

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 records & #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 lyrica 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"!!!!

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Re: a surprise!

Posted by kev - 06 Nov 2013 16:18

Hi gmak, i'd be quite annoyed if my doc was holding info back from me. My surgeon did exactly that! I suspected i had arach and asked him, he went red in the face and almost stuttered that yes indeed there was evidence of arach.

I'm not doing great just now and am due in to hospital next week to have a new treatment for my tennis elbows which i really hope works!

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Re: a surprise!

Posted by gmak - 06 Nov 2013 18:24

I wasnt told by my original NS for 13 years or the pm/anes after him & then my current dr & i was really really mad at the NS the most! My current dr knew i didnt know i think but after i was told he does not make me get epidural steroids like the pm/anes did & he knew! Medically documented that he knew & did injs anyway!

Im sorry that you arent doing well! What will they do in hospital for tendonitis? I have something i think like that above my kneecaps bilaterally, like the thigh muscle hurts bad where it connects to knee. I would be interested in new treatment, just finished medrop dosepak & pain is back. What does tendonitis feel like?

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reply to Gmak

Posted by janette whalan - 27 Nov 2013 02:25

Hiya Gmak, I just read you last info and was struck at the doctor not telling you. I was diagnosed in every scan and 2 myelograms and still specialist didn't explain what AA was, I was left for 11 years wondering why all the surgeries never made me better. In those days computers were not something we jumped on to find info, it was like a blank wall of no information. I think these days some feel inadequate to do anything to alter the situation and the fact that they are doctors and are supposed to have answers to so many medical problems, but when it comes down to AA, all they really can offer is pain medications and then those meds never do much other than provide some masking of pain and back it comes in some hours and that's really only if you are being fairly inactive, but hey, at least these days doctors are more aware and will accept AA, is a very painful life and so provide the more stronger medications. I felt so sad when I read what you had to say and after thinking I guess I felt sadness for myself as well. We don't have a good future to look forward to, because as most of us know, nothing has happened to provide much more help as far as pain relief and all the other stuff that goes hand in hand with it. All we can do is hold on, try to help ourselves by not focusing on the situation, try to find other things to divert our attention from ourselves. I know when things are bad its almost impossible to have the energy to do anything else but spend more time flat in bed. Did we ever imagine thinking of our bed as being like a jail ?

I wanted to come on line and give encouragement and I don't think I have succeeded. Just keep on holding on, a day at a time !! 🍌

Jan W

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Re: reply to Gmak

Posted by gmak - 09 Dec 2013 02:59

Hi janette, But i did find encouragement in your post! The "we are in same boat" type of thing! Not all alone like an albatross among the healthy here at home! Thank God for my loved ones health! But i get so tired of being the "heavy", the broken one, the unfun one, the "i cant" one! I loathe & despise the bed & after spending 4 years there not knowing what was wrong bc i had no diagnosis of arach told to me yet & it still makes me cringe to go in there to bed bc theres no source of distracting my attention off of the pain! I found out the worst thing for me to do is go to bed unsleepy & lie in the dark! It escalates my pain! So, once i finally got up & out of the bed i can barely make myself go back even for a good nights sleep! Its so elusive anyway,sleep is elusive for me. But im in a controlled pain situation mostly now & know physiologically why im having the severe pain so its not all in my head after all! One very important thing i try to do now that helps tremendously is remember that my arach has progressed very, very slowly, if at all over 30 years! So if i dont freak out, & try to remain calm & remember i read arach may not progress at all! Thanks for sharing your time with me & caring, it means alot from a fellow arc patient!

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Re: reply to Gmak

Posted by helen - 11 Dec 2013 18:37

Hi Gmak and Jan

Just read your posts. JAIL is how I view my bedroom. Arach is a life sentence and I often think to myself murderers have an easier life in jail - what did we do to deserve this. Apologies feeling very sorry for myself - severe head and body cramps for yet another 2 days.

Given up on the homeopathic tinctures etc - I think they might have been aggravating my symptoms!

Back to bed.....tomorrow is another day.....

Wish you good days xx

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