

Hi all! Want your help PLEASE! first post

Posted by gmak - 07 Oct 2012 23:14

I have been told i have AA finally after 24 years. My dr of 17 yrs retired & my dr of 12 years left. So, i began the painful search for a new dr. 3 neurosurgeons & 2 pain mgmt drs later i found someone that would treat me, but he is not optimal. I am having neuropathic symptoms like never before. My back buzzes so much i feel like i have a TENS on with power lines shooting down to my feet. My face buzzes & my feet & hands are numb. Besides the incompatible with being alive pain. Has ANYONE ever had this buzzing? Also, my family wants me to see an expert on AA to see if ANYTHING can be done. Dr warnke, a anatomic pathologist, dr burton in Minneapolis, dr Falci @ craig univ, dr green @ univmiami? Has anyone seen one of these guys? Or someone else? Dont want to travel to hear that i just have to live with it? Any help would be so appreciated!

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Re: Hi all! Want your help PLEASE! first post

Posted by old hag - 06 Nov 2012 21:29

just posted on another subject on the forum, re my friend who has AA....all the professionals who cause it assume we will get worn down and they (orthos, neuros) will all be fine,

my friend worn down by it at mo and has retreated to his bed for a while, 42 years old, 3 kids etc, always worked so hard..

so sad...we've been trying hard to get somewhere....i'm bit worn down by it too to be honest...but am here trying as ever

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Re: Hi all! Want your help PLEASE! first post

Posted by gmak - 12 Jan 2013 06:40

Helen, this vibrating, buzzing like im wearing a TENS but im not is starting to feel like its affecting my heart. The heart has its own electrical pattern & this "power" from spinal cord squeezing feels like its messing with my heart. Does this make sense other than how crazy i sound! But, my pulse is over 120 resting & pounding so hard like i just got scared out of my wits but has been doing it for months. I dont ever have to feel my heartrate, i can hear it! Thanks, is yours any better?

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Re: Hi all! Want your help PLEASE! first post

Posted by helen - 14 Jan 2013 14:43

Hi

Yes I have felt it messing with my heart - I feel and hear my heartbeat all over my body and when I have attacks the only way I can describe what I'm feeling is to say that "it latches onto my heart" causing strange spasms!

You are not going mad, our symptoms are multiple and very complex and no two people are the same or progress the same. Every couple of days my attacks are causing very severe cramps all over my face, inside my neck/throat - then I can't see, hear or speak properly. At the same time the cramps are inside and around my chest, and inside my lumbar spine - really torturous!

Not much help, I know but good to be in touch with you all.

Best wishes Helen

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Re: Hi all! Want your help PLEASE! first post

Posted by gmak - 14 Jan 2013 18:12

Hi helen, I am so honored that you wrote to me when you are suffering and going through so much! Thank you helen! Your description of the heart jerks & the heartbeats all over helped me!! Right now my brain is vibrating like nerve shaking and my blood pressure is so high for me & i think for the first time it is a csf pressure in brain because it cant get to area that is "arched out" from L3 caudally. Causing a pulsating superbad headache! Thank you for saying im not going mad! Do i just let this happen without seeing a dr? What kind of dr would i see? Neurologist, cardiologist because i havent been successful in finding any dr that knows about arach only that i have it. Did you see dr? Only pain dr that is a physical medicine & rehab dr that has treated my pain for 12 yrs, before i even knew about aa. He only knows that i shouldnt have injections or surgeries. And treats the pain, nerve symptoms too but all this is getting out of his realm of practice. The pain mgmt drs ive seen have been the most ignorant about aa. I will/have already prayed for you. I would love for us to stay in touch! Please? Can you walk? Have you fallen b/c you cant feel your feet? When you say flares do you mean that you get "honeymoons" (breaks from symptoms)? Thanks helen, you cant imagine how much it helps me that you know what i feel. I only wish that you Never had

to. Do you know what i mean? Ps: i put a "normal" picture of sp nerves for all of us to look at & have faith that by a miracle we will have that again. Naeve? Maybe but i believe in miracles.

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Re: Hi all! Want your help PLEASE! first post

Posted by helen - 14 Jan 2013 19:53

Hi (what is your first name?)

I get meds from my disbelieving GP. The last neurologist I consulted cost £5,000 and he withheld information about me, so I take whatever A does to me and consult doctors if I need to. When I lost my hearing recently I consulted an ENT specialist who unblocked my ears, explaining that due to chronic inflammation of the ear canal my ears can't function normally.

Can't walk far, but often feel dizzy and the constant cramps have caused the muscles in my torso neck and face to contract. During attacks my spine is on fire and it feels like a tourniquet is twisting me up from inside!

I'm with you on miracles - don't give up!

Helen

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Re: Hi all! Want your help PLEASE! first post

Posted by gmak - 14 Jan 2013 23:43

Oh helen, Im so sorry for your pain!!! I find it very hard to just sit back, do nothing and watch & wait for spinal nerves to be destroyed!! But that's what i have done. Havent gone to dr yet other than my regular pain dr. (physical medicine & rehab). Heis not a physio as I think that some would maybe call him. He's a physiatrist that 50% of his practice is treating acute & chronic pain in order to help regain highest function. Do you take ketamine? I seriously can see or feel beginnings of aa affecting speech, the roof of my mouth & tongue are tingling, numb. Feet numb in varying degrees. Ive fallen to ground 4 times. 1000 almost falls like catch yourself on wall, bed, furniture etc. What I need info about if the aa is from L3 to tailbone how can it affect my mouth, heart, scalp, brain? Helen, please lets stay in touch. What did that £5000 neurologist say about arach, you? Sorry, dont mean to intrude just meant what tests did he do? Diagnosis? Treatment plan?

P.s. If you are viewing please post! We care about YOU! Your experience is valuable to us!

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