

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!

=====

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

Posted by kev - 08 Oct 2012 23:04

Hi and welcome to the board. There isn't usually much activity hear so don't expect lots of quick replies lol. As there is no cure for AA many people do seem to be told to just live with it. I was too, though i have been to see pain management drs and exhausted all other options.

Those docs you mention, what would you hope to get from them?

I have the electricity running down my legs too, its horrible. I am in loads of pain, take heaps of meds and try to stay as active as i can, which is not much! There just isn't enough research into AA and whenever i tell someone i have it they say "what is that?". Nobody knows anything, not even my local doc.

=====

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

Posted by gmak - 09 Oct 2012 04:15

Oh thank you so much kev! Im truly sorry that you have this too. I have seen info from cc forum & dr wise young that suggests that those drs do surgery for yethered cord even with aa. But, the neuros i saw said no. I just want to be normal, like you. I had a great dr that i think knew what i had but treated me with pain meds but didnt tell me because i would be devastated. Finding out after 30 years was no picnic. My new dr doesnt get it either but at least will treat the pain. All the 'nerve' stuff is new. Wow, its hard getting new dr & having to deal with this. Is there another group online that you use that is more lively? Do morphine pumps help? Neurostimulators? Whatever you know feel free to hit me with it. Whats your story? Sorry i pushed thank you button! I was trying to thak you!!lol

=====

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

Posted by kev - 09 Oct 2012 10:48

A busy AA forum is COFWA at

health.groups.yahoo.com/group/cofwa/

I believe some AA patients of Dr Aldrete are getting the spinal cord stimulator but any invasive procedure carries the risk of making AA worse. Haven't heard much good things about the pump for AA though.

I had a bike accident 30 years ago and have had back trouble ever since. 2 recent back ops made my pain worse and finally was told i had AA .

There is not much good news about this disease i'm afraid, make sure you get a good pain management Dr and have a read through some of the info Doc Sarah has on this site, it is excellent.

=====

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

Posted by gmak - 09 Oct 2012 13:03

Again, thank you so very much! Kev, im so sorry that the operations that you endured had disastrous results & you have more pain! I should have known something was wrong but, the multiple failed back surgery syndrome & fibromyalgia was all i was told, Major bumner pump doesnt go with AA? I noticed a PM doc that signed a letter to FDA, re: PROP proposal that was president of AMA or something similar. He was listed in my area. And saw a neurosurgeon that recommended stimulator to me, but that was before i knew what AA even was. Will check out other info. Thank you for helping me. Hope i can return good deed sometime!

=====

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

Posted by helen - 14 Oct 2012 19:33

Hi gmak



I also have the constant buzzing and feel a vibration all over my body, including my face & head - no answers other than after a severe attack of muscle cramps, it seems to spread. I agree with Kev to be wary of any invasive procedures. A neuro surgeon offered me a spinal cord stimulator years ago and I'm glad I refused it - there are plenty of stories on www about emergency removal!

Best wishes H

=====