

COPING WITH NF2

Mark Pyeatt Tells His Story



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During the summer before high school, when I was fourteen, I was diagnosed with neurofibromatosis type II (NF2). I first became aware of the problem one morning when my brother could not wake me up. I was taken by ambulance to the local hospital, where CT scans indicated a need for further tests. I went to Texas Children’s Hospital in Houston and there an MRI revealed that I had numerous tumors, on my brain and spine, a signature of NF2.

At the time, the only emotion I felt was anger. Doctors told me that I could not play football in high school. I had played the two previous seasons and I was really looking forward to playing for the high school team. I had no clue what lay ahead of me or what this “NF2” was. I was just angry and unable to



understand what was going on.

add that since the loss of my hearing, I have tried to become more realistic about my career choices. I believe that if I still had my hearing I probably would be studying to become a doctor or lawyer. Now I’m just trying to keep everything in perspective and look forward to a career that can be rewarding and challenging despite my hearing loss.

My family and friends have been a tremendous support system throughout my entire ordeal. My family was there during each of my surgeries and trips to the hospital. I could not have done this without my mom and dad. They were there for me every step of the way. I have an immediate family of eleven people and everyone is trying really hard to learn and incorporate sign language into our family. Currently we are all taking American Sign Language (ASL) classes at the local high school. It is tough to pick up ASL as it is an entirely different language than English.

I’ve had NF2 for five years now. After three major surgeries and the loss of hearing in my left ear, surgery is pending to remove a tumor from my right ear and is expected to result in total deafness. We are hoping that I might be able to finish college before the need for this surgery becomes urgent. In addition, I’m experiencing bouts of tinnitus that drown out the little hearing I have left. I’m only just now beginning to cope and look objectively at NF2 and how it has impacted my life.

In general, plans for my future have not changed at all. I grew up in a family where I was expected to attend and graduate from college. I’m a sophomore this year and look forward to transferring from community college to a university in the fall. I must

Most of my friends have moved away to go to college, so I don’t see them very often anymore. But I work with and see many people on a daily basis. I’ve worked at a municipal golf course for two and a half years, so when I started there I was completely able to hear and have been able to adapt gradually. My co-workers and my boss have had to adapt along with me as I became deaf, and they have been very supportive. I’ve learned to read lips and many people help me by writing things down and going out of their way to communicate. I look forward to working there until I leave for school.

Since starting to work at the golf course, I have come to love the game and have learned to play during time off. I’ve gone from a 36 handicap to a 16. Some of the first ASL signs I learned are golf-related. I think the peace and

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tranquility in the game has helped me as I lost my hearing. But when I make a bad shot, there really isn't that much "peace and tranquility!"

Looking back five years to my first surgery, I now see that day as an important detail in shaping who I am, but NF2 does not define who I am, it's only a small part of me. ❖

“My interest in politics and the economy stems from my grandfather, Ron Paul, and his political message of freedom, liberty, sound money, anti-war and a smaller federal government. But I separate my grandfather from my congressman. I love his message and agree with every word because it makes sense to me

and because it is rooted in the United States Constitution. I voted for my grandfather not because of his kinship to me but because of his message and his promise to uphold the Constitution with every vote he makes in the House of Representatives.”

Mark's mother Lori is proud of the way Mark is handling having NF2 and says that she receives her strength to deal with it from Mark. She remarks on the shock of the diagnosis: "It just struck us out of the blue. No one else in the family has had NF2."

Despite his health and hearing problems, Mark is a normal 19-year-old. One thing he misses is being able to use the drive-thru at fast food restaurants. At school his teachers use a voice recognition

system that translates their speech into words on the computer screen for him to read. The family uses email to communicate a lot more now. Instead of calling, they send Mark emails and he responds on his Blackberry. She adds that Mark is currently enjoying temporary hearing improvement through a recently acquired hearing aid, which is allowing him to communicate more easily.

Lori says that Mark is very passionate about politics. "He's



interested in the economy and pays close attention to what is happening in government. He traveled with his grandfather, Ron Paul, during the campaign of 2008 and attended the presidential debates."

NF2 EXPLAINED

Neurofibromatosis type II (NF2) is a genetic disease of the nervous system characterized by bilateral, non-cancerous, fibrous tumors (also referred to as vestibular schwannomas or acoustic neuromas) that grow on the vestibular nerves. Growth of these tumors results in pressure on auditory and facial nerves that causes hearing loss and facial paralysis. Untreated, these tumors can result in loss of hearing and balance, and ultimately death. Because of their location, removal of these tumors typically necessitates severing the auditory nerve, causing deafness.

When NF2 is hereditary, it results from a genetic mutation and occurs in approximately one in 25,000 live births in the U.S. People with this condition

are born with one mutated copy of the NF2 gene in each cell. In about half of cases, the altered gene is inherited from an affected parent. The possibility of an affected parent passing the disease to a child is 50/50. The remaining cases result from new mutations in the NF2 gene and occur in people with no history of the disorder in their family.

A cochlear implant cannot be used to treat an individual with NF2 because the auditory nerve is not available to carry sound signals from the cochlea to the cochlear nucleus in the brainstem. Instead, an NF2 patient like Mark may benefit from an auditory brainstem implant (ABI), which places tiny electrodes on the brainstem, bypassing the severed auditory nerve to transmit sound information directly to the

brain. "The ABI is a remarkable device that allows many patients deafened by NF2 surgery to hear again," said Dr. Derald Brackmann, a House Clinic neurotologist who is treating Mark. "But as wonderful as the ABI is, we won't be satisfied until we can stop NF2 altogether," Brackmann continued.

To combat NF2, researchers in the Institute's Center for Neural Tumor Research are seeking new drug-based therapies that will lead to future human clinical trials. Utilizing a tumor "cell line" developed at HEI, and unique animal models, Dr. Marco Giovannini and his co-workers are screening selected agents for those with the greatest potential for limiting growth or eliminating entirely the tumor cells resulting from NF2.