

The **INDOMITA**

Molly Brown

Molly with daughter, Melissa.



BLE

Excruciating tooth pain and facial twinges brought Molly to her knees in the summer of 2003. When her dentist was unable to determine the source of her pain, he sent her to a neurologist. Molly was diagnosed with a tumor pressing on her facial nerve producing trigeminal neuralgia, an electrifying and agonizing ailment.

Molly was no stranger to medical adversity. In 1984, Charles Mangham, M.D., removed a large acoustic tumor (vestibular schwannoma) from her left hearing nerve, leaving her deaf in that ear. Over the next few years, the hearing in the right ear fluctuated and Molly was frightened to lose what little hearing she had left. One day she awoke to complete silence. She could not hear her infant son crying in the next room and assumed he'd slept through the night. Soon she realized the truth – her hearing was gone.

A small tumor on the right hearing nerve was the cause of the profound hearing loss. The tumor was removed, and with it, Molly's residual hearing. Molly became progressively more distressed and isolated. She felt inadequate as a caretaker for her three children, because without hearing, she felt she could not keep them safe.

Living in total silence changed Molly's life. Previously an active member of a small community in Washington State, Molly withdrew. She suddenly felt alone in a room

"I didn't feel this decision was just for me at all, but for everyone who would come after me, and possibly, my children..." said Molly.

of 100 people. She would see people laugh and wonder what was funny. She became uncomfortable running errands that involved interacting with others. Such

interactions left her feeling frustrated and defeated, and she became a recluse. Her children Jenny, Melissa, and Michael and her supportive husband, Allen, remained the center of her universe. In her darkest moments, they uplifted her spirits and were understanding of her loneliness and despair. Though she tried learning American Sign Language (ASL), she found this challenging and frustrating – and she missed sound.

Finally, Molly's mother suggested she consider getting a cochlear implant. In 1987, Molly received a cochlear implant, which brought her back to a world of sound. Although the implant did not always provide full benefit,



Molly works with audiologist, Steve Otto, M.A., to program her PABI.

it served her well until that summer of 2003 when she experienced the tremendous pain of trigeminal neuralgia and the possibility of another surgery.

The most frightening aspect of treating the trigeminal neuralgia, was not the excruciating pain or imminent surgery, but the fact that Molly was required to get an MRI. For an MRI, Molly's cochlear implant needed to be removed. The MRI would help the physician confirm his suspicion that her problems stemmed from a rare genetic disease called Neurofibromatosis Type II (NF2), characterized by tumors growing on both vestibular nerves that adversely affect the auditory and facial nerves. She prepared herself to face her worst fear – being returned to the lonely world of silence. Just before the implant was removed, she asked her children to tell her they loved her. Then her audiologist tearfully told Molly that it was time, and that was the last familiar voice she heard.

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Knowing how much hearing meant to Molly, Dr. Backous, her primary physician of many years, suggested she visit the renowned House Clinic in Los Angeles and discuss the tumor removal and possible options for restoring her hearing. She met with House Clinic neurotologist Derald Brackmann, M.D., who confirmed the diagnosis of neurofibromatosis type II (NF2). Both Dr. Brackmann and Steve Otto, M.A., audiologist at the House Ear Institute, outlined a possible plan for Molly. In spite of the necessary obliteration of her hearing nerves to remove the NF2 tumors, she could receive an auditory brainstem implant (ABI) that would function much like her previous cochlear implant had, but with reduced sound quality. The ABI differs from the cochlear implant in that the electrodes of the ABI bypass the

trials to further the development of devices for people with NF2, becoming the second patient in the world to receive the PABI. Perhaps her situation could eventually help others. "I didn't feel this decision was just for me at all, but for everyone who would come after me, and possibly, my children," said Molly.

With no guarantees that she would ever hear again, her surgery was scheduled for November, with the plan to return for the initial "stimulation of sound" in January 2004. Molly was tense with anticipation when Steve hooked up her PABI for the first time. He slowly raised the volume on the first electrode and there it was, a soft, beep, beep, beep. With a lump in her throat, Molly cried with joy and gave everyone on the implant team a hug. After Steve set the levels of the various electrodes using the

tones, he spoke to her, "Tell me, how does my voice sound?" "It sounds beautiful!" Molly answered. At first, she said voices sounded much like Donald Duck, but over time and with practice, voices sounded much more like she'd remembered. "Hearing the voices of my children has been the best thing I could have hoped for. I'm back!" ❖



Children Michael, Jenny and Melissa with Molly

cochlea and directly stimulate the brainstem. Because of Molly's strong passion to communicate in the hearing world, both Dr. Brackmann and Steve Otto felt she was a good candidate for a new investigational brainstem implant. This newer device, the penetrating electrode auditory brainstem implant (PABI) held the potential for some additional fine-tuning of sound and better speech discrimination.

Molly and her family considered the recommendations of Dr. Brackmann and his colleagues, and placed their confidence in the House team. Molly chose to participate in the PABI clinical

Molly returned to her home in Washington and continues the rehabilitation process of learning to use her PABI, reconnecting to new sounds every day. The excitement of recognizing everyday sounds like the familiar tick of a clock is thrilling. She can distinguish between a man or woman's voice and bravely attempts to use the telephone. When she makes a call, she says, "This is Molly. Please don't cry." No one remembers Molly ever using the phone. Although the phone is still a challenge for her, she is determined to continue learning each day. "After receiving the PABI, Mom became alive again," says Melissa when evaluating her mother's progress.

In looking toward the future with her PABI and learning to live with NF2, the indomitable Molly Brown says she will, "Never, never give up. I am the lucky one. I feel a debt of gratitude to so many ... it almost makes my heart hurt to be so happy."