

doctor help please on procedure ? or anyone...

Posted by gmedic123 - 03 Jul 2005 19:54

Hi everyone-

i am new to the forum but not new to the site. I adore the site and give the mods a big bravo! for a job well done-Sooo much info and references are wonderful.

so,here is my question that i am hoping someone can elp with?! PLEASE!!!

I am supposed to have a pelvic laparoscopy done in the next two weeks

My first question: Has anyone had Laparoscopy done? Especially anyone in the Arachnoid group or anyone who has scarring/ fibroid type issues?

I thought it would be ok but my biological mom (nurse)says they see an awful lot of women with fibroids due to the gases they blow your belly up when inserting the probe and ablation tool- there by drying it out causing even NORMAL people to have scarring :eek: !!

second question please- Does anyone know how to get a question answered by Doctor Sarah Jones (Smith) or an American Doc who could Quickly (two weeks) answer the question on the lararoscopy?

then i get even MORE frustrated 🙄
because the decision on the hysterectomy that this is all about may still not be clear even after the laparoscopy....."Ovary going to take those things out or not Doc? LOL!"

i am stuck with a medical system in South Carolina USA that doesn't know arachnoiditis at ALL. I was very luck to find the best neuro doc in North Carolina who diagnosied my arachnoiditis (right on the money!) but that is as far as they go. It does not matter that i have a neurogenic bladder, allydonia,almost complete paralysis in right leg with neuopathic pain but without any pain receptors, over charged reflexes with footdrop(go figure),low back pain,joint sweling and pain ,etc etc. Mri points out encapsulating of nerves in arachnoid menengies and pushing out of dural sac. The docs in S.C. have never heard of arachnoiditis and my North Carolina nero only know arachnoiditis ,not adhesive or any of the other degrees.

so, I have no one to ask questions about secondary surgeries.

Doc Sarah you are the most respectable authority on this disease i know. Could you please give me a response to your opinion on a patient with our disease and the risks multiplied by it, if there are any by these two surgeries? my injury is from L3-S1. I know the final decision will be mine but i'd like to be well informed to make my decision. i thank you in advance for you time and help!

Please, anyone else who may have gone through these procedures and can offer opinions and or advice i would LOVE to hear it! Thanks everyone~G

hope every one has the best day possible and a beautiful sunset to look at!

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Re:doctor help please on procedure ? or anyone...

Posted by Kim - 04 Jul 2005 18:05

Hi there

Gone off to find answers for you. Will try to get for tomorrow.

DocSarah wouldn't give you any advice but would be able to answer general queries about procedures.

Bye for now

Kim 🍌

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Re:doctor help please on procedure ? or anyone...

Posted by Kim - 06 Jul 2005 19:10

Hi

Still waiting for a reply from the Doc but she only works part time and is not online at home yet. Working on getting funding for that so watch this space. I need her to be able to be online when the USA is awake and I have gone to bed!!

Bye for now

Kim

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Re:doctor help please on procedure ? or anyone...

Posted by Marti - 07 Jul 2005 00:15

Dear G,

I have AA and have had a laproscopy done. I have had fibroids removed from my uterus. I scar quickly and well! The only place scaring will be life threatening is my CNS. I have not had any more fibroids by the way. I know we are all a little different but one thing we have in common is that we make excessive scar tissue. I believe down the road they will find the common factor in our genes that causes this. I read about the research being done with posion toads. The toad provides some sort of chemical that prevents the growth of scar tissue. Wouldn't that be something if frog spit could cure us? 🐸

Marti

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Re:doctor help please on procedure ? or anyone...

Posted by gmedic123 - 07 Jul 2005 03:48

hi marty,

thanks for writing. I believe i am going to have the lap done. it is the first step in having a historectmy. my doc thinks he needs to see first what's there 😊
I am glad to hear yours went well! every good response makes me just a bit more at ease.

I haven't heard of the frog thing yet but the sea snail for pain is coming soon i understand.It is only for spinal pumps but it should help some of us and i am always glad to hear of anything that helps-even if it's not me! 🐸

so, how long have you had arachnoiditis and how is your life working with it? I am in southern USA and hope these are appropriate? for this forum and for you. I love meeting new people with archnoiditis. there are not many who understand this disease and how it makes you feel, messing with your daily life. I would love to talk more if you are open to discussing your experiences with this disease and if this is the proper place! 🐸

let me know!-G

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Re:doctor help please on procedure ? or anyone...

Posted by Marti - 07 Jul 2005 11:23

Hi G,

I think this is certainly the place! What a great site this is. There is so much easily understood information thanks to Dr. Sarah. Thanks to Kim for keeping it all available!

I was just told I had AA 6 weeks ago. I had been diagnosed with MS years ago. As the years went by symptoms increased, but the MS plaques in my brain did not. Three years ago I had a laminectomy at c3-4,4-5 due to spinal stenosis. Two years ago, I was sent to infectious disease because I was dumping proteins into my blood from muscle breakdown and I tested positive for trigonosis. (I'm not sure of the spelling). A diagnosis of Whipple's Disease was given. This was a clinical diagnosis since every test came back negative. The pain in my lower body had become so fierce that a pain pump was recommended. I went through a six week trial with the external pcp pump and it was wonderful! I was pain free for the first time in years. The permanent pump was put in, but the catheter fell out within the first three days. Of course the Dr. was hesitant to admit that was the problem until I ended up in the ER in withdrawal. A week later another surgery to place the catheter correctly. Again it worked for two weeks. However, while hospitalized, I had acquired MERSA and VRE infections and I spent seven days in intensive care with meningitis. I had 3 weeks of wonderful pain free time after that. I went for my first refill and the pump was up side down in my belly. The Dr. turned it over through my skin. (That procedure broke the catheter at the pump connection). X-rays did not show this break. A week later I was back in the ER in withdrawal. Backdrawing on the side port of the pump, no fluid could be withdrawn so the Dr. (actually an Intern this time) went in and "repaired" the catheter again. (The break at the pump was missed) I was back in the ER within the week. This time I was put on oral meds since the Dr. insisted the pump was fine and just needed titration. I went in every two weeks for titrations. For 3 months I lived in horrible pain insisting weekly that the pump was not working. In spite of titrating the pump from .5 to 13.0, I had no change in pain relief. Finally, my infectious Disease Dr. insisted on an MRI since I was running a low grade fever all the time. The MRI showed the AA and a huge granuloma surrounding the catheter tip. By this time, I had lost bowel and bladder control, had burning in the saddle area and horrible sciatica down both legs. I had lost 30 lbs and the oral meds were not touching the pain. The pump had to come out. The Dr. waited for over a week to get me into surgery. It was worse than the MRI had shown. Two Dr.s spent 7 1/2 hours trying to get the catheter untangled from the scar tissue and my nerves. They used cadaver material to make my dura larger so I would have some spinal fluid flow. The catheter break at the pump was discovered and coagulase negative strep infected the catheter tip. What a mess this has been. This Dr wants me to wait 3 months before having another MRI. I have not been given any prognosis or even an explanation of the current state of my AA. I know it is at the ossifans stage because the Dr told me the whole cord at t-11 was encased in a calcified material. I am going to the Spine and Nerve Center at Mass. General next week. I will bring all my films and records and hope this team of Dr.s can give me a second opinion, prognosis and treatment recommendations. It is my hope that a pain doctor will be identified for me. The Neurosurgeon does not want to deal with my pain management. I had to find another Primary Care Dr. because the one I have seen for years is unwilling to write scripts for pain meds as well. I am still in shock with all of this. I have permanent numbness in both feet and can't walk very far or long. I am currently on MScontin 100mg three times a day which I hate and is not working. I am hopeful about next week and trying to stay positive. Sorry I got so long winded. Guess it's a long story! I hope it has a good ending. Thanks for asking. Tell me more about yourself.

Marti from RI

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