

Guests, we need your input!

Posted by gmak - 08 Oct 2012 13:17

I see alot of guests each time i log on. Please We NEED your input. PLEASE JOIN So that we all can benefit from your stories and questions. Every site needs new blood, new ideas! Please know that we welcome your input. It is extremely valuable.

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Re: Guests, we need your input!

Posted by ichikirei702 - 15 Dec 2012 09:56

People show as guests until they Log In. As I just did. I joined in June. I posted about AA and high blood serum ACE. Still no one has answered my post. My ACE recently rose to 128. I have been tested 100 % sure for everything known to cause high serum ACE. Im an RN that was pursuing masters for Nurse Practitioner, so Im sure of what other ailments I should have been tested for. Everything listed by the NIH known to cause high serum ACE, I have tested negative for. PLEASE I encourage YOU and anyone else with AA to do a simple blood test called SERUM ACE. Both Quest & APL offer this test. I suspect those of us with AA will test high. We can do some of our own research and see if there is a link if you all get tested. The more we know the better we will be... and closer to understanding AA.

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Re: Guests, we need your input!

Posted by Blondie - 15 Dec 2012 17:17

Great tip on ACE test. I don't know anything about it even tho I am an "old" RN trying as you are to research, understand and educate the medical team here. I seem to punch holes in what the medical professions say about what is going on with me. AA seems to hit all the boxes with my symptoms. Any and all of what you learn will be helpful. I just recently joined this site.

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Re: Guests, we need your input!

Posted by gmak - 15 Dec 2012 18:57

Blondie wrote:

Thank you so much for the info on Craig hospital and Dr. Falci. Have you experienced their help or do you have additional info on the tethered surgery procedure? This is my major problem, ie feeling like my back it "stuck" plus reactions to various foods and additives.

I will research this more and hope you are feeling better.

Thanks.....

Hi all, Well we are 3 R.N.'s now! Maybe thats the common link!!lol I must be rusty but what is significant about the elevated ACE? Is it that we should all be tested to see if its a common denominator among us?Blondie, Its been awhile since i went to dr falci's site. I think when i was researching aa I came across his name in successfully treating a tethered cord & syringomyelia in a spinal cord injury site & another person had been to him as well. I will try to find it. Any answers on this elbow on knees sitting?

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Re: Guests, we need your input!

Posted by gmak - 15 Dec 2012 19:00

Has anyone heard from di? She mentioned the ketamine treatment & i wanted to know if it helped her? What the dr discovered?Sorry to be so brief but truly my elbows are killing me! Have a Merry Christmas to all who celebrate it & Happy Holidays to all!

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Re: Guests, we need your input!

Posted by old hag - 15 Dec 2012 21:27

Small world.....my mate with AA had ketamine infusion on monday last week at charing cross nhs hospital in london,

consultant who diagnosed arach is chris jenner there....he does private work too....

in uk...you seem to need to get the ketamine infusion to see if it helps with pain, as many people do not have the receptors to appreciate the drug....my friend was out of pain on the infusion, so now he can be prescribed it from his gp.....(currently out of stock at boots...might be at the vets as horse tranquilliser)

injection helped will keep you posted on whether the linctus helps...

don't know about the ACE thingy....

cheers

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Re: Guests, we need your input!

Posted by gmak - 07 Jan 2013 22:27

Hi old hag, i hate calling you that! What is linctus? Oh & how is ketamine prescribed for home? I dont think we can even do ketamine in US. Anyway i would be glad to see you here again!

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