

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 helen - 15 Jan 2013 12:19

Hi (did ask for your first name)

The Neurologist diagnosed my A in 2005, but was very reluctant to put in writing, but I insisted so it was on my medical records. He withheld test results on two occasions, failed to fully complete some tests, and had written to my GP stating there was no point in seeing me again! He basically wasn't interested in me, so haven't bothered to consult anyone else. My symptoms affect my mouth, speech and swallowing and I've lost sensation in lots of areas.

Helen

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

Posted by gmak - 15 Jan 2013 20:56

Hi helen, thank you for answering my questions. My vision is affected today. I have another question, please sorry. If i have hi bp associated with the chest thing, & the numb roof of mouth, tongue should i see a cardio before i just assume its arach? And, do i need to show cardiologist my MRI & tell him about atach. Ive seen him twice in ten years but had lots of testing, normal stuff but this will be new. Im having a hard time typing today... hands shaking. Oh, just call me gmak. Helen I admire you strength. im so sorry i know you suffer! I wish i could change it for you! Its really hard to have something so serious but no dr! Its more than hard its inhumane! I feel bad today, im sorry usually more cheery at the lleast. Thanks.

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

Posted by helen - 18 Jan 2013 15:53

Hi gmak

Sorry, but I can't advise you on BP - I've read that A can cause it, but only you can decide whether or not to investigate further, in case it has some other possible cause like medication. I'm sorry to hear you're suffering so much and hope you have a better day tomorrow.

Take care Helen

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

Posted by gmak - 18 Jan 2013 17:23

Hi helen, Thanks! But, wait really? Which medications might cause hi bp? Because i have an arsenal! Lol
How are you today?

I have cardio appt on the 28th. I think its the hardest thing in the world to sit by & watch the nervous system being destroyed & i wish i could have surgery or something to fix it! Btw, numbroof of mouth, lips, tongue, teeth & bp normal. I think i have "beginnings" of arach affecting my eating & speech.

Wheres kev? I wonder how he is doing too.

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

Posted by gmak - 18 Jan 2013 17:38

Hi kev, it bites to have to sit by & have no dr understand. How are you doing now, any better? Where did you go?

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

Posted by kev - 19 Jan 2013 12:33

Hi gmak, no not any better. I don't go online regularly as not only is my AA restrictive i also have quite bad tennis elbow in both arms. Hope you're not suffering too badly.

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