DocSarah

Posted by Kim - 27 Apr 2011 20:57

DocSarah has been admitted to hospital over a week ago and is waiting for surgery (not spinal) for an arachnoiditis related condition.

I spoke to her yesterday and she will keep me informed of what is happening. Although she will be missing for some time I have a couple of her blogs I can post. I am sure that you all wish her a speedy recovery, as being as selfish as I am, we need her back with us. Charles (her husband) so been so supportive during this difficult time and is very protective, so I might have a fight on my hands and a very long wait!

I can answer any general queries and search our website for answers but I am a pretty poor substitute for the real thing.

Please keep her in your thoughts and prayers for a speedy recovery and I will keep you all informed of her progress.

Best wishes

Kim

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Re: DocSarah

Posted by tarlov - 21 May 2011 11:46

Hello Kim...I always tell people to refer to the Aword as to reliable information about AA....But there are also patients that have both AA and Tarlovcysts. As for Tarlovcysts, I have been working for 10 years now, with professionals , I have access to medical information that can be trusted. I read on so many forums things that are told to other members as facts and are not medically correct, people sent to dangerous surgeries by people that have no medical background and no experience, and many , after, suffering from scar tissue and AA...So I am doing that to give reliable information in English about Tcs, to send people that have both to theaword.org,

And I have been obliged to make a similar cause in French. All day long I receive phone calls from French and Belgian people that are searching for information on both pathologies and nobody but me answering. As I am handicaped to 85%, have no pain management because of allergy to narcotic...it makes me very tired, and I am alone to do that. To post information where people can read it somewhere is helping me and others.

As to Procaine, It would be wonderful to have an update...but first of all, Doctor Sarah must have rest, lots of rest, to recover the more she can...Heartfelt kiss.

Take care

Claudine

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Re: DocSarah
Posted by Kim - 23 May 2011 19:41

Hi Claudine

Sorry for the delay in replying (Family weekend trauma)

I have to admit that until I heard from you I have never heard of Tarlov cysts. In fact all I had ever heard of was "cysts"! Not even arachnoid cysts in the early days. That was in the early 1990's. I did increase my knowledge and campaigned until the early 2000's. Nearly 8 years on the helpline, both national and international, people never categorized other than a cyst or cysts. I am still haunted by one young man (local) who had been told he had a massive cyst, covering half his brain and had a clinic appointment where he was told "we could operate or not, it's your choice" No information, nothing! I campaigned on his behalf to the hospital, a newly formed charity British Brain and Spine, without success. In fact it took them 10 years to provide a very bland booklet on Arach Cysts. Of no help to anyone!

I admire your commitment, Claudine, but I cannot give advice as I am not medically qualified. Which is why I left the Arachnoiditis Trust and made my mission to promote DocSarah and her information.

It was and still is a heavy burden that I have given her. Another reason why I am so protective of her.

I have another avenue for an update on lidocaine/procaine to follow, but it will always be with the agreement of DocSarah!

Take care

Kim

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Re: DocSarah
Posted by tarlov - 24 May 2011 08:22

I understand Kim..

As to me, having a scientific background, having specialist in my family, and pharmacists, has been helping me to learn. I did what a doctor does: I studied, at least for that part of the problem, like a real doctor wold have. In september, I'll have a graduation for educating people in the field of Tarlov and meningeal cysts...

It is very dangerous to operate on them and most of people do not get better but worse, like myself. Kim,

I am in severe pain 24/7 and if I could not educate others (always going on to learn in the meantime) I would no more be there.

Take care Kim,

Sincerely

Claudine

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chanyuan

Posted by chanyuan - 28 Apr 2017 01:45

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chanyuan2017.04.28

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