

## See A Specialist If You Can...By Melissa Kienow

**Ed. Note:** *The opinions expressed below are solely those of the author. They do not represent the opinions of the editor, publisher, or this publication. Anyone with a medical problem is strongly encouraged to seek professional medical care.*

I am a 32 year old woman. I just had surgery 3/3/04, so I don't know if I can truly say whether my surgery has been a success or not, but so far I'm very pleased with how things are going.

I was diagnosed with Chiari Malformation I in the spring of 2002. One day in Nov. 2001, I started having daily headaches, and I've been having them ever since no matter what I'd tried. (Until surgery - now I'm making some progress, but I'll get to that)

My major breakthrough was going to see a Chiari specialist. During my search for answers about Chiari, I've seen at least six neurosurgeons, three neurologists, an internist, two gynecologists, my general physician, physical therapists, a headache clinic doctor, plus many more and more tests, such as MRI's, CT scans, EEG's, etc. than I can list. Everyone was trying to treat symptoms separately and they all had bad information to give. Only one doctor actually said, "I don't know" and passed me on. All the rest just quickly answered my questions without checking and all were telling me bad things until I went to the specialist's clinic.

My main symptoms that were creating troubles: daily headaches, fatigue, menstruation problems, trouble regulating my internal temperature, profuse sweating, numbness, hoarseness in my voice, acne, neck spasms, depression, anxiety attacks, etc. Lots of fun, that's for sure. Basically, Chiari took me from a normal, very healthy 30 yr old to an extremely ill 32 yr old. As of right before surgery last month, I had stopped going to work almost completely. I used to be the top employee at my company with regular financial rewards. They did not fire me, but it was so bad that other people have been hired to do my work and it put a strain on the entire staff. This was very hard for me to handle since I take so much pride on giving my best work. I felt isolated and out of the group. This only made my Chiari symptoms worse since stress aggravates all of it.

Without the help of my devoted husband and wonderful three young boys, I could never have survived. My family did all the housework, cooking, laundry, appointments, meetings, etc. so that I was living as stress free as possible. They are my greatest gift.

One of the most difficult aspects of this illness is that so many physicians and nurses are not educated about it. Many of them talked time and time again about drug addiction when throughout it all, I never really got the pain relief to help me until the very last pain clinic doctor who had a working knowledge of the illness. Before her, I'd been on no less than fifty different meds. Every doctor had different ideas and theories and none of them involved actually helping me be comfortable and keeping me active in my life. One of the doctors actually blamed it all on my emotions, was sending me to a psychologist, took away all pain meds, and had me on Nortriptyline and Depakote! I was a zombie in a lot of pain! I also gained 30+ pounds in one month and am still now working on slowly reversing that.

Since surgery earlier this month I'm doing wonderfully. I had the best doctors!. They did wonderful work and they believed in me. I'm on a Chiari support group on Yahoo and they actually go online to read the entries of Chiari patients just to learn more about the illness. Even though I wasn't a patient, one of the specialists answered my email and helped to keep up my faith in myself until I could get the best help possible.

After surgery they came out to my Mom and told her that my spinal fluid flow was down to a trickle and that my squashed pituitary gland had gone back to its full size once they did the decompression. Now, my headaches are few and last only a short time. I'm actually able to help them with one Aleve tablet! I also am no longer sweating and so very hot or cold all the time and have so much more energy. I believe it will only keep getting better once I've had a couple months to get over my surgery. The incision is about ten inches long and I had about 26+ staples. It's all worth it though to feel better!

Another very important point is that, as specialists, they are up on the latest technology. The surgeries used to involve bovine dura, but now they used my own from just above the decompression area. Also, they have color Doppler and the ability to adjust to any pressure that they may be placing on the brain as they work. There is an acronym for this, but I'm sorry I'm not remembering it at this time. They also cover the decompressed area with titanium plastic, which they form right there in the operating room. Many of these new strategies are not being done in the local areas that are doing this surgery. Again, why do they not become more informed? I hate that so many patients are being hurt by this.

I had not let anyone else cut me though until I saw the best. This is very important since so many of the surgeries that these doctors do are clean up from those doctors who shouldn't be cutting Chiari patients! I was a "virgin" Chiari surgery and although it lasted almost six hours, the doctors said it was "boring" since it was so textbook and simple. I was very glad to hear that, believe me.

Another difficult part about fighting the battle to get better is not forgetting to believe in yourself. So many of the doctors and nurses didn't believe in what I was saying and wanted to put my symptoms and problems into their little peg holes. My first neurosurgeon told me that the Chiari decompression surgery could be done as an outpatient surgery and that I'd be better in two weeks. He'd put a hospital bed in my house and would come over and see me. In reality I was actually in the hospital for seven days and will be recovering for at least two to three months. What if I'd let him touch my brain! Very, very scary!

Earlier, I was also told by another surgeon that my problems with heat and profuse sweating had nothing to do with Chiari. When the neurologist who works with my surgeons looked at my MRI in Nov. 2002, he said that it was understandable why I was having this problem; my pituitary gland had been flattened by the pressure in my head from the lack of spinal fluid flow. It sure makes sense when they know what they're talking about!

I'm sure there are other Chiari specialists out there, but I'm not sure who they might be. I think once you receive the diagnosis of Chiari Malformation, you should automatically be sent to a specialist and these doctors without the new information should not be allowed to work on you. It would save the insurance company so much money and the patient, so much suffering.

Before finding my doctors, I had even tried a famous hospital, and they said that it was rebound headaches and that since my 6mm herniation was only 1 mm over the average, I would never have problems with it for all my life. I wasted a lot of months after that trying to gather my courage back up to keep on fighting. They really hurt my cause a lot and when I emailed my current doctor, he said this information was based on scientifically obsolete data. The size of herniation has no bearing on the symptoms and problems; it's how much this herniation is blocking the fluid flow, which obviously it was. I am thankful that God kept me believing in myself and kept pushing me towards the right physicians.

I hope some of this has been helpful. I hate that as there are more and more people diagnosed with this medical problem, most aren't getting the right information.

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

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