing loss in her left ear. To investigate further, an MRI with contrast dye would be needed. Contrast dye is not safe during pregnancy so further testing was postponed until she delivered her baby.



For the next few months, Siwek attempted to treat her symptoms with over-the-

counter medicines to relieve head congestion. Nonetheless, she still had a hard time hearing in

her left ear. She mentioned the problem to a general surgeon she routinely worked with, and he asked about her symptoms.

“I told him I thought I still must have had a cold because nothing had really changed. Then he put his hand on my arm and said, ‘Your eyes are not blinking at the same time and your left eye is bulging open,’” said Siwek. “It was a like a light bulb went on in my head, and I knew that something was truly wrong.”

She called her ENT and requested a non-contrast MRI, which happened in March 2010. “I was 29 weeks pregnant at the time, and not expecting to find anything life-changing,” said Siwek.

With a CD-ROM of her completed scan in hand, she raced back to her ENT’s office. Within seconds of loading the images, Siwek and her ENT spotted a giant mass inside her brain.

“He didn’t even have to say anything to me. I looked at it and time stood still — it was a mind-out-of-body experience,” said Siwek.

Her doctor handed her a piece of paper that said: acoustic neuroma; and sent her home.

“I didn’t have my husband or anyone with me when I received the news, and went home Friday night with the piece of paper. I didn’t have any further information or anyone to connect with. I felt completely isolated,” said Siwek.

Acoustic neuromas constitute 6 to 10 percent of all brain tumors. They are typically non-cancerous and do not metastasize or spread to other parts of the body. However, as they grow, they can push on parts of the brain, impacting functions that can become life-threatening. Among the primary symptoms are disrupted balance and hearing, such as tinnitus or ringing in the ears, and one-sided hearing loss, which Siwek had experienced.

Siwek immediately began researching doctors around the nation and treatment options.

“With a rare diagnosis like acoustic neuroma, I had a lot of questions, primarily if it would be safe to continue with my pregnancy, so I sent my scans to a number of providers throughout the Midwest,” said Siwek.

Finally, after weeks of searching, Siwek connected with [Rick Friedman, MD, PhD](#), neurotologist (an expert who studies neurological disorders in the ear) with UC San Diego Health, who called her at 7 a.m. on a brisk spring morning in Wisconsin.

“The first thing he said to me was ‘congratulations on your pregnancy,’ which meant the world to me because he saw me as a human being,” said Siwek.

After a long phone call that answered many of her questions, Friedman and Siwek had a health maintenance plan in place. He would follow up with daily calls to check in.

“Kristine’s case is a severe example of an acoustic neuroma, but also a great example of how cases like hers are best managed by an experienced team,” said Friedman.

Unfortunately, Siwek was not able to carry her pregnancy to full term because her acoustic neuroma became life-threatening. Her neurological symptoms worsened to where she couldn’t walk unassisted.

At 34 weeks pregnant, Siwek flew to California to meet Friedman and [Marc Schwartz, MD](#), neurosurgeon, at UC San Diego Health.

She delivered a healthy boy named Parker just days after her arrival, and two weeks after that, Siwek underwent surgery to remove her brain tumor.

Although Siwek’s tumor was very large, Friedman and Schwartz resected 99.9 percent of her tumor, allowing for total preservation of her facial nerve. With essentially all of the tumor removed, Siwek has not had to have any additional surgeries or radiation treatments that are sometimes needed.

“Dr. Schwartz and I were not only able to save Kristine’s life, but her baby’s as well, making it even more rewarding,” said Friedman.

UC San Diego Health’s [acoustic neuroma program](#) is one of the most comprehensive in the nation and manages the highest volume of acoustic neuroma patients in the country. The program is designed to optimize care for 85 percent of patients who live more than two hours from the clinic. When a patient is deemed a candidate for treatment, the doctors provide a wide array of surgical approaches that yield a higher-than-average success rate for hearing preservation — a primary concern for many acoustic neuroma patients.

“Patients benefit from a team with unsurpassed expertise and experience,” said [Jeffrey Harris, MD, PhD](#), chief of otolaryngology, a specialty in ENT and related structures of the head and neck. “Both Dr. Schwartz and Dr. Friedman have high hearing preservation and low complication rates — the best in the country. Together, they have helped thousands of patients with these difficult tumors.”

Given the severity of Siwek’s case, which was atypical, recovery was not easy. Beyond learning to be a new mother, she had to adjust to deafness in one ear, and because removal of the acoustic neuroma also impacted her sense of balance, she needed to retrain her eyes and brain to compensate.

“To this day, every picture I look at, it’s like my life is broken up into two parts — before surgery and after surgery. I had to learn a new normal and a new me,” said Siwek.

“Recovery for every patient is different, but we do our best to educate patients on what to expect post-operatively. This helps reduce the fear and anxiety that is often associated with surgery,” said

Friedman.

A year into her recovery, Siwek attended a patient symposium meeting for the



Acoustic Neuroma Association (ANA). Instantly she felt a connection with others who had suffered and recovered from the condition. She discovered a drive to help future patients. Siwek joined the ANA board of directors and became an active, vocal patient advocate.

It was through her role with the ANA that Siwek reconnected with Friedman, who asked her to speak publicly about her experience. That opportunity grew into Siwek working with Friedman to accomplish his vision of a more patient focused program.

“I wanted to create a new model of comprehensive care and a multi-disciplinary approach that involved long-term connections with our patients,” said Friedman.

Eventually, Siwek moved her family across the county to start working on Friedman’s team full time as a patient navigator, assisting with user friendly web site updates, guiding patients from diagnosis to recovery and leading support groups.

“Since this disease typically affects young, healthy adults in the prime of their lives, we strive to provide empathy throughout the entire treatment process,” explained Friedman.

“Our patients become like family to us. I call Drs. Friedman and Schwartz ‘The Dream Team,’ not only because they saved my life, but because together we make up a support structure so no patient with this rare diagnosis feels the way I did when I was diagnosed,” said Siwek.

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