

Recent conclusion

Posted by Marcie - 04 Jun 2016 15:58

First time on this site. I'm a senior citizen. Recently concluded that the daily headaches I have been suffering for 14 years may be caused by arachnoiditis. Yes, I had a myelogram in 1978 with Pantopaque dye prior to a laminectomy, and a recent CT scan of the lower spine for upcoming reconstructive back surgery identified arachnoiditis ossificans. I never thought to look it up until recently. In the past I have had MRA, MRI, MRV, CT scans, 3 Botox injections (useless), 3 sessions with acupuncture, hospitalization at Thomas Jefferson Headache Center, numerous neurologists in New Jersey and now Virginia, psychiatrists, psychotherapy, biofeedback. The most recent neurologist identified a contributing component--hypnic headache-- which wakes me in the early morning hours. The doctor recommended a trial of caffeine, and for the most part half a cup of coffee at night prevents the hypnic headache. But not always. There are times, mostly in the late afternoon, when it comes on suddenly, like walking into a wall, and I cannot function. For the last several years I have been alternating Relpax (a triptan) with Excedrin for Migraine even though rebound headaches are a consequence. I had no idea arachnoiditis could be so devastating. I have many, but not all, the possible symptoms, the most serious being constant head pressure, sore scalp, debilitating headaches, proprioception and imbalance. Due to upcoming extensive reconstructive back surgery and recent colonoscopy I cannot take aspirin, and I am trying to "suck up" the pain and get off medication, but it is hard! Major back surgery due the end of June. Wear a back brace at all times, even when sleeping.

Any comments would be most welcome. I just wish a doctor (even my orthopedist on Long Island all those years ago) had read the CT scan report back then and had alerted me. From what I know, nothing can be done, but I thought I'd mention my situation anyway. Thanks for listening (reading).

Marcie

=====

Re: Recent conclusion

Posted by kev - 15 Jun 2016 10:30

Hi Marcie, welcome to the forum. I'm no expert but if you've had a diagnosis of Arach ossificans, then further surgery has a high risk of worsening the Arach.

=====

Re: Recent conclusion

Posted by Marcie - 15 Jun 2016 17:06

I realize surgery is the last thing I would want to consider....it's totally out of the question. Just trying to handle the head pain.....

Marcie

=====

Re: Recent conclusion

Posted by ann - 17 Jun 2016 19:05

Hello Marcie,

Welcome to the group.

I did look up arachnoiditis ossificans on our search menu for you

But I realised that you have already looked up arachnoiditis ossificans yourself

and would know as much as what is on this site already

I am so sorry that you have to live with such pain and headaches

I wish and pray that one day we will all have a easy answer!!

Up to now no such luck but fingers crossed and everything else crossed as well !!!

We are all surprised at what arachnoiditis can do to a body no matter how long you have had it

We are all still learning what it can do.....If I find out anything about headaches I will let you know

As I have quite bad one's myself..... sorry I don't mean headaches but bad pains in my head

Anyway you take care... lots of love

ANN

=====