

## Overcoming Arrogance & Ignorance Of Chiari

**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.*

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June 20, 2006 – I have been dealing with Chiari/syringomyelia since 2002. This rare disease has altered many aspects of my life-my career, my family, friends, hobbies and more. One thing it has brought with it is the chore of explaining my condition, only to be told that such a thing can't exist! I WISH!

Outwardly, I show few symptoms, unless stressed or tired. Then my gait drags, and my speech becomes canted or slurred. I struggle with double vision, memory loss, tinnitus and temperature spikes, not to mention the spasms and pain we all live with. Physical therapists try to work within my limits, only to repeatedly overtax me.

Doctors abuse my condition like a guinea pig- trying new meds on me only to make it worse. I am known around their circles simply as the lady with the SYRINX.

Conflict came about when friends and family tried to coax me back to the old routines, most of which were now dangerous to my surgically stabilized condition. Camping was out, because of the extremes of hot and cold, the lifting and carrying the weight of the historical costumes and the demands of distance walking. Sitting became problematic as I was unable to get out of most camp chairs. Who wanted to tackle being my adult caretaker at a camping event? The list dwindled quickly as friends found it too much "work". So did the phone calls. I would soon spot them scurrying away from me in public, trying to avoid contact. Unable to volunteer at my past levels, I was quickly written off by many. My usefulness was at an end, apparently.

Driving is best only for short periods. Things like bowling, reading, and even computer time all come with a high price. Housework is done in short spurts, to allow for rest in between. Sometimes even that's not enough.

Family members were yet another front. My Parents and Siblings, while sympathetic to my problem, were resistant to the idea that it could be a genetic condition, refused to accept or seek out information that might help me, or them. This persists to date, and frustrates my efforts to remain in decent health. To them, then, I am a freak of Nature, and they remain steadfast in their ignorance.

My daughters are at present, ignoring the possibility-but I have extracted promises from them to get checked at first odd symptom. Paranoia? Excessive? Not when I think about my girls in this much pain.

My one supporter is my husband of 7 years. He knows the pains and struggle too well- having many of the same issues. I love him dearly for it. Without him- I might not have faced this quite the same way.

Arrogance reigns in the doctors office as I am sent from to another to try and find one with the knowledge I need in my court. I've been told that chiari/syringomyelia causes no pain, and therefore no nerve damage. I've tried meds that made my head hurt more than it did right after surgery- only to be told that was NOT a possibility. Labeled an obese hypochondriac before my diagnosis, I am careful to space my visits for only VALID reasons-since I know that AC/SM gets met with blank stares. Now, I come prepared with internet info, and copies of my most recent MRIs, ready to educate yet another new person. Its getting OLD fast...

My biggest battles are not becoming addicted to meds, and trying to lose the weight that they bring with them. Not easy by anyone's standards.

Having a rare disease hasn't helped in the paperwork front either. I applied for SSDI/Disability, and fought the stacks for over 3 years, only to be granted a partially favorable decision- told I was "cured" and to go back to work- without ever seeing a doctor. Their ignorance and arrogance was undeniable- and I have started my struggle with the paperwork drill again. At least my past research stood up with time, and I come across as knowledgeable instead of terrified.

My first days and weeks with AC/SM were like that- terror. how could I explain something I barely knew how to pronounce? An unwilling ambassador, its now my job to educate- even those who insist that this just can't exist because THEY have never heard of it.

My best advice when dealing with these same issues- don't let them stay ignorant. Don't let them force you into doing things you know will hurt you later. THEY will not be hurting in the late night hours. You must be comfortable within your OWN limitations-without guilt or shame.

Keep copies of everything, and set up files for easy access. Seek opportunities to educate people about it. The more you talk about it- the more people understand.

Whether you live in a small town, like me, or a major metroplex - the need is the same - get the information out there! You will find lots of people willing to listen and maybe even some help. Its lonely having a rare disease-but new people join our ranks daily and they are terrified. Just like me. But now, I know how to deal with it.

Ignorance and Arrogance are out there EVERY day. Just because THEY never heard of it doesn't change your diagnosis. Its up to you how you want to change their narrow views. be your own ambassador.

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