
From: **Safavi, Farinaz (NIH/NINDS) [E]** <farinaz.safavi@nih.gov>
Date: Mon, May 24, 2021, 6:05 PM
Subject: Re: Covid-19 vaccine reaction set back
To: Kristi D <[REDACTED]>

Hi Kristi,

I am sorry about your diseases.

I suggest to make an appointment with a neuromuscular specialist at Wash University in St Luis and share my email with her/him. I would be more than happy to speak and share our understanding with her.

You need to get following tests including autonomic testing, EMG-NCS and skin biopsy if you still have pain and tingling in your extrimities.

You can tell the neurologist that it is most likely immune mediated snall fiber neuropathy and/or dysautonomia that likely responds to high dose corticosteroid or IVIG and I would be more than happy to share our knowledge with them.

Hope it helps

Farinaz

From: Kristi D <[REDACTED]>
Sent: Monday, May 24, 2021 3:37:20 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <farinaz.safavi@nih.gov>
Subject: Covid-19 vaccine reaction set back

Good Afternoon Doctor Safavi,

I am reaching out to you once again to let you know that I am having a very bad set-back in my progress to health. I reached out to a doctor that has been treating covid long haul patients, and he suggested modified cyclosporine. I have taken the cyclosporine for 7 days with no help in lessening my symptoms.

You had reached out to my Neurologist here, with no response back to you or me. He has dismissed my issues since day one, so it wasn't a shocker that when he said he was dismissing me, that he washed his hands of me. If you know of a good neurologist that you could collaborate with-in the Missouri, Kansas, Arkansas, Oklahoma area? I will go!

I would also be more than happy, at this point, to come to Maryland to see you, but I would have to make advanced arrangements for myself to get there, and then for childcare for my 4 kiddos.

I am grasping for anything again, because I don't know how much longer I can continue this personal pain. My back hurts all the time from the internal tremors, and from my lymph nodes that are still massively swollen. My muscles are weak, I can't sleep, I'm cold all the time, the tinnitus, dizziness, and tremors in my hands are lowering my ability to perform daily tasks.

I'm sorry to whine, but I just need help! I have been reading that this is being recognized by physicians better than it was 4 months ago when I first started this journey, but I just have very limited resources here in my small town.

I have an appointment with my Allergist/Immunologist June 10th. I am going to see if he can order EMG, and SFN biopsy. I have heard that IVIG, or pulse steroids are really the only tx options at this point, but there has to be an underlying cause. My only underlying cause is still only the vaccine. Every test I take is "normal" or "unremarkable". I say this in quotations, because I am not normal, and I am not unremarkably healthy. There has to be an answer, and I have spent 20 long hard weeks searching.

I would just appreciate some direction again.

Thank you, as always, for your time!

Kristi Dobbs