

Progression,other pain,help in docs

Posted by gmedic123 - 03 Jul 2005 20:31

not sure i posted correctly. i had a very serious question for doc sarah on the other forum. will she still see it or do i need to put it over here?

my other questions- has doc sarah ever written any articles dealing specifically with:

1-paralysis or progression of arachnoiditis later in life-possibly years after initial flare up has occured and settled?

2-how does arachnoiditis affect other body parts above the area of injury? such as joint pain or neuropathic pain in another extremety way above the injury sight that wasn't there before the arachnoiditis?

3-does she have a list of doctors in the USA that are knowledgeable in arachnoiditis or a source to find some?

thank you for your help- i know this is a lot to ask, but there aren't to many knowledgable sources out there.your website is a Godsend! Thanks Gina

=====

Re:Progression,other pain,help in docs

Posted by Kim - 05 Jul 2005 17:54

Hi Gina

I honestly thought I had posted a reply to this last night but can't find it, so here goes again.

1.

Personally speaking I don't think it is progressive but hey I am not medically qualified. But I have spoken to many thousands of people over the years on the Helpline and it was one of the top ten FAQ's so what did I do? Got DocSarah to do me a chapter and here is the link

www.theaword.org/index.php?option=com_co...40&Itemid=51

2.Check out the survey to see what other symptoms people have and see if this makes sense

www.theaword.org/index.php?option=com_co...19&Itemid=44

that is for diagnosed cases but also look at undiagnosed cases and spot the difference!!

www.theaword.org/index.php?option=com_co...14&Itemid=44

Check out also

www.theaword.org/index.php?option=com_co...50&Itemid=41

3.

I know that DocSarah has contacts with Chas Burton and Aldrete and a couple of anaesthesiologists but not in a formal way.

However I have found that Veterans Hospitals have a much better track record at treating Neuropathic Pain because of their experience with amputees.

Hope all this helps, get back in touch if there is anything else I can help with. The search engine on this site is quite good but I am sad to say I know every word on this site!!



If you have specific questions to ask and I can't find it for you, still ask. I am hoping that DocSarah can come online later this month to answer the queries I can't deal with. We will have to take it slowly at first so as not to frighten her off! 😊

Take care

Kim

Post edited by: Kim, at: 2005/07/05 17:56

=====

Re:Progression,other pain,help in docs

Posted by gmedic123 - 05 Jul 2005 21:04

kim,

thank you so very much for your help with my questions. i am so excited about this website! I can find almost anything i have a question about here, just wish i could stay comfortable long enough to read more than an article at a time.

i still do not understand- and neither do my docs, they actually think it is something different going on- how a lower disease process can cause say the upper joint pain that plagues me. or the neuropathic pain in my arm? i KNOW it is arachnoiditis it FEELS like it.(if that makes sense) i didn't need the 1000 dollars worth of testing from the arthritis doc to know it's not RA. 🙄

is there anything MORE medically specific on this?

thanks- if you don't mind me asking, how did you get started with this? are you a suffer too? what area is the site set up in? usa? uk? etc? hope you are not a cper but if so i hope you are having a painfree day!--Gina

=====

Re:Progression,other pain,help in docs

Posted by Kim - 06 Jul 2005 15:14

Hi Gina

Compression Neuropathy try this one

www.theaword.org/index.php?option=com_co...88&Itemid=41

actually I would recommend all of Itches and Twitches as it is a hotch potch of queries from the helpline which I asked the Doc to do.

www.theaword.org/index.php?option=com_co...76&Itemid=41

I have just remembered something in Whoa so I'll go off and find it

www.theaword.org/index.php?option=com_co...99&Itemid=41

Right at the end under miscellaneous.

Will keep looking there is something at the back of my mind and it has to do with the Doc's dog and advice from the vet. It's relevant because vets protect their animals more than doctors protect their patients!!

Yes I live with arachnoiditis and cope quite well most days. Of course I have an altered lifestyle but my drive is for information.

I often ask myself if I knew then what I know now would I have made different decisions?

Perhaps not in the early days as I was so sure I could get back to a pain free life again, I just hadn't found the right doctor yet. How naive and trusting was that.

This worm turned when they started to suggest this was all in my mind. Well they had wrecked the body

but they weren't going to do that to my mind.

I just needed more information so I joined the committee of a support group I had belonged to for some while. I only meant to stay 3 months but stayed over 7 years. That's when I met the Doc on the helpline looking for information. WoW just what I needed and the rest is history. DocSarah went out and started to fill in the gaps of information

I left that group over two years ago now and concentrated on the local support group here in Liverpool and Knowsley. It's much easier to get grants locally than nationally.

We have a library and self help books/tapes/CD's/DVD's and I will be doing book reviews on the website soon. I have got lots more planned but it's time fitting everything in as like you I can't sit for long.

Keep asking the questions but please understand I am not medically qualified so can't diagnose. If the Doc doesn't have the answer, it doesn't exist!

Bye for now

Kim

=====

Re:Progression,other pain,help in docs

Posted by gmedic123 - 07 Jul 2005 14:24

well,

i just spent a good long time writing back to you kim. thanking you for you help and your story of how you got to have AA. then "poof" the word theif came and stole it off my screen 😊

to shorten up my last mail...i am posting my story over on the other forum/thread with marti. would love to have you join us. it never ceases to amase me what great simple ideas peolpe come up with to make everyday life easier!

i am also veryvery excited about speaking to doc sarah and letting her know how much her writings have meant to me and explained thing to me! if you have put this site together then major kudoos to you too! my hats off 😊
what a work load!

would love to speak with you more when you aren't scrambling to find answees for people like me! thanks
~ gina 😊

=====

Re:Progression,other pain,help in docs

Posted by Kim - 07 Jul 2005 19:31

Sorry today was just too devastating 🙄

=====