

AA

Posted by michaelg - 18 May 2013 14:38

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Pain pain all day and all night why will the doctors not believe me to the point of not recognising arachnoiditis as a condition caused by myodil I do not want to sue them I just want relief from the pain, is it because they know there is no cure and try to hide the condition. It must be terrible to be a doctor and know you cannot help somebody in so much pain.I have had my moan, but I don't feel any better. Good luck to everybody who has got myodil in their spine.

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Re: AA

Posted by gmak - 19 May 2013 22:37

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Dear michaelg, im so sorry that you, i & everyone has pantopaque, myodil in their spine too, especially the ones with aa. Im having what i would say the worst attacks of pure arach pain as it is so localized, so very severe it breaks through fentanyl & morphine like im taking water. An animal is chewing, gnawing on my spinal cord at L4-5, or it feels like it! I had csf leaks, esi's tntc, 4 surgeries, so i will never know exactly which source & it doesnt matter. Looking ahead i have to find the next step. Ketamine injections, scs put in peripherally so as not to disturb balance of sp nerves, pump but No. No dr in Tx i can find that knows about arach other than i have it on mri. Ive had it 24 years but found out last fall. Ketamine \$5000 a 4 hr treatment.What about you?Im so glad that you posted!

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Re: AA

Posted by janette whalan - 20 May 2013 08:28

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hiya Michael g, its so awful to read what you have shared, but I totally understand. I had three myodil, and so wrong that aa sufferers have to suffer such pain, all the studies say its hard to treat this kind of pain because of where the disease is, in the layers outside the spinal cord and so that kind of pain it hard for anything to work well. There are no answers, and that's what makes it depressing stressful isolating and damn hard. Hang in, try to find another doctor, ask around, if you talk with other aa sufferers or even chronic back pain or cancer patients, sometimes they have a good doctor.

There are doctors out there, its finding them.

You are in my thoughts

jan w

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