Hi to everyone

Posted by DocSarah - 10 Nov 2005 21:30

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Dear All,

it is great to be back online.

I'm hoping to visit the forum at least once a week.

For anyone wondering what I'm up to these days: I am still working at the Pain Clinic in Plymouth, just put my hours up from 16 a week to 30. I am also in the middle of a Masters degree in Pain Management.

Right now I'm working on an essay on epidural steroid injections: showing that they are not effective, especially in chronic pain. They are still, however, widely used. Whilst getting their use reduced by demonstrating lack of effect doesn't tackle the safety issues and arachnoiditis in particular, it might at least minimise the number of people put at risk unnecessarily in the future. I will still be working towards raising awareness of arachnoiditis, have no fear!

I am now able to see out-of-area referrals of arachnoiditis patients so if you want to trek down to Plymouth I'd be glad to help.

I am also running a study with Arthritis Care looking at the benefits of a self-management education programme (a bit similar to the Expert Patient Programme but more specific for pain). We are very much looking at trying to get pain managed more effectively at an early stage, and preferably out of hospital, in the community.

So you can imagine I am pretty busy!

All the best,

DocSarah

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Re:Hi to everyone

Posted by gmedic123 - 21 Nov 2005 00:21

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hey doc Sarah!

Glad to hear things are going well for you. When you say you are in Plymouth, you mean UK not Massachusetts right? I am positive i remember reading you are in the uk but I can wish for a small time til i hear back from you!

Also wanted to say thank you for answering my shoulder question.I am finishing PT w/o much improvement.But I am still going to pass on the steroid injection, better pain that could be fixed vs my luck. (ie a pain that would be permanent!)

I would love to see some type of research or official opinions on how progressive this disease gets with some time of time frames in general. I was 28 when all this started and it was relatively just pain then. now i am 31-close to 32- and have neuropathy, atonic neuropathic bladder, no pain sensation in my leg (rt),foot drop and (rt) arm neuropathic pain. my screwed up sense of touch goes up to my bra area in front and back pain in all ways on my back, primarily right sided. then there are the swollen joints on and off. all this from a L4-L5 and L5-S1 injury?!?! I have yet had a plato hit and it has been since 2002. I have read all the info I can find about progression, but it doesn't seem to match what the patients WITH Arach tend to find. I personally believe we will find this to eventually be an immune disorder with triggers for certain people being the cause to start it. Do you have any info on this or thoughts? I have begin to sense I will be wheelchair bound eventually with this as i haven't hit a plato yet. do you hear this from many people? I have been tested from every way i can imagine for other disease. they have all been negative. Mri shows arach, but you specify a T-weighted dye. can you explain what this is so i could ask for it my next mri round? my herniated disc was a central herniation which I have been told is kind of rare and hard to see.(the other L5-S1 was a rupture and is now fused with my bone-in 2003)

OK so, I have asked plenty of ? for any doc to answer much less a busy one working on her master's (good-Luck!) but one last one please?!- has the new drug using marijuana parts helped arach type pain with any success like it claims for MS patients? I'm finding my duragesic fentanyl patches becoming less useful for pain. My PM has tried a bunch of other things but with allergies and high tolerance immunity we are at our wit's end!

thanks for all your time ,I know this is a long one to answer. anyone else who has knowledge or advice respond too please. I'm living for e-mail and HGTV!!!! UUGGHH!!

HAA HAA HAA! --Gina

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HAA HAA HAA! --Gina

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Re:Hi to everyone
Posted by DocSarah - 25 Nov 2005 17:01

Hi Gina,

sorry to take a while to get back to you, my pc went haywire when I tried to upgrade it. Am sorted out now tho' back up and running (well the pc is, I don't do running any more

Yes, I am in Plymouth UK, where it is snowy and dark just now!

Yes, my hunch is that there is a link between arach. and autoimmune disorders. You might like to check out the 1999 survey results as they make interesting reading. Plus there is a section in my long article on AA.

AA is not just a spinal problem, it is a neurological condition that affects lots of different parts of the body. I'm sorry to hear you have so many problems at such a young age. I was in the same situation as you at the same age, and 10 years later haven't got too much worse overall. I do have bladder and bowel problems which are being treated as if I have a spinal cord injury, but I am still pretty mobile and not on too many meds. I have my bad times but try to take little notice of them.I hope this gives you some hope that life will carry on despite AA !

You don't need dye for the MRI these days, but it is important you have high resolution scans with axial views (these are pretty standard for spine MRI scans nowadays anyway) The newest scans are dynamic MRIs which look at the patient upright as well as lying down. This helps to show any changes that might occur when someone is sitting/standing, which is far more reflective of daily life.

In answer to your question about cannabis, we don't have research on AA, but anecdotally quite a few people seem to find it helpful for pain and muscle spasms. MS research at my hospital has found cannabis srpay from GW Pharmaceuticals has been helpful although ealry data was a little disappointing, the longer term results are looking more hopeful and again anecdotally patients report significant benefit.

The other thing that I find has helped patients with neuropathic pain is Lyrica (pregabalin). Opiates like fentanyl don't always seem to work that well and lots of people have trouble with side effects.

All the best,

DocSarah

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1 last ? please doc
Posted by gmedic123 - 27 Nov 2005 20:50

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thanks Doc Sarah,

I appreciate the info. I am hoping my AA platos out soon. My life is completely upside down due to it. II feel like a fish out of water.

One last question please, Are you set up at your office to see overseas patients? At this point I am willing to travel to anywhere for a closer look at what's happening to my bodyy and possibly get info to help my life turn back around. If you do see patients from the USA, could you let me know how to start the process?

Also thank you so much for your time and this web site (kim) is amazing! i am glad to know I am not alone in this...that means more than I could ever say! 🙂

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Re:Hi to everyone

Posted by DocSarah - 30 Nov 2005 11:17

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Hi Gina,

I think seeing overseas patients wouldn't be a problem, it would be similar to the 'out of area' UK patients I see. I'd be more than happy to help if you feel the journey would be worthwhile, but do bear in mind that I won't have any easy answers and I'm not sure you would gain enough benefit to warrant the strain (and cost!) of the travel.

Regards,

DocSarah

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