

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 - 08 Jan 2013 20:22

I love being an old hag...no worries....my close mate with arachnoid is on liquid ketamine (i called it linctus) 4 times a day and it has helped with his pain....sounds bit like the effect of pethadine which is what you are given during labour in uk if not going well....i had it 3 times.....the pain is there...but it feels like its is not happening to you...just a few feet way ...so can disassociate from it and have a bit of relief for 2 hours after each hit....hope that explains it....

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Re: Guests, we need your input!

Posted by gmak - 08 Jan 2013 23:37

Thanks for answering. Have you ever heard of that being used in the US? I remember using it in pediatrics in the 70's to put babies "under" for painful procedures but dont know if its just not used anymore or if its illegal here now. Glad your friend is getting help. I had the worst pain i ever had earlier today! I hope it doesnt go up again! I took 6 morphine pills today. Two every four hours & still it was a 10. Finally it went to a 6! Thanks so muc, lets try to stay in touch. Gmak

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Re: Guests, we need your input!

Posted by old hag - 09 Jan 2013 09:09

My friend had to go to the hospital and have iv ketamine to see if it helped....some people don't have the receptors for it to be of any use. It really helped him, so the pain consultant prescribed the liquid ketamine for him. His local chemist and GP were somewhat surprised but it seems to be easing the pain a bit.

The key is a decent pain consultant...who accepts the arachnoidits diagnosis, cares about his patients and is keen to steam in and help. Christopher Jenner is fantastic....but it took a while to find him....fobbed off by so many consultants on the route to him.

Hope you have decent pain consultant in US.

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Re: Guests, we need your input!

Posted by gmak - 10 Jan 2013 02:25

Hi oh, of course, i have been unable to find a dr that even acts like they have even ever heard the word arachnoiditis! Just told i have it. Any particulars unheard of. I even emailed dr aldrete, who was kind enough to write back. I will have to go there im afraid if i want to see a dr that knows about arach. Only 3 states away! But he doesnt know of a dr in texas either! My dr treats the pain under the diagnosis intractable pain even though he has my mri disk & report showing advanced adhesive arach. So glad your friend has a dr. I may be asking you questions if thats alright with you!

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Re: Guests, we need your input!

Posted by old hag - 10 Jan 2013 09:01

Hi gmak

Feel free to ask any questions

I have learnt alot since my friend got it post disectomy in march 2011...

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Re: Guests, we need your input!

Posted by gmak - 10 Jan 2013 17:28

Hi o.h., thank you so much. Im having electricity coursing in my body i presume from spinal nerves being squeezed. Im actually vibrating or "buzzing". I know it sounds crazy but i can feel it affecting my heart. Do you know if it can make my pulse way too fast. Like > 120 resting, over 150 standing? When i think of more i will ask. I cant think now due to pain buzzing & pulse 148.

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