Electrical Implant Provides Relief

My name is Kristy Helm and I live in Colorado Springs Colorado. I was first diagnosed with Chiari in 1997, however, I was not experiencing any symptoms so the doctor said not to worry. I have struggled with severe headaches for years and have been on every prescription medication ever made and have not experienced any relief. I started graduate school in 2003 and noticed my headaches getting more severe, more frequent and longer lasting. My mood changed, I lost interest in activities and kept to myself. I missed a lot of work due to headaches and began to wonder if I would ever be headache free. Towards the end of 2003 I noticed that I was loosing strength in my grip and began to drop things and stumble quite frequently. I then began to have problems with my gait. I started walking into walls and door frames which really scared me. At that point my primary physician sent me for an MRI where she re-diagnosed the Chiari disease and she sent me to a neurosurgeon.

The neurosurgeon did a thorough exam and confirmed a diagnosis of Chiari malformation (15mm). At that point he told me that my best course of action was to go through brain decompression surgery with a c1, c2 laminectomy. He told me that if I did not have the surgery that my symptoms would become more severe and eventually I could be wheelchair bound. At this point I freaked out and so did my mother who happened to go to the neurosurgeon with me. We talked with the surgeon for a long time about the surgery and he told me that it was not an easy surgery to go thought but that his success rate was high. After a lot of thought and discussion with my family I decided to have the surgery. The surgery was done in February of 2004, I was in the hospital for 6 days. The recovery was horrific, I have never felt such intense pain in my life. I was on a Morphine drip which barely even touched the pain. I was supposed to be released in three days, however on the third day or evening I started vomiting and could not stop. I spiked a fever and could not keep anything down, even the pain meds. At this point I really thought something serious had gone wrong and that I was going to die. The doctor came in the next morning and told me and my mom that I had meningitis and that I would be placed on a heavy duty antibiotic by IV and that I would not be going home for a couple of days. The next 24 hours were terrible. All I remember is going in and out of consciousness and my mom standing over me with a cold towel on my head. My mom stayed by my side the entire day and when she left a dear friend of mine stayed with me until my mom came back.

I was released from the hospital on the sixth day and then spent the next 4 weeks at home recovering. I had to put both work and school on hold. Approximately four weeks after being released, I went back to work and school, however, I still had to take it very slow. Approximately 6 months after surgery, I really thought I was cured and that everything would be ok. I was not having headaches and the incision was healing nicely. A year after my surgery I noticed the headaches slowly coming back and growing in intensity. I also noticed that the back of my head was very sensitive to the point of not being able to even lay my head on a pillow. I had to sleep on my side because of the pain when I lay on my back. I went back to my neurosurgeon and he told me that surgically there was nothing to be done. He said that the surgery had aggravated the nerves and that that was what was causing my pain and the headaches. I was not satisfied with his answer and I was also having severe short-term memory problems which made graduate school impossible. I looked up a neurologist in Denver and wane to see him. He diagnosed me with Occipital Neuralgia and referred me to a pain specialist.

I saw the pain specialist late 2006 into 2007. He did several cortisone injections which lasted approximately two weeks. He then mention a new device that was being used in trials to help severe migraines. He told me that the device was originally used for people with severe back pain but that it was now being used in trials for headaches. He described the device as a mini electrical stimulation implant that would be placed under the skin in my chest with lead wires running into my head along my occipital nerves. He said the procedure was in the early stages but that he had done several and been very successful. At this point I was open to anything. We started with a trial device where the battery pack was on the outside and the wires went in at the base of my skull along the occipital nerves. I wore it for two weeks and was actually headache and pain free for the entire two weeks. This little device was my miracle. I decided to have the permanent one put in and had the surgery (which was outpatient) in June 2007. I was out of work for 1 week. The device has now been in for 5 months and I am 90% pain/headache free. When I do feel a headache coming on I turn up the electrical stimulation with a remote control and the headache goes away. I have been spreading the news about this device to everyone I know who might benefit.

I am not sure that my Chiari is totally controlled but I do know that for now I am almost pain free and that the electrical stimulation implant has literally saved my life and my sanity. I have permanent damage to my short-term memory but with extra help and willpower I have been able to continue with graduate school and in October 2008 I will graduate with my doctorate in Psychology.

Anyway, I wanted to share my story about my Chiari experience and my recent success with my electrical implant. The company that makes the implant is called Advanced Bionics (www.advancedbionics.com). I really recommend looking into this if you have chiari and are still suffering from headaches after decompression surgery.

Would you like to share your perspective? Submit to: director@conquerchiari.org Type "Perspectives" in the subject line.
