

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 gmak - 10 Jan 2013 19:05

Dear o.h., I thought of a question. My spinal nerves are a part of my dura now imbedded so much that the dura & spinal nerves are one, the sp nerves arranged in dura like the numbers & slash marks on the face of an analog wristwatch. So when speaking of an intrathecal pain pump the neurosurgeon would have to cut my dura in order to put in the catheter, how can he do that without severing spinal nerves? Aa is present from L3 caudally, in other words starting @ L3 I have a tethered spinal cord & from there to tailbone the sp nerves, cauda equina are "arached"; out. So where could they cut? If above L3 would it help the area BELOW where the pain resides? Thank you!

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Re: Guests, we need your input!

Posted by old hag - 11 Jan 2013 00:39

Hi gmak

Not medical enough to know the answers to this.....re cutting you up....

You sound medical though?

There is no cure...just need someone to help with the arachnoid predicament.../pain/symptoms

If you have not got decent pain management your pulse will be all over the place...pain/stress cycle...

The london pain clinic where christopher jenner is based do have an online client assessment for people out of the country...probably expensive and we know you have AA...but sounds like you have different

drug options in US rather than UK...i know nothing about this field

I can only suggest sending them an email...Jenner seems well connected in UK...maybe his team can recommend someone your end...

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Re: Guests, we need your input!

Posted by kev - 11 Jan 2013 00:49

Hi gmak, hope you don't mind me putting my tuppence in but i was offered the spinal stimulator a while back and my understanding is that they place the electrode above the Arach so it can disrupt all pain signals from further down. However, it is more successful on leg pain than back pain apparently.

I have read probably hundreds of online posts by sufferers who underwent this procedure and they just do not fill me with confidence.

Kevin

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Re: Guests, we need your input!

Posted by gmak - 11 Jan 2013 00:51

Thanks so much! Im sure you can tell i dont trust any dr because they say i have aa but when i ask questions it seems that they forgot arach & mixed me up with a normal person! Will check out dr jenner! Thank you again!

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Re: Guests, we need your input!

Posted by gmak - 11 Jan 2013 00:54

Hi kev! So glad to see you there! I was offered scs but i heard "cut on dura & that was out! As you can see i am worried about a "cut for intrathecal catheter! Comment away! How have you been?

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Re: Guests, we need your input!

Posted by kev - 11 Jan 2013 01:25

Pretty awful lately. I feel the cold terribly nowadays, every morning when i get up i shake as my core body temp feels very low. It takes either a hot shower or leaning against a hot radiator for 20 mins to heat me up. I'm like that all winter. I also have abdominal adhesions from 2 ops there that are causing me pain and bowel problems but the AA pain is the worst.

To top it all i've had the worst xmas in a long time for bad news: my mothers cancer returned for the 4th time, my daughter 12, who doesn't live with me, is causing lots of trouble to her mother and we've just found out she may have kidney problems. My rent is going up, which i can't really afford and as well as a few other problems i'm very stressed and at the end of my tether.

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