

severe gnawing pain

Posted by gmak - 31 Jul 2013 17:24

Today i woke in #10 pain, gnawing pain, arach pain. Irregardless of anything i have read i have not given up hope of being able to somehow live with advanced aa. My sp nerves all of them are lined up against dura, one with dura, tethered cord, empty sac syndrome. I dont know when it got this way bc it has been on MRI for 24 years, but in 2012 i was first told so i developed the notion that being 57 the aa was now in place but progressing so slowly that i would die of old age before aa took me to a wheelchair & beyond. Waking in such severe, irreversible pain shakes me to the core & basically shows me that the hopeful scenario i have is fallacy. Everything within me wants to go for help. Here is where the hopelessness enters.... where? Where could i go to get someone to "fix" this for me? That place doesnt exist. A few minutes have passed does anyone know a place in houston texas that i could receive help? Not narcotic help, but arach dr, ketamine possibly, some new treatment anywhere in the world? To say im at wits end is ridiculous bc i lost "wit" about this already. Desperation, i know already we all are. Any suggestions would be awesome, a needle in 100,000 haystacks but is there anything? My head feels weird & i dont want to even go there, to the CSF pressure in brain, too complicated & scary i dont even want to know. If i sound crazy im sorry. But, believe me i am ungloriously fine in my mind. Maybe i need to be impaired so i couldnt put 2&2 together.... sigh

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Re: severe gnawing pain

Posted by kev - 03 Aug 2013 00:45

Hi gmak, so sorry to hear how you are suffering just now. I'm afraid i don't have any answers, my only rayof hope is that somehow stem cell treatment may offer us some kind of cure or at least relief. Its almost 2 am here and i can't sleep, again! Apart from the other symptoms, i'm very tired all the time, no energy at all. In the last year my vision has deteriorated noticeably too.

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Re: severe gnawing pain

Posted by gmak - 03 Aug 2013 13:43

Hi kev, It happened again. I wrote you a long reply but its gone! I had multiple eye issues blamed on my meds (lyrica, morphine) but i had glaucoma. My ophthalmologist said that the "puff of air" glaucoma test is only 85% effective in detecting it & not good at all for early detection. He deadened my eyes with numbing drops then took a measurement directly by touching my cornea really fast with something but its a way better test to find glaucoma & i wanted you to know. Im still waking up in horrid pain but more successful in getting it down to a 5-6 last few days. Its so hot here! Thank God for central a/c! We just move from one air conditioned "box" to another around here! House, car, store, car, house or otherwise we would melt!

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Re: severe gnawing pain

Posted by helen - 03 Aug 2013 21:32

Hi Kev and gmak - re stem cells 🟢

I wrote to a Professor at University College London who is a leading expert in stem cells and he wrote back saying that stem cell treatments were in their infancy and he wasn't optimistic they'd be effective for a post-inflammatory condition such as ours.

Really sorry to read how bad things are for you - also sympathise with the feeling that you want to find a doctor who can help, but there just aren't any. Hope tomorrow is a better day for all!

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Re: severe gnawing pain

Posted by kev - 03 Aug 2013 23:55

Who would have thought a bad back could lead to damage in so many different areas and organs in the body! I'm just wondering what and where it's going to hit me next. Glaucoma is a nasty one gmak.

Speaking of air con gmak, I've had to use my car's air con for the first time in years this summer in Scotland as we're actually getting some sun and heat this year! However I wouldn't like it as hot as you are getting gmak!

Helen, thanks for the info, even if it's not what I'd like to hear at least I can cross that one off. It's difficult to know where to turn to for a ray of hope.

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Re: severe gnawing pain

Posted by gmak - 04 Aug 2013 01:54

Kev i distinctly remember a pm from winter about your not seeing the sun for a long period of time which stuck in my mind of course, living i houston. So, im so glad to hear that you have the sun! Heat too remembering back from winter! I hate to say it it sounds so trite, but theres a ray!

Hi helen! Good to hear from you!

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