

IS ANYONE EXPERIENCING THE SAME AS ME ?

Posted by helen - 21 Oct 2008 13:06

Dear Doc Sarah, or anyone with some feedback please

I have total spine arachnoiditis (10 years)and my whole body is becoming very stiff and crunchy. Now its reached my neck and head I'm feeling petrified. I'm finding it hard to cope with symptoms and would really appreciate response from fellow sufferers - I feel very alone.

Thanks Helen

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Re:IS ANYONE EXPERIENCING THE SAME AS ME ?

Posted by kev - 05 Nov 2008 12:50

I'm so sorry to hear things are so bad for you Helen. As far as i know my Arach is only at L4/L5 but my symptoms are sometimes similar to yours so i'm wondering if it has spread. I'm having an MRI done next month but my Ortho has been very 'shifty' recently since i started asking probing questions about my Arach.

You're not alone Helen, have you joined COFWA? there is quite a bit of activity on there when you just need to talk to someone.

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Re:IS ANYONE EXPERIENCING THE SAME AS ME ?

Posted by helen - 05 Nov 2008 15:34

Thanks for your response Kev. Things just seem to be getting worse every day. All my internal muscles are going into spasm and I feel like my whole body is being mangled and strangled! I am a member of COFWA, but I stopped the e-mails a long time ago as I found them too depressing.

Best wishes Helen

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Re:IS ANYONE EXPERIENCING THE SAME AS ME ?

Posted by kev - 06 Nov 2008 00:40

I know that horrible feeling of muscles in spasm all too well, my upper back, neck, abdomen, legs as well as lower back all have their turn at going into spasm at times and sometimes there seems to be no rhyme nor reason for it. I find **Baclofen** to be a great help in those times, have you tried it?

I know what you mean by Cofwa being a bit depressing, it's good to hear others stories but all the terrible suffering of others gets me down too. Its good to know its there though.

Have you been getting worse for a long time or do you think this could just be a 'bad spell'? I've been suffering more recently and believe it's possibly down to the weather. I'm going to buy an electric blanket soon! Do you take a large cocktail of meds? I'm also on Dihydrocodiene, Diclofenac, Gabapentin (lifesaver!) and Baclofen all for pain and Docusate sodium (constipation) Omneprazole (Stomach ulcer caused by Diclofenac!) and Venlafaxine(Depression). I keep hoping there might be new drugs coming along to better help the pain etc but they never come. Have you found any that really help? Have you thought about the Stimulator or pump?

Kevin

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Re:IS ANYONE EXPERIENCING THE SAME AS ME ?

Posted by helen - 07 Nov 2008 11:17

Hi Kev

Unfortunately my spasms/cramps are set off every day by defecation due to extensive bowel damage. I have been experiencing this for 10 years and every 2 days it's so bad I am laid up! Prior to this I had an intolerance to drugs, and although I've tried many to alleviate symptoms the side effects are so bad for my bowel I've always had to discontinue them. My gastric consultant does not recommend drugs because while things are working there is nothing he can offer me. The only drug I have, which I use to knock me out for some sleep is valium!

I was given Sativex recently to try, but it caused blood blisters in my mouth, so am waiting for them to advise me further.

The thing that really upsets me Kevin is that our only hope is stem cells, but my research on the internet hasn't shown up any research into our condition other than a trial with the Thalidamide drug (not sure of

spelling!).

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Re:IS ANYONE EXPERIENCING THE SAME AS ME ?

Posted by kev - 12 Nov 2008 16:07

Helen,

About the stem cell research. I know there is not much going on at the moment but Barack Obama announced that one of the first things he aims to do in power is reverse Bush's decision to block stem cell research in the US. This should give research a big boost and i pray you and i will benefit from this in the not too distant future.

Kevin

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