Introduction Posted by Juva - 15 Oct 2010 07:23

## Hi Everybody,

I'm new here & desperate for information & support. My name is Juva, I'll be 50 next month. I've had chronic pain for the past 12 years.To make a long story short..(kind of) LOL

Two years ago, I started experiencing sciatica, my doctor ordered an MRI, which showed a bulging disc & a nerve sheath cyst. I had a series of epidural steroid injections, which only served to make things much worse. I had a consultation with a neurosurgeon last month who told me that because nothing is touching the nerve, he can't help me. I now have an appointment with a neurologist on 10-19-10. I've been on 10mg Lortab & muscle relaxers, which barely touch the pain.

I've had to take a medical leave from my job & can't stand or sit up for more than 10 minutes at a time without experiencing excruciating pain.

The strange thing is that the pain doesn't seem to hit until later, not during.

After researching this condition, I afraid that the neurologist will dismiss the possibility immediately, because of the stigma & it is so seldom diagnosed.

I have all of the symptoms, except for the feeling of something running down my legs. I even had a hysterectomy 5 years ago because of abdominal pain, which I now contribute to this.

Any suggestions on how to approach the possibility with the neurosurgeon?

I'm looking forward to getting to know everybody & I apologize for such a long post.

Juva

P.S. I had an epidural with one of my children that went bad & the dr had to do a blood patch & I also had an epidural with a c-section years ago.

Re: Introduction Posted by ellijaygal - 18 Oct 2010 02:48

I think most people who have AA have a long story to tell because it is generally YEARS before a physician will finally admit it. In my case, my neurosurgeon felt no fear of admitting I had it and even showed me the MRI features that proved it because I had the spina bifida when I was born and various other things that could have caused it rather than any fellow colleagues. Even though that was the case it still took years for them to stop labeling me as "major depressive disorder" to oops you have a tethered spinal cord and it's pulling your brain out of your head and splitting your spinal cord-we need to do emergency surgery. Grrrrrr It took them about 5 years to even do a darn MRI!!!

Juva I went through hell trying to figure out what was wrong with me. I gave up for a long time and it got to where I cried when I tried to sleep because my legs jerked and twitched and felt like electricity running through them so bad I never slept. So I tried again to figure out what was wrong. Finally I got a P.A. that would listen to me since a doctor would not. I wasn't happy to have the condition/disease, but I wanted to go stand on a mountain and scream to everyone that thought I was a hypochondriac and depressed person "I TOLD YOU I WAS SICK!!!!!!!!!!" It really is horrible when you are happy to find out you have a progressive disease because you have been treated like a nutjob for so many years.

Barb

Re: Introduction Posted by Juva - 18 Oct 2010 22:57

Hi Barb,

It is extremely aggravating. I don't understand how some doctors sleep at night. I didn't even take an oath, but if I know that I can help somebody I do everything in my power.

What is a PA? I'm very nervous about my appointment tomorrow, because with each ppointment I have such high hopes of finally getting answers & some sort of relief. I don't expect to be pain free, just to have the pain tolerable & to be able to have a somewhat normal sleep pattern.

If I don't get satisfactory answers tomorrow, I'm planning to make an appointment with Dr. Aldrete & just spend the money for the trip & the \$1000.00 fee. I'm not getting anywhere otherwise.

I know how you feel about shouting it from a mountain top. My PCP retired & I had to see a new Dr. he flat out refused to refill the light pain meds that had been prescribed. I'm tempted to go & show him my diagnosis if I ever get one.

Politics & the buddy system have no place in medicine & I'm hoping that someday things will change.

((gentle hug))

Juva

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Re: Introduction Posted by ellijaygal - 19 Oct 2010 03:50

I typed something and then hit a wrong button I think. haha

Anyway, I said a PA is a physician's assistant. I got further with a PA than a doctor!!

It is horrible when you know something is wrong and hurt all the time and nobody listens to you or takes you seriously. Don't be nervous about your appointment. Whatever is wrong is wrong, and if they don't give you answers eventually you WILL get some answers. Just don't give up.

Good luck and I hope things work out well tomorrow and you get some answers and some relief soon!

Re: Introduction Posted by rita - 26 Oct 2010 21:17

Thought you might like to know that I met a young sympathetic lady doctor recently when I spent a couple of days in hospital. She was waiting for the specialist to come back and started chatting to me. She stated that she had read a lot about this Arach condition and said " It is a horrible and very nasty condition". Unfortunately the Doc arrived and our conversation came to an end.

Hopefully there may be a few more like her coming through the ranks. After 19 years it's the first time I have heard a doctor comment on how bad it is. I felt like shouting "EUREKA".

Best wishes to you all

Rita

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