

NF2



Dan Knodel was a typical, energetic teenager who loved skateboarding, visiting with friends and listening to 70's era music. He was a Boy Scout and did volunteer work on fundraising drives. Dan spent most of his free time attending parties and concerts.


LIVING WITH NF2

He had no hearing problem until one day when he was 16, he noticed that he could hear better on the phone with one ear than the other. A quick visit to the doctor resulted in an MRI, which revealed a large acoustic neuroma (tumor) pressing on the auditory nerve in his right ear. The neurologist reading the MRI referred Dan to the House Clinic and Dr. Derald Brackmann.

His diagnosis was Neurofibromatosis Type II (NF2), a genetic disease of the nervous system characterized by non-malignant, fibroid tumors growing on both vestibular nerves. Although NF2 typically runs in families, Dan's parents and three siblings all have tested negative for the disease. Doctors Brackmann and William Hitselberger removed the acoustic neuroma. As frequently happens, removal of the tumor necessitated severing the auditory nerve, resulting in the loss of hearing in Dan's right ear. He received an auditory brainstem implant (ABI), but he experienced some non-auditory sensations, and the quality of sound it produced was not what he had hoped so it was seldom used.

Despite the presence of a small acoustic neuroma growing in his left ear, hearing in that ear remained good throughout high school, and Dan was able to participate in most school activities. He took classes in American Sign Language in preparation for a future that he knew would include deafness. "I had no other choice than to wait to become deaf and enjoy the hearing I had left during that time," Dan said. Once each year from age 16 to 22, he needed surgery to remove additional tumors, mostly along his spine. By then the acoustic neuroma in Dan's left ear had diminished his hearing completely and was removed. At that point Dan became totally deaf. In the hope that an improved ABI might net a better result, Dan decided to try a second implant. "I didn't want to neglect any opportunity to be able to hear again," he said.

The results this time were only marginally better than the first. Dan felt that the dizziness and buzzing eye sensations he experienced outweighed any of the hearing benefit to be gained. "I've been told that these side-effects could subside if I used the ABI more, but I would rather not hear at all. Most of the people I know who use the ABI rely on it as a tool to supplement lip-reading more than as a hearing device," he notes.



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“It’s a matter of public perception as well,” Dan indicated. “When people who are unfamiliar with the ABI see what looks like a hearing device on your ear, they think that you can hear them. For me, sign language is a more effective communication tool for in-person conversations. Sign language also provides a source of culture that connects me with other people who have a world view similar to my own. It’s fun to use too, and people don’t misunderstand me when they see me signing,” he continued.

“I’m very grateful to Dr. Brackmann. He is one of the most compassionate men I know. Even after I myself no longer wanted to hear with the options available to me, Dr. Brackmann never gave up hope. He does everything in his power to bring hearing to every person he encounters and he has saved many lives. I would not be here if it were not for him and the many other doctors and

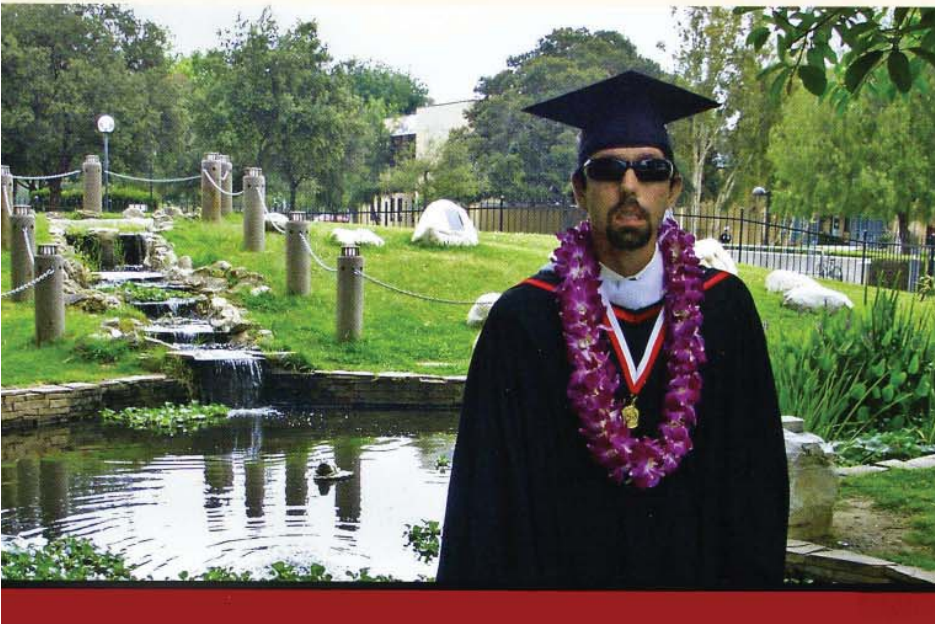
scientists at HEI who have helped me in my struggles with NF2. I would like to take this opportunity to thank them all for a job well done,” Dan said.

Despite his health concerns, Dan persevered in school achieving high marks and honors. “During the last semester of my associate’s degree I became deaf while still completing my classes. It was very hard for me to tell my professors that I could no longer hear their lectures as I did when the semester began,” Dan stated. “My counselor set me up with a captionist – an interpreter who types out what is being said, similar to a court reporter. I received copies of the transcripts to review at home. It was time-consuming to read all that was said during lectures. This took up much of my personal time, but

enabled me to take excellent notes,” he continued. Dan got straight A’s that semester and transferred to the University of Southern California (USC).

He continued to work with captionists while earning his bachelor’s degree at USC and a master of arts in clinical psychology at California State University, Northridge (CSUN). “I also used a voice-synthesizer on my laptop computer to give lectures and present reports. The voice-synthesizer would read aloud statements that I typed before class. Socially, I communicated with sign language,” Dan stated.

Some of his educational experiences turned Dan into an activist for deaf students. At one institution he was initially told that sign language was “not acceptable” on campus. He protested and the situation was rectified. Now, thanks in large part to Dan, American Sign Language is accepted as a second language there. For a time at CSUN, under the supervision of a Ph.D., he interned as a counselor in psychotherapy working with deaf students. Dan established a much appreciated deaf counseling program while there, and is considering pursuing



“I carry a pen and paper everywhere I go. I need to write out my order whenever I go to a store or restaurant.”



Dan and Dr. Brackmann

a Ph.D. in the future. “Overall, I think my education is what saved me in a terrifying situation. I agree with Socrates who said, ‘Learning is an ornament in prosperity, a refuge in adversity.’”

Dan acknowledges that deafness has impacted his life socially. “I’m much more reclusive than most people. I think I would be married by now if I could still hear well. Also I miss music very much, Bob Marley most of all. Sometimes I think that if I could hear for just one more day I would spend every second listening to him... although I might take a few minutes to hear the USC song, which I never heard, but watched the band play at all of our football games,” Dan stated.

Continuing to treat the tumors associated with NF2, Dan has undergone other less invasive surgeries and has tried radiation. He will soon begin

treatment with a new medication and remains hopeful that studies in the newly established Center for Neural Tumor Research at House Ear Institute will make possible the therapeutic suppression of NF2 tumors one day soon.

Adapting to the many challenges he has faced, Dan comments, “I have encountered more obstacles than most people do by my age. And while I haven’t so much overcome them as accepted them... in the process I’ve empowered myself. There comes a point when we stop grasping to overcome obstacles and trust that the universe is unfolding as it should.” ❖

*You can visit Dan’s website at
<http://www.myspace.com/danielknodel>*

“Many beautiful sounds exist that I miss, like the sounds of the beach, the sounds of laughing, ... my friends’ voices whom I’ve never heard, rain and storms, ...flowing water, sounds of things that have come into this world since I haven’t been able to hear.”