

Guests, we need your input!

Posted by gmak - 08 Oct 2012 13:17

I see alot of guests each time i log on. Please We NEED your input. PLEASE JOIN So that we all can benefit from your stories and questions. Every site needs new blood, new ideas! Please know that we welcome your input. It is extremely valuable.

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Re: Guests, we need your input!

Posted by old hag - 06 Nov 2012 21:20

This is a horrible illness.... a friend of mine developed AA post surgery march 2011, he has seen so many neurologists, orthopods, pain management specialists. I honestly can't decide whether they don't know about AA, or there is a conspiracy theory going on....? Am not remotely wacky at all. I am a "get things sorted" person, but arachnoid has really thrown me and sent my friend back to his bed even though he takes 24 tablets, including opiates daily. If he bends or walks a few times in a day, his pain his dreadful. Previous to this he was a work driven self employed plumber....

yeah we need to introduce some energy into doing something....but it's the hardest thing to even get it diagnosed...

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Re: Guests, we need your input!

Posted by di - 11 Nov 2012 03:30

Hi old hag, ☺

I put up a post on the wrong thread... it's on the 'General Discussion'. ☺

Not to worry because it certainly doesn't look as if many people are frequenting this forum at all.

That's a shame because the information here is great.

I've taken the advice given in one of the posts on here and sent my request to join the cofwa site.

I will stay on here as member now that I've joined and I just hope others also do the same or more readers join. ☺

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Re: Guests, we need your input!

Posted by di - 11 Nov 2012 03:32

Sorry gmak, I meant to say hi to you too.

big wave to gmak. ☺

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Re: Guests, we need your input!

Posted by gmak - 11 Nov 2012 18:58

Thank you all for the welcome. Had opportunity last night to start my own type of grassroots effort to educate about AA. At, retirement party, my niece & husband are both nurse anesthetists. She works for PM/ANES dr, he (her husband) teaches nurse anesthetists, drs, also some continuing education for professionals @ huge famous hospitals in Texas Medical Center. Its @ least 40 hospitals. So, I told them I had AA. They flipped that @ their level of education they had never heard of AA. Explained how no dr told me from 1988, when first on MRI, until 2012! That I had to learn myself everything about AA myself, and that NO doctor explained what it was even after I found out. They PROMISED they would take info back to their anesthesiology community & research AA. Inform PM/ anes dr that YES, he could get a patient like me, chronic pain patient, who has 32 grafts on dura, CUT dura to put in pain pump or SCS & he could SEVER the nerves/a nerve that served the lower body. HE COULD POTENTIALLY take the " wrap" for that patients AA! This should help to stop the PUSHING of procedures(i.e. epidural steroid injs, spinal cord stimulators & morphine pumps etc) & REAL surgeries that can HURT an AA patient! Just give us our medicine & stop pushing the money making surgeries, procedures UNTIL WE decide the symptoms are so severe that it is WORTH the risk!!! I will do whatever it takes until DRS KNOW that they can hurt is & understand the disorder called AA & first do no harm! Thank you for hearing this rant! gmak

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Re: Guests, we need your input!

Posted by gmak - 11 Nov 2012 19:05

Hi! The people that have arachnoiditis should come to this site first thing after their coffee! What about Newly diagnosed people? That have a copy of their MRI & Cant get anyone to tell them the truth! It happened to 99% of us. Are we really going to let the hard work of creating this site & posting all the info become a waste of effort! Please think of others!!

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