

a surprise!

Posted by gmak - 10 Oct 2013 20:19

Hi all, I miss talking to you kevin & helen so please let me know how you are doing. Thanks!

Also, very sorry, more than sorry to read bad news about kim.

And, to new people who have been diagnosed with arc or are looking for info there IS a plethora here BUT you know what? Your information, diagnosis, support or anything that you could offer, even to vent or rant MAY be the exact info or idea or the very hope that we search for! So, PLEASE SHARE!!! A new friend would be SO awesome!!

Now, my surprise. I have seen the same dr for 13 years for pain control. For 24 years i had arach on my MRI's & no one told me until a new neurosurgeon told me last fall but even then JUST that i had it, no info about it. So, i have searched for an arach dr in Texas for a year. Ive been in contact with Dr Burton, Dr Aldrete, Dr Tennant & lo & behold MY very own dr was "holding out on me"!!!! My last visit he spilled the beans & he knows everything, yes, everything about arach! He said I found out last fall but he has known for 13 years, since i walked in the door with my recoreds & #1 he never had the courage to tell me such a cruel diagnosis when i was doing well & he was watching me so carefully so no need to throw me into a dreaded depression! #2 He has been studying arach ever since i became his patient & said he did an EMG himself & knew i had severe nerve damage 5 years before i ever complained about the 1st feet symptom! My arach extends from L3 tethered cord at L1 caudally or to tailbone. So, Go Figure.... i had hit a gold mine & never knew!

We discussed ketamine coma, peripheral nerve field placement scs, morphine pump & he says that it is too early for any of these because i am at least 50% pain relieved with oral & patch opioids. So, for now i sit & feel my spinal nerves,cauda equina die slowly. Take lycra for the neuropathy, narcotics for pain & try as hard as i can to "suck it up" & "be normal for me" because i cant run away from the condition, i mean we are stuck in our body so i pray & pray that my future wont be as bleak as my imagination can make me see!

Thank you for reading this long post & please let me hear from you, i need support from those that "know"!!!!

=====

Re: reply to Gmak

Posted by helen - 04 Jan 2014 15:27

Hi Gmak, Kev and all

5 day attack and really think I'm going to go crazy!!! I take my meds and they just make me sleepy and wobbly. My husband's at his wits end and doesn't know what to say or do.

I've received many good wishes for 2014, but all seems hopeless, no doubt you feel the same, but I sincerely wish that one (or more) of us has a breakthrough.

Thanks to you all, for your kind words of comfort and I pray for miracles...

Love Helen

=====

Re: reply to Helen

Posted by kev - 12 Feb 2014 12:28

Hi Helen, are you feeling any better? You sounded like you were in a really bad way.

Over the last few years i've put on a bit of weight and even got slight man boobs! As if that wasn't annoying enough one of them has become painful. My doc was stumped until he read about the side effects of Pregabalin (Lyrica). Breast enlargement in men and breast pain were 2 of the rarer side effects! So now i am looking for a change of med. not an easy thing to find!

=====

Re: reply to Helen

Posted by gmak - 13 Feb 2014 20:28

Hi, I take lyrica & it really helps neuropathy symptoms for me! At one time i took cymbalta & it really helped too but, it increased the pressure in my eyes however now i have glaucoma so it mightve been that i was just getting increased eye pressure anyway not necessarily from cymbalta as it turns out. I did read that lyrica was invented from neurontin & that topomax works for alot of people too as non narcotic adjunct pain therapy & to relieve nerve symptoms & helps with weight gain. Hope dr can find a replacement med that works well! Have you ever seen an endocrinologist?

=====

Re: reply to Gmak

Posted by janette whalan - 21 Jun 2014 01:00

Hi Gmak and Helen, its been some time since I last checked in, life has been so busy with my elder sons immune illness attacking his muscles so he and I live together. It was all too hard for my husband of 43

years so its just me and my son. I think our struggle surviving AA is made so much harder because those around us don't see the struggle every day all day, years. They think we should improve or we are not trying to find solutions they get tired of us not being able to go out with them for outings and so we are seen as isolating ourselves. I am 63 now and finding I am getting worse, the intensity of back and leg spasms that I have to fight to walk get so bad I battle to get to my bed to lay flat. I do my home chores and its so painful to hand our washing, I have to go lay over the bonnet of my car. To do shopping for food, I need to get a small trolley to make it in to the store and these days I can only cope with the food shop because the agony is not worth it. I am at the stage of needing a walker but our money is tight with us both on pensions. Our government did a roundtable discussion on AA they compiled a small soft cover book all about living with AA and what they are planning to do to help sufferers !! amazing !!! check it out if you can google roundtable discussion living with the pain of adhesive arachnoiditis.gov.au

I get told I should be not isolating but go to our church, which call ecclesia. After my week its not a possibility to dress up and go to our ecclesia. My faith is vital to me and helps me so much, at least I can take part and listen to everything via a phone link service and my hands free phone. honestly without faith and knowing these is so much more to life than this life....give me strength.

I am so glad your doctor finally fessed up, but I can see how he was thinking, however we need honesty. I hope Helens tennis elbow op will help, no one needs more pain or problems. I live in Australia close to Lake Macquarie. It is a perfect sunny day today... Saturday. Our weather is much warmer than it should be in our winter it is 20c it should be 16c.....climate warming I guess...I will sign off for now...sending my best thoughts to you guys..xox 🍌

=====

New here!

Posted by Nicinpain - 28 Sep 2014 22:32

Hi, everyone! I'm so glad ya'll are here. Can someone please tell me if it looks like my nerves are sticking together. It sure would explain a lot. This is from 6 months ago.

=====

Re: New here!

Posted by gmak - 29 Sep 2014 00:45

Hi nicole, I can tell alot more on the axial view i think its called like a cross section. Do you have one or a view that shows the lower lumbar from L3- S1&2?

=====