

re: Doc Sarah's help with Cochrane Review article

Posted by yankeewhiskeyvictor - 04 Jan 2006 17:59

Hi, DocSarah,

I am a member of ARAC arach support group; we, that is, our members, have been working what is left of our tails off trying to educate the world about arach, as you have. One of our members, Rod, has gotten the interest of the Cochrane Neurological Group, who has stated they would publish a 400 word synopsis about arach for their doctors if we could get a doctor to summarize and critique this ARC/AA condition.

Is there any possibility you would do this for us? We have tried to contact others and have gotten little interest, since there are few doctors who are knowledgeable about ARC. This one organization seems interested in at least describing arach to the medical profession. Don;t know if they are sincere or not, but they keep answering our queries, and stressing we need a physician or researcher with credentials to advocate for us.

Thanks for your site, and for what you are doing to bring this horrid condition to the public, and to spine patients. Appreciate your considering this request.

Al

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re: Doc Sarah's help with Cochrane Review article

Posted by helen - 06 Jan 2006 16:24

Hi Ali

I was interested to see your post on Cochrane Review. They kindly posted my "Feedback" on their website for the article on INJECTION THERAPY FOR SUBACUTE AND CHRONIC BENIGN LOW-BACK PAIN, and included me in their review as a consumer. Regards Helen:cheer:

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re: Doc Sarah's help with Cochrane Review article

Posted by DocSarah - 09 Jan 2006 12:15

Hi Al,

I could certainly send the Cochrane people a review as I have written one in the past, but to do an update would take time that I can't be sure I can commit to at this point. However, I will have a think as to whether I can find the time (maybe do without sleep for while or develop a 36 hour day!!)

Seriously, I want to support your very worthy endeavour so I will do what I can. Sign me up by all means. I do need to know what format and length the review needs to be. If as much as 10,000 words, I might be able to use the forward I did for Wendy Anderson's book, edited to include papers published since then (about 18 months).

Let me know what you want me to do...Kim will forward on any mail you send her.

Well done for getting Cochrane's attention!!

All the best,

DocSarah

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re: Doc Sarah's help with Cochrane Review article

Posted by yankeewhiskeyvictor - 09 Jan 2006 13:25

Hi DocSarah,

Thanks for considering this request!! As you can see, xxxx suggested writing the article, a min. of 400 words, then later suggested managing a formal review study (for later I presume- the long article you mentioned).. review Group co-ordinator, who can either accept your article, or relay it ... However, I am not so sure ARC is as rare as she thinks it is...

Hopefully we can get some coverage on this. I am still working on the Neurology Now US magazine, who promised to do an article on ARC/AA a year ago, but never did.

Thanks many tons for your assistance, and best wishes for a better New Year for you and all arachniacs.

Sincerely,

Alex

FROM>

Review Group Co-ordinator

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Latest Cochrane reviews: www.cochrane.org/reviews/

I have had an e-mail reply today from Janet at the Consumer network at Cochrane. She suggests that you write an article drawing attention to Arachnoiditis for the Cochrane Newsletter, how it is caught/contracted normally and how it affects the individual sufferers to explain to those who don't know. Within the article you can highlight how little evidence there is available on treating this condition and highlight

that it would perhaps benefit those suffering from this condition to have a systematic review written on it drawing attention to the lack of research available and if anyone is interested then contact (probably our group I guess) etc. I would suggest that you write between 400-500 words and send it to us and we will copy edit it and check it before sending it on to the Editor of the newsletter.

I am concerned that Cochrane may not be the best place for you to be putting your energy in to, however, as this is a condition with very little data. If a systematic review was to be written, chances are it would most simply highlight the lack of available evidence on this condition, which is not necessarily un-helpful, as this too can be useful. However, it is quite probable that as this disease is so rare, it will be difficult to ever gather randomised controlled trial data on it which is what Cochrane Systematic reviews base there searches upon.

I am not trying to put you off writing this article, however, as it may be fruitful as many clinicians do work in association with Cochrane and it might grab their attention. The only other journal I can think of where it might be helpful for you to discuss trying to get some focus on this disease is the British Medical journal or BMJ, but I am afraid I have no contacts with them so cannot advise you on who to contact there.

Please let me know if you are happy to go ahead and write this article so I can know to expect it in the new year.

Best wishes

Post edited by: yankeewhiskeyvictor, at: 2006/01/20 12:12

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re: Doc Sarah's help with Cochrane Review article

Posted by DocSarah - 27 Jan 2006 11:46

Let's hope this comes off and we can raise awareness!!

regards

DocSarah

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