

## TO DOC.SARAH

Posted by jeff - 26 Jun 2006 15:33

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HELLO, AND THANK YOU FOR YOUR INCREDIBLE WORK THAT YOU HAVE DONE ON ARCHNOIDITIS. IN 1973 AND AGAIN IN 1975 I HAD MULTIPLE PANTOPAQUE MEYLOGRAMS. THEY WERE FOR TRYING TO LOCATE A TUMOR OSTEOBLASTOMA THAT TOOK 12 DOCTORS TO FIND IT. I HAD SURGERY 2 TIMES ON MY SPINE BOTH IN THE SAME THORACIC AND 7TH CERVICAL AREA. IN 1995 I BEGAN TO HAVE SEVERE PAIN IN MY THORACIC REGION, EVERYTHING SHOWED SEVERE DETERIORATION OF THE THE SPINAL CHORD, BUT NOTHING MAJOR. IN 2000 MY FEET BEGAN TO HURT, THEN NUMBNESS CAME AND THEN PAIN AND NUMBNESS. I FOUND THE BOOK BY DR. ALDRETE ON LINE AND DIAGNOSED MYSELF. I HAD BEEN TOLD I HAD NEUROPATHY AT ONE DOCTOR THEN AT THE UNIVERSITY OF CHICAGO I WAS TOLD I HAD RIDICULAROPATHY, THOUGH THE HEAD NEUROLOGIST THOUGHT I WAS PRE-DIABETIC, THOUGH I HAD NO BLOOD PATHOLOGY TO VALIDATE IT. KNOWONE WAS LOOKING AT MY PAST HISTORY. I FINALLY FOUND ANOTHER DR. INDR. ALDRETES BOOK CLOSE TO ME SO I WENT TO SEE HIM, THINKING THANKFULLY HE`LL FOR CERTAIN SEE IT. HE COULD NOT SEE HOW AFTER 20 YEARS IT COULD BE POSSIBLE, I REMINDED HIM OF HIS MENTOR DR. ALDRETE WHO SAID IT WAS. I HAD A COMPLETE SET OF MRI`S DONE IN AN CLOSED AT THE LEVEL IT SAID IN THE BOOK, AND AT L-4 L-5 S-1 THERE WERE MULTIPLE BLACK DOTS SHOWING NERVE CLUMPING. EVEN AFTER SEEING IT AND THE RADIOLOGIST SAYING THAT THEY SAW MARGINAL ARACHNOIDITIS HE AGREED BUT VERY RELUCTANTLY. MY G.P IS GREAT FOR TREATING MY PAIN BUT DOES NOT AGREE WITH ARACH, IT ALSO SHOWED BI-PAR FRACTURES, MY MUSCLE`S ARE ACHING ALL THE TIME IN MY ANKLES AND THIGH`S MY FEET ARE SO SORE THAT I USE A CANE. WHY IS IT THAT IT IS SO HARD TO FIND DOCTORS THAT WILL DIAGNOSE ADHESIVE ARACH I RECALLED ALL MY OLD RECORDS EVEN SHOWING THE MULTIPLE PANTOPAQUE INJECTIONS. YET STILL EVEN AFTER SEEING THE NERVE CLUMPING I COULD EVEN DIAGNOSE AFTER READING AND SEEING PICTURES THEY ARE STILL RELUCTANT. I GUESS MY QUESTION TO YOU IS WHY? AGAIN THANK YOU FOR YOUR WORK ,FOR ALL OF US.

SINCERLY, JEFF

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## Re: TO DOC.SARAH

Posted by DocSarah - 04 Jul 2006 13:32

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Dear Jeff,

Sorry to hear of your experiences. Sadly your story is by no means unusual. it is hard to be sure why arach. is so 'hidden'. I think there are a number of explanations:

1. the medical profession regard it as a rare condition
2. they are reluctant to diagnose an iatrogenic (caused by medical procedures) condition

3.the condition is incurable so doctors feel it is a 'no hope' diagnosis

I was at a meeting just the other day, with a group of doctors: radiologist, neurosurgeon, pain doctors, chiropractor, physiotherapist etc. Arachnoiditis showed up in 2 out of the 10 or so cases we discussed. In one case, it hadn't been noted before, the neurosurgeon picked it up but the radiologist was 'unconvinced' and admitted he only ever reports it if it is 'barn door' and unequivocal. This highlights the sort of problem we are dealing with.

You and others on the forum may be interested to know I am currently doing my Masters degree in pain management and as part of it am about to write a 20,000 word dissertation on recognition of adhesive arachnoiditis: aetiology (causes) and clinical presentation. In it I am including a case series with details on 10-15 cases. I am also going to be working with Kim Nevitt on a Cochrane Review of treatment of arachnoiditis. So I am always trying to raise the profile of the condition.

regards,

DocSarah

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**Re:TO DOC.SARAH**

Posted by jeff - 05 Jul 2006 11:16

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DOC SARAH,

THANK YOU FOR YOUR REPLY.I HAVE ALL MY MEDICAL RECORDS FROM 1973 AND 1975.THE ONE FROM 1973ACTUALLY STATES HOW MUCH PANTOPAQUE WAS PUT INTO MY SPINE 9cc,AND THEN ALSO STATES ALL WAS REMOVED EXCEPT FOR A FEW DROPS.I WOULD GLADLY SHARE ANY INFO I HAVE.

ALL THE BEST ON YOUR FUTURE WORK,

SINCERLEY,JEFF BECKLER

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**Re:TO DOC.SARAH**

Posted by DocSarah - 14 Jul 2006 11:22

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Hi Jeff,

even when it was aspirated, some dye persisted within the system. A few droplets is enough to cause inflammatory reaction. However, for those unfortunate patients who didn't have the dye aspirated and who have substantial residual dye, problems can be very severe and widespread.

Regards,

DocSarah

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