
From: [b6]
Sent: 5/16/2021 1:27:50 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
CC: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: Covid-19 Vaccine Reaction

Thank you, Dr. Nath, for your quick and kind response. It meant a great deal.
Best regards,

[b6]



Virus-free. www.avg.com

On Tue, May 11, 2021 at 7:34 PM Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

I am terribly sorry to hear of your illness. I have copied Dr. Safavi who is a neurologist working with me and is following patients with vaccine related complications. She will see if you might be eligible for our study.

With best wishes.

Avi

Avindra Nath MD

Chief, Section of Infections of the Nervous System

Clinical Director,

National Institute of Neurological Disorders and Stroke

National Institutes of Health, Bethesda, MD

[b6] (Office)

[b6]

From: [b6]

Date: Tuesday, May 11, 2021 at 7:14 PM

To: Nath, Avindra (NIH/NINDS) [E] [b6]

Subject: Covid-19 Vaccine Reaction

Hello Dr. Nath,

I was given your information by a few in the NIH study group. I understand you are involved in overseeing current studies on patients experiencing adverse, Covid long haul-like reactions to the vaccines. Allow me to preface the rest with gratitude, thank you. I'm sure you receive several of these emails on the regular at this point, and each represents more questions than answers. Lives that have been disrupted along a spectrum of variability. I'm a [b6] close to [b6] out from my first Pfizer vaccine [b6] and have experienced what I'm sure must be a familiar symptom set to you by now. My progression started gradually, slight tingling in the fingertips a few minutes after injection, several hours to headaches, a couple of days to bilateral paresthesias/dysesthesias (my entire body has been involved at this point, it fluctuates and migrates), pain in my ears, ear 'fullness', dizziness and vertigo when the headaches ramp up, joint pain, muscle pain, chest pain, diaphragm tightness, intestinal motility has slowed way down, temperature dysregulation, internal tremors, mild numbness, mild heaviness (hoping it stays that way), etc. I don't seem to have the HR or BP issues many are having. I'm sure you also understand how difficult it is for each person in this situation, particularly without answers or guidance, but especially without acknowledgement by many in the medical community. It's one thing to be a medical anomaly and quite another to be brushed off as simply "anxious." I'm not a person given to panic or anxiety, never have been. I still hold the view that this will resolve or we'll eventually figure it out together. The medical community needs to know this is happening though, and at least be given rudimentary ideas on how to treat symptoms, if nothing else. They need to know we exist so we can be heard.

Are there any treatment suggestions for immunomodulation and inflammation control until we figure the root of this out?

Is the study currently accepting new participants?

I look forward to hearing back from you. And want to thank you again, for hearing us. We're kind of floating around hoping the next specialist we see will even believe and take us seriously. Most of us understand the answers are limited.

Kind Regards,

[b6]

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246-**b6**
Sent: 5/18/2021 8:39:54 PM
To: **b6** Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6-**b6**
Subject: RE: neurological complications of Pfizer vaccine

Dear **b6**

I am sorry for your illness. We can schedule a televisit and discuss how we can proceed. I will send you a different email with my availabilities.

Best
Farinaz

Farinaz Safavi MD, PhD
Division of Neuroimmunology and Neurovirology
NINDS, NIH, Bethesda, MD

From: **b6**
Sent: Tuesday, May 18, 2021 4:36 PM
To: Nath, Avindra (NIH/NINDS) [E]; Safavi, Farinaz (NIH/NINDS) [E]
Subject: Re: neurological complications of Pfizer vaccine

Dear Dr. Nath,

I appreciate your response very much and look forward to speaking with Dr. Safavi.

Thank you again, and best wishes,

b6

b6

From: Nath, Avindra (NIH/NINDS) [E] **b6**
Sent: Tuesday, May 18, 2021 11:00 AM
To: **b6** Safavi, Farinaz (NIH/NINDS) [E] **b6**
Subject: Re: neurological complications of Pfizer vaccine

CAUTION: External Sender

Dear **b6**

Sorry to hear of your illness. I have copied Dr. Safavi, who is a neurologist working with me. She has kindly agreed to discuss your symptoms with you and see what we can do to help.

With best wishes.

Avi
Avindra Nath MD

REL0000229100

Chief, Section of Infections of the Nervous System
Clinical Director,
National Institute of Neurological Disorders and Stroke
National Institutes of Health, Bethesda, MD

b6

(Office)
(cell)

b6

From: b6
Date: Monday, May 17, 2021 at 8:09 AM
To: b6 Nath, Avindra (NIH/NINDS) [E]
b6
Subject: neurological complications of Pfizer vaccine

Dear Drs. Das and Nath,

I hope this finds you well.

I write to you because of your connection with the *Annals of Neurology* podcast of March 12, 2021 ("ANA Investigates: Neurological Complications of COVID-19 Vaccines"). The podcast write-up was one of the few places where I have seen a clear statement* that some of the symptoms I've been experiencing have been associated with the vaccines. I hope that you will not mind my sharing my experience.

I received dose 1 of the Pfizer vaccine on b6 On b6 I began experiencing muscle twitching in the arch of my foot. Fairly quickly the muscle twitches/spasms spread over the whole of my body, and I also began to experience vibration sensations (especially in my feet but also in a few other places). Unfortunately, I did not immediately connect these strange new occurrences with the vaccine because no one else I knew had experienced them. This meant that I ended up getting dose 2 of Pfizer on b6 The muscle twitches/spasms and vibrations continue to this day, b6 later. One day last week, one of my big toes twitched while also vibrating for about 30 minutes. Since the condition is worse when I lie down or when my legs are outstretched, I have not slept in a bed for several days. Sometimes the twitches and sensations are visible to the eye, and sometimes they are not. Occasionally, I will also have shooting burning sensations and perhaps mild pins and needles sensations (though with the heightened awareness of my body it is hard to tell whether the latter are psychosomatic or real). My GP--the only doctor I have seen--also diagnosed b6 b6 Otherwise, he said he thinks I am merely anxious. I am b6 right now, but the idea that these symptoms are primarily rooted in anxiety is rubbish. (Incidentally, I have reported my symptoms to VAERS, and I do not pretend that they are the worst neurological symptoms.)

I understand that correlation is not causation, and in five years, I expect to read that a large-scale epidemiological study shows that the neurological effects allegedly associated with these vaccines cannot be definitively linked to them because the incidence was no greater than what one would expect to see in the general population, or something to that effect. Again, I do think this is rubbish in some cases.

Besides a general concern about a push to vaccinate young children for what is by no means a "childhood illness" like polio or the measles, I am of course concerned about whether the vaccine has done some sort of

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lasting damage to my body or prompted some horrific autoimmune disease. Unlike some vaccine neurology patients, I do not seem to be in the midst of an emergency, and I have been unable to get an in-network neurology appointment prior to September. I do know that my physical state could change for better or worse quite quickly.

I know that you are both incredibly busy men, so thank you for reading this long note. Any advice or suggestions you have would be most appreciated.

Best,

b6

*"The most common neurological symptoms included dizziness, headache, pain, muscle spasms, myalgia, and paresthesias, which are expected to occur as acute, transient effects of the vaccination. Rare cases of tremor, diplopia, tinnitus, dysphonia, seizures, and reactivation of herpes zoster have been reported."

b6

From: [b6]
Sent: 5/22/2021 2:09:37 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
CC: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: I am a patient with an adverse neurological reaction to the Pfizer Covid vaccine [b6] Hoping for some help

Thank you so much for your response. I will definitely share your contact information when I am able to see a neurologist. I want to get well again as soon as possible.
Thank you again

Sent from my iPhone

On May 21, 2021, at 7:38 PM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

I am terribly sorry to hear of your illness. Your symptoms seem very complex. Certainly neuropathy has been seen with the vaccines, but would be hard to diagnose or treat via email/internet. Good that you have an appointment with a neurologist who would be the best person to determine the underlying cause. We would be glad to talk to your doctors if it would help. OK to share my information with them. We will be glad to share our experience with them.

With best wishes.

Avi

Avindra Nath MD

Chief, Section of Infections of the Nervous System

Clinical Director,

National Institute of Neurological Disorders and Stroke

National Institutes of Health, Bethesda, MD

[b6] (Office)

[b6]

From: [b6]
Date: Friday, May 21, 2021 at 7:12 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: I am a patient with an adverse neurological reaction to the Pfizer Covid vaccine [b6]
[b6] Hoping for some help

Dear Dr. Nath,

I sent the below email to Dr. Safavi earlier this week. I am physically devastated since I received the first Pfizer Covid vaccine. I am feeling even worse since I sent her the email. I'm having even more difficulty with severe neuropathy, muscle cramps, muscle twitching and pain throughout my body, and walking is becoming increasingly difficult (poor balance, extreme stiffness, unable to stay on my feet for very long.) I was hoping that I might start to improve as now it has been [b6] since receiving the vaccine.

Today, I was unable to perform my job as [b6] Everything hurts and I have extreme fatigue. I am having more brain fog episodes. My local physicians do not know how to help me. I've seen my primary care doctor, medical oncologist, and rheumatologist all since receiving the vaccine.

I was prescribed [b6] for [b6] and I am almost to the end of this treatment. Prior to the vaccine, I had [b6] for [b6] and I have been stable for that timeframe and did not medicate for it. My [b6] and my [b6] my [b6] at [b6] All of my labs are [b6] (I have all of those details below in the email to Dr. S. and can send complete labs on request). My rheumatologist even ran [b6] and there was [b6]

In 2020, I was treated for [b6] I did very well with the treatment. Pre-vaccine, I was fully recovered, daily exercising (either outdoor biking; 15 miles; indoor cycling for an hour, or 3 mile walks). My labs were all [b6] [b6] I was enjoying life and recently [b6] which would require travel, thus based on my doctors' recommendations and encouragement to do so, I received the vaccine.

The rheumatologist prescribed [b6] in assumption that this is [b6] [b6] prior to [b6] As noted above, those labs are [b6] [b6] There is no change in [b6] or [b6]

Currently, I have no diagnosis. Other than that I have an adverse reaction to the vaccine. I am having extreme difficulties in getting a diagnosis, a treatment plan, or answer on whether or not I should continue to [b6] or if I should be on another type of treatment or if I'm supposed to be waiting this out somehow. I don't even understand what is happening in my body and it is very frightening.

I am waiting to hear back on a neurology referral and I'm hoping you or Dr. Safavi could consult so that I could receive the proper treatment.

My life has been turned upside down. I am not sure if I will be able to be at home this weekend or if I will end up in the ER. This morning I woke up at 3 am feeling like I was shaking internally (not sure how to explain that) and feeling like I had rubber legs but was still able to stand and walk so I decided to stay home.

I have no idea what is happening to me or who can help me. My current doctors told me they've heard nothing of these types of reactions and my rheumatologist has said I am in uncharted waters.

Is there some direction you can offer? I need to be able to support me and my family as I am [b6] [b6] and I feel like I'm heading downhill. I don't want to lose my [b6] job due to my current inability to function and eventually travel.

I have multiple questions listed below for Dr. Safavi and I hope that you might also be able to provide some answers to my questions.

I am happy to discuss with you or Dr. Safavi further. I can be reached at [b6] I am desperate for answers and a treatment plan to help me recover so I can return to how my life was pre-vaccine.

Thank you for your time and consideration.

Sincerely,

b6

Sent from Mail for Windows 10

From: b6

Sent: Thursday, May 20, 2021 12:09 AM

To: b6

Subject: I am a patient with an adverse neurological reaction to the Pfizer Covid vaccine. b6
Hoping for some help

Dear Dr. Safavi,

I recently received information that you have been helpful to other patients suffering from adverse nervous system reactions to the COVID vaccine and I'm hoping you could help steer me in the right direction as I am also in that circumstance.

I received the first Pfizer vaccine on b6. Four hours after the shot, I started to experience side effects consisting of fever, brain fog, muscle aches and pains, difficulty walking, diarrhea, and abdominal pain. The flu-like symptoms lasted 4 days; however, the muscle aches and joint pains continued and worsened in my legs, arms, hands and feet. Since receiving the shot, I have suffered for b6 weeks with stiffness, aching, muscle cramping and twitching throughout my body. I have extreme neuropathy in both my hands and feet (burning, stabbing, pins and needles, numbness, and itching). I can't even sleep with a blanket on my hands and feet due to the nerve pain. I have difficulty walking due to pain and stiffness in my legs and I have poor balance. I have light sensitivity. I also suffer from fatigue and nausea - sometimes the brain fog returns. If I push myself to do my regular level of daily activities, housework, computer work, etc. the fatigue increases. I have pain, numbness, and tingling in my fingers which makes my job very challenging and exhausting to perform as I spend a significant amount of my day on the computer.

I am definitely not the same person post COVID vaccine. I did not have any of these issues prior to the vaccine. I was a highly functioning person b6 that incorporated daily exercise into my routine (outdoor cycling 10 to 15 miles each weekend, indoor cycling an hour every other day, and 3 mile daily walks).

Hoping these are pluses:

- All of my vitals are normal, blood pressure, oxygen rate, and pulse.
- I still can stand on one leg if necessary but it takes effort and concentration.
- I can balance on a bike but do not feel well enough to ride it. I tried riding it last week even though I am in pain, but it just exacerbated things and made me feel a lot worse.
- Bloodwork has b6
b6
- b6
- I wasn't exposed to and I've never had COVID so the severe reaction to vaccine #1 was not due to a prior COVID 19 infection.

I've consulted with my primary care doctor, medical oncologist (I survived b6 b6 hard to swallow that I am b6 but got my butt kicked by the COVID vaccine), and with a rheumatologist.

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The rheumatologist put me on [b6] for [b6]
[b6] I also take Tylenol to help some of the aches but it does nothing for nerve pain.

I have now been referred to a neurologist and I was told it could take over a month for me to be seen. I've also been told that if I experience muscle weakness where my legs give out or I can't pick up items due to muscle weakness I need to go to the hospital. This is a terrifying way to live and the local doctors do not know how to help as there is no information available to help those that are experiencing adverse nervous system reactions to the vaccine.

I am hoping that you could provide me with some thoughts to my questions where so far I have received no answers.

- Am I in some sort of immediate danger? Can I safely follow the advice of my current doctors, see the local neurologist in a month or two from now and monitor myself in the meantime for muscle weakness or other issues like swallowing difficulties and respiratory distress? Is there anything else I need to watch out for that means I should go to the ER?
- What types of tests should the neurologist run based on my symptoms?
- Is [b6] helpful or should I stop taking it?
- Should I be on some other type of medication that can help me?
- Can I develop CDIP? Or would this have already happened?
- Do I have some sort of neuropathy? Did the vaccine cause permanent nerve damage? Is it progressive?
- Is my condition permanent or will this somehow resolve on its own?
- Is it safe for me to travel? I need to travel by car to rural communities in the month of July for my company and I'm nervous to be too far from a hospital that could handle issues of the nervous system. At this point, I don't even feel well enough to travel but don't want to risk losing my job. I am [b6]
- Is there any protocol I should follow to help me recover?
- Should I push myself to do some type of exercise or movement? I'm afraid to do anything at this point. If I do exercise, I will be exercising in pain, but I'm in pain all of the time anyway. I just don't want to cause more damage.

I would appreciate any help that you could provide. I have seen in Medscape and Neurology Today posts from others like myself that are having these reactions. We are in need of help from the medical community to figure out why this reaction is occurring and to find a treatment for us so we can be helped by our local doctors.

I have been advised by my doctors that I should not receive the second COVID shot so it's distressing to me that I am living in this condition without even feeling protected from this horrible virus.

I also reported my reaction in the VAERS system and on the Vsafe check ins, I haven't heard back from anyone on my reports of the adverse reaction.

Thank you for your time.

Sincerely,

[b6]

From: [b6]
Sent: 5/22/2021 9:37:35 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6]
Subject: Re: URGENT- Vaccine neuro reaction- Referral note needed by the 24th please.

[b6]

Thank you so much Dr. Nath, the problem is that my PCP from the County Hospital doesn't even want to refer me to a regular cardiologist or neurologist, let alone [b6] Covid Long Haulers Clinic. The problem is that they don't believe us. They don't want to acknowledge this is a vaccine reaction and the fact that our tests are "normal" doesn't help.

I'm gonna tell them to reach out to your office if they need more information and see if that helps. My appointment is this coming Tuesday finally.

I'm [b6] I hope to get better soon and continue with my plans. I also had to stop working, which means less money for medical attention too.

Thank you so much for taking the time to reply to me even during your weekend! That speaks volumes about the quality of a person.

Best regards,

[b6]

On Fri, May 21, 2021, 8:58 PM Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

If they need a doctor's referral they mean from your PCP.

Will be glad to share our experience with your doctors if it will help.

Avi

From: [b6]
Date: Friday, May 21, 2021 at 3:14 PM

To: Nath, Avindra (NIH/NINDS) [E] [b6]

Subject: Re: URGENT- Vaccine neuro reaction- Referral note needed by the 24th please.

[b6]

Dr. Nath,

Thank you so much for your reply. I appreciate your time.

Will your email reply be sufficient for them to accept me in the program at the Covid Long haulers clinic? They want a Doctor referral because they only see patients that are or were positive with Covid-19, not people that had reaction to the vaccine but my doctors don't believe me, they said they haven't seen those reactions from the vaccine.

Maybe they can call you if they have any questions?

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b6 also told me that you were helping people like me by talking to their neurologists. Would you please be so kind to help me if I needed?

Thank you so much, May God bless you for helping us.

b6

On Thu, May 20, 2021, 10:20 PM Nath, Avindra (NIH/NINDS) [E] **b6** wrote:

My suggestion would be to see **b6** at **b6** who is a neurologist and superb neuromuscular specialist. He would be the best person for such symptoms.

Avi

Avindra Nath MD

Chief, Section of Infections of the Nervous System

Clinical Director,

National Institute of Neurological Disorders and Stroke

National Institutes of Health, Bethesda, MD

b6 (Office)

b6

From: **b6**

Date: Thursday, May 20, 2021 at 11:07 PM

To: Nath, Avindra (NIH/NINDS) [E] **b6**

Subject: RE: URGENT- Vaccine neuro reaction- Referral note needed by the 24th please. **b6**

Dear Dr. Nath,

My name is [b6] and I would like to first THANK YOU for all that you have done for others in my situation. These have been the darkest months of my short life.

[b6] gave me your contact information to please ask you as a big favor to help me with a referral note to be accepted at a Covid Long Haulers Clinic (that is our best bet right now?) I urgently need this reference by the 24th please if possible, they called me today with a cancellation. I lied to them telling them I have tested positive just to get in : [b6] Covid Long Haulers Clinic and [b6] Covid Long Haulers.

I'm a [b6] Onset of symptoms following Pfizer Covid vaccination. Symptoms manifested within 24 hours. [b6] I received both Pfizer vaccines on [b6] My first symptom was a movement on my hands similar to trigger finger - tendon inflammation. Has remained chronic to date and it's severe at night.

A couple of days after my second dose I started feeling numbness and tingling on my hands (especially on the pinky and ring finger) and left foot, weakness in my extremities.

Onset of nausea during this time period, continuing to date.

MRI of brain and cervical [b6]

[b6]

An orthopedist told me my numbness and tingling could be ulnar nerve neuritis or cervical neuropathy as a vaccine secondary effect, and prescribed [b6]

[b6]

Everyday symptoms: hands, feet, legs, and buttocks numb when sleeping (laying down) when this happens my body enters in this panic/startle like feeling and my heart starts racing waking me up, dizziness (on and off), tachycardia 24/7 HRR 100-140. Tinnitus, dry mouth, and throat are more noticeable when I'm sleeping. Nausea, shortness of breath, fatigue. Head feels heavy, left arm and legs weakness.

Some other symptoms that come and go: Irregular blood pressure, trouble swallowing, tingling, tingling on left side of my brain, dizziness, slow speech, head feels heavy even when I'm resting it against the seat or pillow.

I was taking [b6] from [b6] to [b6]

I'm currently taking [b6]

Medical records are available for interventions listed above. Several labs were taken during this timeline and before the vaccine.

I enormously appreciate your time to read my email, I can only imagine how busy you are. Thank you so much for your help. May God bless you!

Kind regards,

[b6]

From: [b6]
Sent: 11/13/2021 1:56:57 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Neurological symptoms

Dear Dr. Nath:

I hope this email finds you well. I am part of a large and growing number of people who had an adverse reaction to the Covid vaccine. I will not go into a lot of detail but basically had immediate reactions, followed by "brain-zspping," vertigo, high and low blood pressure, severe stomach pains, tinnitus, twitching, tingling, etc. it was awful and changed my life in a negative way. It has been [b6] since the one dose of moderna and I still have neurological issues. I had no known prior illness and on no medications.

I would appreciate if you could tell me if NIH, CDC or FDA are seeing any neurological safety signals associated with the vaccines. Looking through VAERS, these reactions are increasing in numbers.

Thank you in advance.

Peace and blessings,

[b6]

From: [b6]
Sent: 10/30/2021 10:06:59 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: RE: Acute and chronic neurological disorders in COVID-19: potential mechanisms of disease [data to support your paper]

Thank you for confirming that. Did I misread this:

From: Nath, Avindra (NIH/NINDS) [E] [b6]
Sent: Tuesday, October 26, 2021 11:03 AM
To: [b6]
Subject: Re: Acute and chronic neurological disorders in COVID-19: potential mechanisms of disease [data to support your paper]

Typically the manufacturers of a product are held responsible for any adverse events. Maybe they would be the best ones to contact.

Avi

Who have you alerted about the concern as you're receiving a growing number of reports and we now know the discrepancy and the imperative impact it is having for doctors not believing it exists if the NIH has not updated the information, despite manufacturers confirming reports of neurological adverse events in at higher rates than normal post vaccination? You are higher than me – because your email signature and address says NIH/NINDS, so it does appear you are affiliated.

I would be happy to follow up with whoever you alerted within NIH now that you know what is occurring. Maybe it takes multiple of us outside the organization plus someone inside who has heard the increasing reports.

From: Nath, Avindra (NIH/NINDS) [E] [b6]
Sent: Friday, October 29, 2021 6:48:58 PM
To: [b6]
Subject: Re: Acute and chronic neurological disorders in COVID-19: potential mechanisms of disease [data to support your paper]

This is not correct! I am not NIH, I just work at NIH. I do not have any authority over NIH websites.

Hope this clarifies the situation,

Avi

From: [b6]
Date: Friday, October 29, 2021 at 9:19 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: RE: Acute and chronic neurological disorders in COVID-19: potential mechanisms of disease [data to support your paper]

I've got some information in case anyone else asks after me.

I contacted the manufacture at 4:30pm PST (Janssen Info line provided on EUA). They confirmed the following:

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- Yes, they have enough reports of neurological conditions post injection to have updated their EUA Fact Sheet – this means they have received reports of neurological events following vaccination at higher rates than normal in the population
- I let them know that NIH said NIH has no power over what is on the website, and that I needed to contact the manufacturer because NIH cannot update the content – but rather the manufacturer has that power
- They confirmed (by contacting a supervisor) that they do not offer the updated adverse report information voluntarily, but rather it is NIH, CDC, and FDA responsibility to contact the manufacturer to get the updated information for each website that is public facing.
- They state that the content on NIH website is the responsibility of NIH
- As the only info line provided to contact the manufacture (all bring back to this line), they said they could not provide any information, contact, or department to contact to identify the gap in information.

So, my next line is to contact FDA to let them know that this major and serious gap in information is existing and I have had people identify the gap as the failure of NIH, FDA, and CDC to request the information from Janssen, because Janssen will not voluntarily offer this information to update.

But it does seem it is not the manufacturer who has control over NIH content as you thought might be the case. At least we have that cleared up.

The danger of lack of accurate and updated information is the impact it is having on clinician/specialists decision on how they pursue a set of symptoms. With the absence of an update, clinicians and specialists are trusting NIH, CDC, and FDA to present them the most accurate and up to date known information. If it is not there, they believe the post stating none have been reported. If none have been reported, they don't believe diagnoses related to vaccination is possible.

This is a massive gap.

I will let you know what I find, especially now that I know you have been getting an increasing number of reports. It must feel horrible not to know what to say to people who are suffering and hurting and feel like your hands are tied if you have not been given information either, know that reports of sever life-altering events are occurring but feel you are powerless to help get this accurate information out to help others.

But, now that quite a few people are alerted to the gap, I have followed directions from people to go directly to the sources, there will be no reason why the information will not be quickly updated to correct the error.

Sincerely,

b6

From: Nath, Avindra (NIH/NINDS) [E]

Sent: Thursday, October 28, 2021 7:52 AM

To: b6

Subject: Re: Acute and chronic neurological disorders in COVID-19: potential mechanisms of disease [data to support your paper]

I have not idea who at NIH handles these issues. I am just low on the totem pole.

Avi

From: b6

Date: Thursday, October 28, 2021 at 2:14 AM

To: Nath, Avindra (NIH/NINDS) [E] b6

Subject: Re: Acute and chronic neurological disorders in COVID-19: potential mechanisms of disease [data to support your paper]

Are you saying NIH has no power or authority over correcting the website representing NIH despite being aware of reports? Considering Janssen lost three of my adverse reaction reports, and I went to OCOD, is your recommendation that I go back to OCOD to ask for assistance in finding the barriers prohibiting NIH from providing correct information on their own website? Janssen manufacturers are responsible for not providing updated information to NIH and NIH does not report their own knowledge of adverse reactions to vaccinations, but can update adverse reactions to COVID-19 section?

From: Nath, Avindra (NIH/NINDS) [E]: [REDACTED] b6
Sent: Tuesday, October 26, 2021 11:03 AM
To: [REDACTED] b6
Subject: Re: Acute and chronic neurological disorders in COVID-19: potential mechanisms of disease [data to support your paper]

Typically the manufacturers of a product are held responsible for any adverse events. Maybe they would be the best ones to contact.

Avi

From: [REDACTED] b6
Date: Tuesday, October 26, 2021 at 1:05 PM
To: Nath, Avindra (NIH/NINDS) [E]: [REDACTED] b6
[REDACTED] b6 NINDSPostCovid19 <nindspostcovid19@ninds.nih.gov>
Subject: Re: Acute and chronic neurological disorders in COVID-19: potential mechanisms of disease [data to support your paper]

Who can I contact?

From: Nath, Avindra (NIH/NINDS) [E]: [REDACTED] b6
Sent: Tuesday, October 26, 2021 5:58:42 AM
To: [REDACTED] b6
NINDSPostCovid19 <nindspostcovid19@ninds.nih.gov>
Subject: Re: Acute and chronic neurological disorders in COVID-19: potential mechanisms of disease [data to support your paper]

Thanks for following up. I have no authority over websites or decisions on how research is funded or directed. All the same many researchers have pointed out to me that rare adverse events may be more accurate, if one considers that 100's of millions of people have received the vaccines.

Avi

From: [REDACTED] b6
Date: Tuesday, October 26, 2021 at 12:58 AM
To: Nath, Avindra (NIH/NINDS) [E]: [REDACTED] b6
[REDACTED] b6 NINDSPostCovid19 <nindspostcovid19@ninds.nih.gov>
Subject: RE: Acute and chronic neurological disorders in COVID-19: potential mechanisms of disease [data to support your paper]

Hello Dr. Nath,

I wanted to check in again for two reasons:

1. So far, there doesn't seem to be a research study in place, or a way to participate yet? Is this correct?

2. Coronavirus and the Nervous System | National Institute of Neurological Disorders and Stroke (nih.gov) appears to not have been updated for COVID-19 vaccines still, although the other parts of the page have been updated to reflect reported neurological conditions as a result of COVID-19. However, the section on vaccines still says "none have appeared as of yet." And, there is only one mention of "someone" indicating only one case. This is in direct conflict with the Janssen COVID-19 Vaccine - EUA Fact Sheet for Healthcare Providers Administering Vaccine (janssenlabels.com) that provides a range of neurological conditions that have been reported, as well as a growing collection of research literature, in addition to those of use who have alerted you personally.

I am aware of [b6] case, along with the now thousands of us experience moderate to severe neurological conditions, as well as people from Italy who have 100+ people all with neurological conditions post injection, and another group from Germany.

I am aware that in a message to [b6] family that it is not for lack of reporting adverse neurological conditions:

On May 25, 2021, at 10:27 PM, Nath, Avindra (NIH/NINDS) [E] [REDACTED] >
wrote:

Dear [b6]

Sorry to hear of your daughter's illness. Sounds like she has been through a lot and been investigated extensively. It is hard to make a diagnosis over emails, but if it would help we would be glad to talk to her physicians or the neurologist who took care of her. We have certainly heard of a lot of cases of neurological complications from the vaccine and will be glad to share our experience with them. You are welcome to share my contact information.

Best wishes.

My question then, is why does the website still say: "none have appeared as of yet" when a lot of cases of neurological complications have been known and reported?

In addition, I have found for myself that the CICP program is not functional. September 1, 2021, they posted that they have not compensated one claim because no one has been able to meet standard of proof. I asked for the guide, test, or standards used to compare claims with standard of proof in order to deny claims, as burden of proof is on the injured, with no support from experienced legal experts. The vaccines are not included on the Table of Injuries. They could not provide me with any guidelines for standard of proof that they used. So, I established a stronger framework that exceeded what they said would be necessary for standard of proof (quantitative data/biomarker, and peer-reviewed scientific published research). If the program was functional, and the only reason the claims were denied was because the claimants failed to meet standard of proof, the thorough documentation I provided would have provided evidence. I am providing a link to OneDrive here so you now have been notified and have access to my medical records as well:

<https://1drv.ms/> [b6]

CDC has access to the document I submitted to CICP on October 1, 2021, so do my clinicians and [b6]
[b6] At this point, it is unreasonable to believe that no reports have appeared as of yet, especially since I have sent a report to OCOD when Janssen lost my adverse report data 3 times. That means FDA and OCOD are also aware of my reports. I have reached out to you myself on more than one occasion, as did [b6] on my behalf.

I also reported concerns on "Was this page helpful?" (as included in the screen shot) that the information was out of date, and even included links to published research identifying neurological conditions post injection. That removes the argument that patient reported cannot be trusted and only research supported reports could be acknowledged. I am beginning to become concerned that with the sheer amount of notifications and reports of neurological conditions post

vaccination, the update of other parts of the website, this was not just a matter of accidental oversight. It is beginning to appear that there is a concerted effort to not acknowledge reports.

My greatest concern here is the now mandated EUA vaccinations for children. I am a [b6] I am still [b6]
[b6] The severity and absence of acknowledgement of my case, parents hearing there are no reports of adverse reactions, and pages like this that still say "none have appeared as of yet" are sending conflicting messages to intelligent people who truly are seeking accurate, scientific information. They are coming to me and asking if I think information is being hidden intentionally. I am asking you now to provide me with something logical to explain back. Without me being able to provide a logical explanation, the choice to continue to fail to acknowledge neurological injury is actually fueling conspiracy theory that more is known and it is intentionally being withheld from the public. It is decreasing confidence and trust in the population that is hesitant and on the fence, looking for assurance of authentic, transparent, and accurate reporting.

I have held off for [b6] months of checking with every possible avenue to find logical explanations. It is getting harder and harder for me to defend, to make excused for, to say "they probably didn't know until me."

I am asking you once again to help me disconfirm the swirling misinformation and give me solid evidence I can bring back to people to show NIH is taking action, is acknowledging, and is providing accurate, updated information to the general public once they are alerted to what is occurring.

I have also communicated with Xavier Becerra HHS Office of the Secretary, Health & Human Services, Dr. Rochelle P. Walensky Director, Centers for Disease Control and Prevention, Dr. Janet Woodcock Interim Commissioner, Food & Drug Administration, Dr. Peter Marks Director, Center for Biologics Evaluation and Research, Dr. Tom Shimabukuro CDC, COVID-19 Vaccine Task Force. I know I am not the only one who has brought the concerning information to their attention. I am doing my very best to keep combatting misinformation, and keep pointing to the emerging data in peer-reviewed published data. When there is disconnect between sources, it loses unity of messaging, and it opens the door for many people to try to fill the gaps. I am not doing that. I am going to the sources and asking each person I contact to provide accurate information for me to bring back. I have not been given the same respect in return as I have given. This is not a freedom of choice concern for me. I got the vaccine. This is a ethics and data concern for me. This is a concern about clinicians not getting access the most updated information, a way to identify and diagnose MIS post vaccination (even though EUA requires reporting, without guidance for clinicians – or even a formal acknowledgement – how are they able to follow EUA and meet mandatory reporting)?

Thank you,

[b6]

Does the COVID-19 vaccine cause neurological problems?

Almost everyone should get the COVID-19 vaccination. It will help protect you from getting COVID-19. The vaccines are safe and effective and cannot give you the disease. Most side effects of the vaccine may feel like flu and are temporary and go away within a day or two. In early vaccine development, there were extremely rare reports of unexplained neurological illness following COVID-19 vaccination, but regulators found no evidence the vaccines caused the illness. The U.S. Food and Drug Administration (FDA) continues to investigate any report of adverse consequences of the vaccine and none have appeared as of yet. Consult your primary care doctor or specialist if you have concerns regarding any pre-existing known allergic or other severe reactions and vaccine safety. Scientists are studying the risk to benefit ratio of the vaccine in someone who previously developed Guillain Barré syndrome after a vaccination. The general sense is the COVID-19 vaccine is safe in individuals whose Guillain-Barré syndrome was not associated with a previous vaccination.

The U.S. Centers for Disease Control and Prevention (CDC) [site offers information on vaccine resources](#). The National Institutes of Health (NIH) [has information on vaccines for the coronavirus](#).

[top](#)

Was this page helpful? ☐ Yes ☐ No

Next

Form Approved OMB# 0925-0548 Exp. Date 06/2024

Date last modified: Thu, 2021-09-02 16:19

Sent from [Mail](#) for Windows

From: [b6]
Sent: Tuesday, August 31, 2021 1:00 PM
To: Nath, Avindra (NIH/NINDS) [E]; [b6] NINDSPostCovid19
Subject: RE: Acute and chronic neurological disorders in COVID-19: potential mechanisms of disease [data to support your paper]

Thank you. I appreciate it.

I let them know that I'm in contact with a group with over 2000 people post vaccine and another with over 900 people post vaccine. I can help get the word out for the survey when it is ready.

[b6]

From: Nath, Avindra (NIH/NINDS) [E]
Sent: Monday, August 30, 2021 7:12 PM
To: [b6] NINDSPostCovid19
Subject: Re: Acute and chronic neurological disorders in COVID-19: potential mechanisms of disease [data to support your paper]

Dear [b6]

Thanks for your interest in participating in our research study. I have copied our research team who can guide you on how to participate in our online research study. We are gathering information at the moment.
Best wishes.
Avi

From: [b6]
Date: Monday, August 30, 2021 at 8:19 PM
To: Nath, Avindra (NIH/NINDS) [E]; [b6]

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b6

Subject: RE: Acute and chronic neurological disorders in COVID-19: potential mechanisms of disease [data to support your paper]

Thank you for the reply. I saw your quote in this article that you didn't have access to data to study: Federal vaccine court hasn't helped those whose lives were altered by COVID-19 shots (yahoo.com)

My offer still holds. I have all the data, and I have the links now between the vaccine and my injuries. Now that I know you are interested in studying that but just missing the data, I am offering again.

I was also wondering why the NIH website still says there were not other reports of neurological symptoms after vaccination, since there are now.

Thanks for the work you are doing to advance science knowledge!

b6

From: Nath, Avindra (NIH/NINDS) [E]

Sent: Friday, August 27, 2021 8:21 PM

To: b6

Subject: Re: Acute and chronic neurological disorders in COVID-19: potential mechanisms of disease [data to support your paper]

Dear b6

Sorry to hear of your illness. Thanks for your interest in our review paper and for sharing your ideas and insight with us. With best wishes.

Avi

From: b6

Date: Thursday, August 26, 2021 at 3:40 PM

To: b6

Cc: Nath, Avindra (NIH/NINDS) [E] b6

Subject: Acute and chronic neurological disorders in COVID-19: potential mechanisms of disease [data to support your paper]

Hello Dr. Power and Dr. Nath,

A colleague just forwarded me a link to your paper – titled in the subject.

I want to thank you for doing this work.

I have data that may help support your work further. I want to help in any way I can.

While I am not a medical doctor, b6

b6 That work gave me the foundation to keep searching for answers. I was specifically focused on how to study phenomena that did not have standards or precedent in existence to base my work on known solutions.

I have included an email thread below that a colleague of mine, b6 wrote to Dr. Nath in July.

b6 was referencing me.

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I also wrote NIH/NINDS twice asking if there was information as a web page noted rare neurological events were identified in clinical trials, seeking more information.

I have been keeping substantial documentation since my Johnson and Johnson COVID-19 Vaccination on **b6**
b6

last week, I gathered a collection of research between screen shots of my medical labs, clinician notes, and links to research papers surrounding the latest on SARS-CoV-2, mechanisms and other supporting literature to provide a bigger picture of parallels in COVID-19 as a vascular disease and the parallel symptoms I experienced following injection in the absence of viral load.

The hope is, much like neurological research looking at lesion studies to understand, comparing parallel injury post vaccination (in the absence of viral load) and injury in the presence of viral load (natural SARS-CoV-2) there might be a chance to narrow down more efficiently the mechanisms as part of viral impact vs impact of spike protein, localized inflammation and epithelial cells that go beyond the brain.

I have been in contact with Dr. Cynthia Magro (COVID-19 Research | Pathology & Laboratory Medicine (cornell.edu)) and Dr. Bruce Patterson (<https://covidlonghaulers.com/>).

While I was **b6** and I have what amounts to baselines of blood work that show **b6** and my antibody test **b6** and **b6** have been ruled out across **b6** extensive testing, Dr. Patterson's blood work labs resulted in showing **b6**
b6

I also believe I have been able to narrow down mechanisms of injury based on what is already know (ranging from injectable adjuvants, to the ingredient in Janssen's adjuvant hydroxypropyl- β -cyclodextrin, to what is known about adenovirus vaccines pre COVID-19, and soluble spike protein, and autopsy studies finding spike in absence of viral load). I have found research on known vaccine-induced encephalomyelitis with parallel symptoms to what is proposed as a methyl-group assault during SARS-CoV-2 (and I suspect there is similar mechanism), where I believe it is possible to explain a constellation of symptoms that may seem unrelated on the surface once the mechanism is narrowed down.

While it appears a tangled mess on the surface and incredibly difficulty to separate out mediating variables, I am an atypical case that may be able to help do just that – with baseline data **b6**
b6 that may be able to provide clues or puzzle pieces.

There has been consideration surrounding PEG and Polysorbate 80 as mechanisms of injury in COVID-19 vaccines (both by Dr. Patterson and Dr. Magro), but I have labs that show **b6**
b6 This is relevant because **b6**
b6 I have parallel neurological symptoms (as well as other symptoms outside of neurological parallel to acute SARS-CoV-2). We have been able to rule out actual virus from SARS-CoV-2 and PEG/Polysorbate 80 from the vaccines. I have, however, not yet been able to rule out spike protein as a mechanism. In fact, I am seeing hints of that support spike as possibly the primary mechanism of neurological in the absence of the other potential mechanisms. My quantitative spike protein antibodies **b6**
I know now elevated sCD40L has implications for blood-brain barrier. Autopsy studies have found little to no viral load and spike protein in the brain.

My neurological symptoms have presented as parallel to those with acute SARS-CoV-2 **b6**
and continually testing **b6** but there seems to be corroborating evidence that may help narrow down the mechanisms of injury as I have far fewer mediating variables than many clinical subjects and with more prior data than most even in clinical trials. I even have MRI **b6** pre and post. Complete bloodwork pre and post. Endocrine pre and post.

No underlying health conditions

No prescriptions/medications/drugs (before or during)

Never taken/used any form of birth control (removes the question of increased risk of stroke from birth control)

Never smoked

No alcohol, coffee, caffeinated drinks

Mediterranean diet (vegetarian)

I was a dancer/dance instructor (runner/weights) as a baseline for physical and vestibular ability

Published author and public speaker (videos/records) as a baseline for cognitive (my [CV is here](#))

Background in: b6

helped in my data collection even while I was the most sick (sometimes that was all I could do in a day, but I made sure to document symptoms)

If I am going to have to experience the severity of this suffering, I am not willing to let it go to waste. I want to help solve at least some of the complexities of the neurological aspects in this war against COVID that are the enigma machine of SARS-CoV-2 as mutations continue like the unbreakable code that took Allen Turing to create a machine.

Dr. Patterson has made major strides in using Machine Learning. Dr. Magro is investigating skin for nuances machine learning can't identify in a way a trained researcher can. I believe there is strong corroborating data across their work, and I am physically a puzzle piece that can help rule out and narrow down mechanisms to then help define questions and narrow down a focus sooner.

Why?

Because this is absolutely crucial and urgent:

Established diagnostic tools are limited by a lack of clearly defined COVID-19 specific neurological syndromes. Future interventions will require delineation of specific neurological syndromes, diagnostic algorithm development, and uncovering the underlying disease mechanisms that will guide effective therapies.

It is impacting insurance company denials of health coverage and disability. It is impacting clinicians who don't know what to do. It is impacting the social and emotional well being of people who are becoming suicidal because they are not being believed, have lost their jobs to debilitating impact, and it is taking people like me out of the front lines of

b6

where I am needed during COVID-19.

Sincerely,

b6

From: b6

Sent: Wednesday, July 14, 2021 7:53 AM

To: b6

Subject: FW: long-term neurologic sequelae from vaccine

FYI...

REL0000229126

Sounds like asking our Congressional reps to apportion funding to NINDS to study COVID might be a good idea...

b6

From: Nath, Avindra (NIH/NINDS) [E] **b6**
Sent: Tuesday, July 13, 2021 10:01 PM
To: **b6** Patterson, Amy (NIH/NHLBI) [E] **b6** Wright, Clinton (NIH/NINDS) [E] **b6**
Subject: Re: long-term neurologic sequelae from vaccine

Dear **b6**

I am terribly sorry to hear of these illnesses. Unfortunately, the intramural program at NINDS has not received any funding for COVID research. I have copied Drs. Patterson and Wright who are managing the portfolio and would be in a better position to respond to your concerns.

With best wishes.

Avi

Avindra Nath MD

Chief, Section of Infections of the Nervous System

Clinical Director,

National Institute of Neurological Disorders and Stroke

National Institutes of Health, Bethesda, MD

b6

From: **b6**
Date: Tuesday, July 13, 2021 at 2:56 PM
To: Nath, Avindra (NIH/NINDS) [E] **b6**
Subject: long-term neurologic sequelae from vaccine

Dear Dr. Nath –

Hello! I'm a **b6** and have two acquaintances who have had persistent and debilitating neurologic symptoms that seem to be in response to the COVID-19 vaccine. Apparently there are many others out there with similar symptoms and folks have started forming groups, such as <https://www.vaxlonghaulers.com/>. The symptoms seem to be similar to those of Long COVID, with the exception of respiratory symptoms. As a **b6** I am well aware that many of these symptoms can be due to depression, anxiety, and a whole host of other causes, both organic and non, but I am struck by the case of a colleague, a bright and highly successful **b6** who has been completely debilitated since her vaccination with exhaustion, weakness, vestibular dysfunction, trouble with word-finding, problem-solving, and memory. She was a true champion for science and mitigation measures at her school this past year and happily received her vaccine. Unfortunately, not only has she been debilitated since then, but multiple attempts to seek answers or assistance from V-SAFE, VAERS, FDA, Janssen, and CDC have been unsuccessful. In fact, it's been a comedy (more of a tragedy) of errors, with lost case numbers, disconnected phone calls, CISA consults that were cancelled without her knowledge, and more dead ends and frustration than you can imagine.

I'm writing to you today to ask that NIH begin to seriously study these potential neurologic adverse reactions to vaccine. I know you have a lot on your plate, with acute and long-COVID and their neurologic manifestations being very

REL0000229126

important, and the meeting the next two days. But these folks are also suffering, and we owe it to them to first recognize and acknowledge what is happening, and then try to figure out why it's occurring and what therapeutics may be useful. We also owe it to medical professionals and citizens to gather good data to help us understand this phenomenon and then communicate about it, so that these poor folks will no longer be dismissed out of hand and told that they're imagining it all.

I would also appreciate any efforts you could make to send the message that the V-SAFE system and other safety measures we've put in place do not seem to be working as intended or as promised to the public.

Thank you so much for all of your excellent work. Good luck with the meeting this week. I'll hope to see some investigation into potential long-term neurologic sequelae of COVID-19 vaccines in the very near future.

Sincerely,



b6



b6

From: [b6]
Sent: 10/24/2021 3:13:17 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: Covid vaccine neurological issues

[b6] but I'm willing to travel anywhere in the world for someone to help me. I have had a terrible last year and this has really broke my spirit having all these problems with this vaccine. I can't find anyone in [b6] that has any idea how to help me.

Sent from my iPhone

On Oct 23, 2021, at 8:48 PM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Where do you live

From: [b6]
Date: Saturday, October 23, 2021 at 9:25 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Re: Covid vaccine neurological issues

Thank you so much for this information. I don't live in New York but will travel anywhere to feel better. Will I be able to get around New York if I haven't been fully vaccinated? I have been advised to not get the second shot. My doctor would give me an exception letter too. Thank you so much for replying! You are a blessing. Have a great weekend!

Regards,

[b6]

Sent from my iPhone

On Oct 23, 2021, at 8:12 PM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

Sorry to hear of your illness. If you live in the NY area, I would suggest seeing any of the following:

[b6]

They are all well versed in these complications and will investigate and treat you.

Avi
Avindra Nath MD
Chief, Section of Infections of the Nervous System

Clinical Director,
National Institute of Neurological Disorders and Stroke
National Institutes of Health, Bethesda, MD

b6

From: b6

Date: Friday, October 22, 2021 at 11:36 AM

To: Nath, Avindra (NIH/NINDS) [E] b6

Subject: Covid vaccine neurological issues

Good morning,

I'm writing to you today out of desperation. I'm looking for anyone who can help me recover after my first Pfizer vaccine. Almost immediately after receiving it I had lightening bolt of pain on the left side of my brain and after that I have had a multitude of symptoms. I felt electrical sensations all over my body with a revved up feeling internally. I had very deep sleep but also was not my normal sleep. I was having lucid nightmares. At one point I almost felt like I was losing my mind when I would go to sleep. That has gotten better but I am still having vivid dreams. I developed diarrhea, tinnitus, sensitivity to sound/light/touch, paresthesias in all limbs and numbness in limbs, headaches unlike any I have ever felt before, brain fog or difficulty concentrating, skin feeling sensitive and burnt but I haven't been in the sun, random areas of intermittent pain on my skin as well. I saw Dr. Thakur as an author of a review in a neurology journal and he mentioned talking with you. I got your email off of the internet. I have reached out to many others as well as Mayo Clinic and come up short. Please help me or point me in a direction of someone that can. I have 3 kids to care for that are b6 Thanks so much.

Regards,

b6

Sent from my iPhone

From: [b6]
Sent: 9/28/2021 1:19:57 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
CC: [b6]
Subject: RE: Neurological complications from COVID-19 Moderna vaccine

Dear Drs. Nath and [b6]
Thank you so much for all your time and effort to review and discuss [b6] clinical status. It is a huge relief for the family that there is [b6] for her, so that she could concentrate on the rehabilitation plan.
The family is very grateful for the care from [b6] Dr. Nath's consultation. On behalf of [b6]
[b6] I want to express their appreciation for your kindness, sincere caring, and concern that make everything better and are a great encouragement.
I believe that [b6] will feel better and better, as she is working with the best of the best doctor, very luckily. Thank you again for your time and consultation.
Best regards,
[b6]

From: Nath, Avindra (NIH/NINDS) [E] [b6]
Sent: Tuesday, September 28, 2021 8:48 AM
To: [b6]
Cc: [b6]
Subject: Re: Neurological complications from COVID-19 Moderna vaccine

Dear [b6]
Thanks for the detailed information. [b6] and I have communicated and discussed the clinical presentations, the investigations and the plan for care. The investigations have been very thorough and I agree [b6]
[b6] She is receiving the best care possible and am sure she will continue to keep getting better.
With best wishes.
Avi
Avindra Nath MD
Chief, Section of Infections of the Nervous System
Clinical Director,
National Institute of Neurological Disorders and Stroke
National Institutes of Health, Bethesda, MD
[b6] (Office)
[b6] (cell)
[b6]

From: [b6]
Date: Tuesday, September 28, 2021 at 4:59 AM
To: [b6] Nath, Avindra (NIH/NINDS) [E] [b6]
Cc: [b6]
Subject: RE: Neurological complications from COVID-19 Moderna vaccine

Thanks you for this information. As we stated yesterday, [b6]
[b6] We will review this information with

Dr Nath, and anyone else that the family wants to involve. I am confident in her recovery. Avi, if you want to talk off-line, I am happy to do so.

b6

b6

b6

b6

b6

From: **b6**

Sent: Monday, September 27, 2021 10:22 PM

To: **b6** 'Nath, Avindra (NIH/NINDS) [E]' **b6**

Cc:

Subject: FW: Neurological complications from COVID-19 Moderna vaccine

External Email - Use Caution

Dear Drs. [b6] and Nath,

I would like to express the gratitude on behalf of [b6] family to both of you for providing guidance and support for [b6] treatment. We had a very productive conference call with [b6] to discuss [b6] diagnosis and treatment plan, involving [b6] and friends at [b6]. The family felt very relieved and confident in [b6] after talking to [b6] today.

I am writing to address one of the concerns that the family are still having. They would like to rule out [b6]

First, please allow me to provide some background information about [b6] health status, as some information may not be on file. I have copied [b6] in this email so that she could correct me if any of the statement is not accurate.

(1) Brief description of events before and after the Moderna vaccine shots

[b6] has received a number of injections of vaccines or immunity enhancing agents listed as bellow:

a. SinoVac (Chinese COVID-19 vaccine, inactivated virus, received in China),
<https://www.who.int/news-room/feature-stories/detail/the-sinovac-covid-19-vaccine-what-you-need-to-know>

2 shots, on [b6] respectively.

b.

b6

c. Moderna COVID-19 vaccine, 1st shot on [b6] 2nd shot on [b6]

(2) Reactions to Moderna COVID vaccine

After the 1st shot, high fever for 2 days, hives on skin;

After the 2nd shot [b6]

[b6] high fever, muscle soreness. Took advil;

[b6] felt a little bit better, had a routine exercise;

[b6] after vaccination), felt more tired.

[b6] after vaccination, went to ER due to extreme chest pain. Got discharged.

[b6] went to ER. After checkup, got discharged.

[b6] rested at home;

[b6] after vaccination), felt extreme chest pain. Fainted after a walk outside. She was then sent to ER, received [b6]

[b6] got discharged from ER in the morning. But then lost the ability to move.

[b6] went to [b6] ER due to losing the ability to move.

[b6] Thursday evening, transferred from [b6] ER to Neurology inpatient care.

As you can see from the above description, [b6] appears to suffer from neurological complications from Moderna COVID-19 vaccination.

It would be extremely helpful if she could focus on treatment [b6]

[b6]

[b6] I understand that there may have been some tests that have been done which may help to address these issues.

It is highly appreciated if you could review the information stated above, and advise if further immunological tests will help to address the concerns on potential immunological abnormality, which may worsen or retain the neurological complication.

Please let me know if you need more information. I appreciate your time and effort to address these issues that the family are worrying about.

Best regards,

b6

From: Nath, Avindra (NIH/NINDS) [E] [b6]

Sent: Monday, September 27, 2021 7:48 PM

To: [b6]

Cc: Moir, Susan (NIH/NIAID) [E] [b6] Smith, Bryan (NIH/NINDS) [E] [b6]

Subject: Re: Neurological complications from COVID-19 Moderna vaccine

Dear [b6]

Glad to hear that [b6] is the best of the best! You are lucky to have him. We know each other well. I am always delighted to talk to him

Avi

From: [b6]
Sent: 9/12/2021 8:50:17 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: Cardiologist from [b6]

Thank you very much dr Nath.

Have a great Sunday.

Regards

[b6]

On Sat, Sep 11, 2021, 11:15 PM Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

OK. I will be glad to talk to him.

Avi

From: [b6]
Date: Saturday, September 11, 2021 at 10:00 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Cardiologist from [b6]

Good evening doctor Nath,

I hope you are doing well. I had to travel to [b6] to look for treatment options and I met [b6] [b6] from the [b6]. He would like to possibly talk to you about a treatment plan for me and he is also very interested in starting a research about people that develop dysautonomia post vaccination. He is [b6] [b6] and has written multiple research papers as well. He will publish my case and also gave me a letter that advises not to get a third vaccination or booster after developing [b6] post vaccination.

I have given him your contact information, as you suggested in one of your emails that you would gladly talk to our doctors to offer advice, which I really appreciate.

Thank you very much,

[b6]

From: [b6]
Sent: 8/19/2021 3:21:18 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: Please Help-Covid Vaccine Reaction

Thank you, Dr. Nath.

Thank you,

[b6]

Sent from my iPhone

On Aug 18, 2021, at 11:02 PM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

Sorry to hear of your illness. We did see a few patients, but have not been able to add much to what the local neurologists can do. My suggestion would be to continue to work with them. This is all very new to all of us, so really none of us can claim to be experts.

Best wishes.

Avi

Avindra Nath MD
Chief, Section of Infections of the Nervous System
Clinical Director,
National Institute of Neurological Disorders and Stroke
National Institutes of Health, Bethesda, MD

[b6]

From: [b6]
Date: Wednesday, August 18, 2021 at 12:48 AM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Please Help-Covid Vaccine Reaction

Hi Dr. Nath,

I hope you are having a great day so far! I read the LA Times article about how you are studying people who've had rare reactions to the Covid-19 shot. My experience was similar to [b6] after I got the Pfizer shot [b6] I'm currently [b6] because I broke out in hives, been having numbness and tingling, and have an accelerated heart rate. My lymph count [b6] [b6] My doctors cannot figure out what's causing my reaction and I believe it could be mast cell activation syndrome. I'm currently located in [b6] but I would love to speak with you about it and hopefully get answers. I'm [b6] and was [b6] so this experience has been awful.

Thank you,

b6

Sent from my iPhone

REL0000229160

From: [b6]
Sent: 9/9/2021 2:58:25 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: COVID-19 vaccine reaction [b6]
Attachments: [b6]

Hi,

My name is [b6] I am a [b6] in [b6] I have been in touch with [b6] about my confirmed case of [b6] immediately post COVID-19 Moderna vaccine in [b6] now with [b6] [b6] I would really like to know in addition to the support of my neurologists if this is meaningful. I would really like to have some help with guidance. Maybe some other specialists that can help me with this specific [b6] [b6] Are there other cases like this?

I am a [b6] and need help. I am [b6] [b6] I am on a dangerous path and was told you may be of some guidance.

I have attached my records.

Kind regards,

b6

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From: [b6]
Sent: 8/20/2021 12:03:50 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: Covid vaccine and rare neurological response

Thank you so much for responding.

We are getting an MRI in early September but cannot get into a neurologist until November.

If NIH is ever looking to study rare vaccine reaction, are offering experimental treatment or even have guidance on what care path to take, I would love to submit [b6] in hopes we can find some way to treat her symptoms. Her quality of life is so low at this moment.

Thank you so much for even taking the time for your kind reply.

Warmly,

[b6]

On Aug 19, 2021, at 2:33 PM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]
Sorry to hear of [b6] illness. Is it possible to have her seen by a neurologist who can do some investigations? They might be able to treat the tremors etc.
Avi

From: [b6]
Date: Thursday, August 19, 2021 at 1:00 AM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Covid vaccine and rare neurological response

Dear Dr. Natha,

I found your contact information from tan LA Times article about rare Covid vaccine injury. [b6]
[b6] has been experiencing ever-increasing neurological distress since receiving the first dose of the Pfizer vaccine in [b6]

It began with drastic fatigue, brain fog, inability to track print so she can no longer read, light sensitivity, decreased appetite and trouble focusing. Since then, the symptoms and deterioration has progressed into a 15lb weight loss - she's now only 100lbs - instability that has caused a fall, tremors in her hands, massive anxiety and decreased cognitive function. Her blood pressure and resting HR have [b6]
[b6] in only weeks since receiving the shot.

She has been in the ER six times in less than seven weeks, but with no real "diagnosable problem," she is always sent home. I'm trying to get her into a neurologist - we are based [b6] but no one can see her before November. I have her signed up for [b6] [b6] which took more than three months to get an appointment - but I'm near certain they won't even consider her case as [b6]

I am desperate to find help for her as she was a fully functioning woman who lived alone and managed her entire life wonderfully until getting vaccinated. She is now a shell of her former self who requires 24 hour care and is hardly recognizable to her [b6]

I suffer tremendous guilt as she was very reluctant to get the vaccine - I pushed it as I felt it was very important but she always felt her sensitive system would react negatively.

I would never consider reaching out if I was getting anywhere with the medical care I'm attempting to access now. But I'm afraid [b6] before we ever figure out what's wrong.

I'm so hopeful you might be able to even point me in a helpful direction.

Thank you for all you do.

Sincerely,

[b6]

[b6]

From: [b6]
Sent: 8/28/2021 3:21:47 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Automatic reply: Acute and chronic neurological disorders in COVID-19: potential mechanisms of disease [data to support your paper]

My [b6] has been extended [b6]
[b6]
[b6] I took the Johnson
and Johnson vaccine on [b6] and have been experiencing severe adverse reactions since. Doctors
have ruled out [b6]
[b6]

I appreciate your patience as recovery from vaccination is taking far longer than anticipated.

[b6]

From: [b6]
Sent: 8/17/2021 6:08:59 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: Possible vaccine reaction

Dr. Nath,

Thank you for the prompt response. I will continue to work with our local physicians. I am currently waiting to hear if [b6] [b6] will see her. I've also reached out to [b6] [b6] to see if they will see her. I am just waiting to see who will respond first. If it turns out to be vaccine related, I can let you know. Just for your own curiosity I suppose. If you'd want to know.

Thank you for responding. It means so much to know you took time out of your schedule to respond. I know you can't really make a diagnosis but it is helpful to know that it could be a possible vaccine reaction.

Thanks,

[b6]

Sent from my iPhone

On Aug 17, 2021, at 09:38, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

Terribly sorry to hear of [b6] illness. I am sure this is hard on you and the rest of the family. Thanks for reaching out for advice. From what you describe, it could very well be vaccine related, although I do not know of others with similar symptoms. Hard for me to make clinical diagnosis over email and internet. I would suggest that you continue to seek care from your local physicians, if needed an academic center might have more resources for investigations so might be worth considering if not already.

Best wishes.

Avi

Avindra Nath MD

Chief Section of Infections of the Nervous System

Clinical Director, NINDS, NIH

Bldg 10; Rm 7C-103

10 Center Drive

Bethesda, MD 20892

[b6]

From: [b6]
Date: Tuesday, August 17, 2021 at 11:47 AM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Possible vaccine reaction

Hello,

I hope this email finds you well. I will get right to the point.

[b6] received her second Covid vaccine on [b6] No issues until she stopped urinating on [b6] We took her to the ED on [b6] as we thought maybe she was dehydrated

from [b6] that weekend. They pumped her full of fluids and she still couldn't urinate. Long story short, I have to now straight cath her twice a day. She is unable to feel the sensation to urinate nor does she have the full sensation either. She cannot relax her sphincter to urinate and can only eliminate her urine by either physically pushing on her bladder or by me cathing her. Other complaints she has since [b6] include kidney pain, headaches, fatigue, lightheaded, and dizziness. She has had blood tests and and MRI of her head and CT and MRI of her abdomen. [b6]

[b6] The only thing that [b6] after her symptoms began and [b6] that is being treated now. She has seen a urologist and a neurologist. The neurologist said [b6] and recommended she see a neuro-urologist. The urologist thinks that maybe this happened because [b6] But the problem with that is 1. This all started in July and 2. She had not been in school all year due to Covid (except half days starting in April through May).

Currently, I am trying to rule out depression or psych conditions, any urological conditions, any neurological conditions, and have even sought out a Chinese medicine doctor. I had always wondered if this could be a side effect from the vaccine. What are your thoughts and how do I go about the process to report it to the cdc if it is. I just don't know what else to do. It has us all devastated and exhausted.

Thank you,

[b6]

Sent from my iPhone

From: [b6]
Sent: 7/23/2021 7:31:28 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6; [b6]
CC: NINDSPostCovid19 [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=7288bc48d86f4f5fb796620bda298e7f-nindspostco]
Subject: Re: Somewhat unusual vaccine side effect

Hi Dr Nath-

I am so glad to hear you are collecting this information. I know more than a dozen people who are experiencing neurological side effects from the vaccines, particularly people with pre-existing ME/CFS. Should I have all of them write Angelique?

Do you have a link to the protocol I can publicly share?

Thanks,

[b6]

On Fri, Jul 23, 2021, 1:40 AM Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

Sorry to hear of your illness. At the moment we are collecting data of patients who are having neurological side effects from the vaccine. If you would like to help us with that, we would be most appreciative. I have copied our team on this email and they can collect the information.

Wishing you all the best.

Avi

From: [b6]
Date: Friday, July 23, 2021 at 12:27 AM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Somewhat unusual vaccine side effect

Hi Dr Nath-

I saw you mentioned neurological side effects seen after Covid vaccines on a Body Politic webinar. I was wondering if you knew any researchers looking into other types of side effects? I've had a low-grade fever (100-100.2 many days) since I had the first Pfizer jab [b6] ago. My body temperature had previously run low (typically under 97) for at least a decade.

I haven't had a second shot as my doctors recommended I not get the second shot. I have met several other people who have had multi-month fevers after getting vaccinated, although that of course seems rare. I also

now have [b6] but I am not
as sure it coincided with getting vaccinated as I didn't do a lean test right beforehand.

Is there anyone at NIH that you think would be interested in this issue? I tried [b6]
[b6] but haven't tried the much longer course an immunologist I know suggested.

Thanks,

[b6]

From: [b6]
Sent: 7/20/2021 3:54:07 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
CC: Brown, Warren (NIH/NINDS) [C] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=bef0730648434bb69542199fca79f67e [b6]
Subject: Re: Ongoing health issues post Pfizer Covid vaccine

Hi Dr.Nath,

Thank you so much for responding so quickly to my email, I am very grateful and am looking forward to chatting with you.

Thank you again,

[b6]

On Mon, Jul 19, 2021 at 9:49 PM Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

I am terribly sorry to hear of your illness. I will be glad to talk to you. I have copied Warren who maintains my calendar and can help set it up.

Best wishes.

Avi

Avindra Nath MD

Chief, Section of Infections of the Nervous System

Clinical Director,

National Institute of Neurological Disorders and Stroke

National Institutes of Health, Bethesda, MD

[b6]

(Office)

(cell)

[b6]

From: [b6]
Date: Monday, July 19, 2021 at 4:51 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Ongoing health issues post Pfizer Covid vaccine

Hi Dr.Nath,

I received your email from [b6] of whom was helped immensely from her treatment at the NIH, as I have been having difficulty reaching out to Dr.Safavi and she thought you may be able to help me. Below is the email that I sent Dr.Safavi of which I have not received a response. Any advice or recommendations that you could provide me with would be greatly appreciated.

Thank you,

[b6]

----- Forwarded message -----

From: [b6]
Date: Fri, Jul 9, 2021 at 1:05 AM
Subject: Ongoing health issues post Pfizer Covid vaccine
To: [b6]
Cc: [b6]

Hi Dr.Safavi,

My name is [b6] and I'm a [b6]
[b6] I have been suffering from an ongoing Pfizer vaccine reaction since [b6] I was previously healthy and never missed time off work before the vaccine. I can't seem to recover from my vaccine induced illness and I wanted to reach out to you to see if you could potentially help me. I received your information from [b6] of whom you have helped immensely, and I hope you don't mind me reaching out.

Here is my story: I received the second dose of Pfizer on [b6] 13 hours after receiving the vaccine, I started with flu like symptoms (HA, neck pain, body aches, fever, restless, nausea, vomiting). 36 hours post-vaccine, I had profound fatigue, still felt feverish, scattered hives, headache and neck pain, and had intermittent dizziness. Day 3 and until this day I have had vertigo. That first week I had chest pain and dyspnea that would come and go, lasting until 2-3 weeks (ish) post-vaccine before seemingly resolving (more on this later). I was hospitalized [b6], had extensive testing, and was diagnosed with [b6] from the vaccine. Headache and neck pain lasted through [b6] The weekend of [b6] I had paresthesias of my hands, feet, L forearm and L cheek that seemingly resolved. The vertigo was the main symptom (with the exception of hives that would occur nightly on my chest/back/neck for about 30 minutes (ish) and would self resolve) from [b6] The vertigo slowly improved over this time [b6]
[b6] My husband and I would notice that I had issues with short term memory and word finding at times, with making easy decisions, and crowds would flare up all symptoms. PT reported that [b6]

[b6] I don't know if this is important or not, but I started having hair loss in [b6] and my menstrual cycles were irregular for [b6] In [b6] things unexpectedly progressed.

Early [b6] I started with tinnitus which is still present to this day. [b6] I suddenly had a return of paresthesias, this time ascending, starting from hands/feet that progressed up my entire arms and legs bilaterally. I also developed weakness in my legs and arms where it was difficult to go upstairs and brush my hair. I saw my pcp, had a [b6] neuro exam, and was referred to neurology. I also had a return of chest pain this day which was largely ignored in my appt with my pcp and starting having issues with intermittent brain fog. I saw neurology on [b6] The weakness was coming and going, not frequently, but the paresthesias persisted. I had a [b6] EMG on [b6] and was diagnosed with [b6] No further work up or medications recommended by my neurologist. Since [b6] I've had 4 discreet episodes of muscle weakness where walking any significant distance/up steps is difficult as noted above, lasting half a day to 48 hours when it comes. The paresthesias have been persistent since [b6] It's mainly in my hands/feet, forearms, and mid shins. Intensity waxes and wanes, sometimes I can't sleep due to the intense burning sensation. Sometimes I have issues where my hands feel clumsy such as with texting or some of the procedures I perform at work.

[b6] I again had another progression of symptoms while at work. I had worsening vertigo and paresthesia first, followed by intense chest pain with intermittent dyspnea, and later in the afternoon brain fog. I had been having intermittent chest pain since [b6] but this was worse than I had ever had, and I also noted I was having intermittent palpitations/tachycardia. I blew off the issue until I went home and found my HR 100-120s for an hour while at rest. The tachycardia at rest did normalize after that hour. What I've had since then is intermittent tachycardia with standing/short walking and persistent frequent episodic chest pain both at rest and with exertion, long episodes (rare that I don't have pain), worse with exertion. Have been profoundly fatigued since this started. I woke up Sunday around 4am with intense chest pain and rapid HR and confusion, I think it lasted for a few minutes before I went back to sleep. Sunday daytime I had to stop in the middle of a flight of steps due to chest pain and dyspnea which is unusual for me. [b6] I was essentially confined to my couch due to feeling unwell/lightheaded/weak with any light activity (such as walking from the living room to the kitchen). Today my symptoms were slightly better, I was able to go to work for 3 hours administratively but again worsening symptoms with activity. I did see my pcp today, have a [b6] and an echocardiogram to be scheduled.

I'm not sure if you have the availability to help me, if I'm too late in asking for help in terms of effectiveness of potential treatments, or if I'm not sick enough to be considered. I've been praying that this would all go away and working with my local physicians for months now and I'm still not doing well. My fear is that I have some sort of smoldering demyelinating illness that would explain my ongoing and progressive symptoms but this is just a guess. I thank you for reading my email and for your time and consideration.

Sincerely,

[b6]

[b6]

b6

b6

From: Google Calendar [calendar-notification@google.com]
Sent: 7/30/2021 2:34:35 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6- b6]
Subject: Accepted: Meeting [b6] to discuss COVID Vaccine Allergic Rea... @ Fri Jul 30, 2021 11am - 11:30am (EDT) (Nath, Avindra (NIH/NINDS) [E])
Attachments: invite.ics
Location: Zoom
Start: 7/30/2021 3:00:00 PM
End: 7/30/2021 3:30:00 PM
Show Time As: Tentative

Recurrence: (none)

[b6] has accepted this invitation.
Meeting [b6] to discuss COVID Vaccine Allergic Reaction

When Fri Jul 30, 2021 11am – 11:30am Eastern Time - New York

Where Zoom ([map](#))

Calendar Nath, Avindra (NIH/NINDS) [E]

Who

- Nath, Avindra (NIH/NINDS) [E] - organizer
- [b6] - creator

Topic: Meeting [b6] to discuss COVID Vaccine Allergic Reaction
Time: Jul 30, 2021 11:00 AM Eastern Time (US and Canada)

Join ZoomGov Meeting

[https://nih.zoomgov.com/j/ \[b6 \]](https://nih.zoomgov.com/j/ [b6])

Meeting ID: [b6]

Passcode: [b6]

One tap mobile

+16692545252 [b6] US (San Jose)
+16468287666 [b6] US (New York)

Dial by your location

+1 669 254 5252 US (San Jose)

+1 646 828 7666 US (New York)

+1 551 285 1373 US

+1 669 216 1590 US (San Jose)

Meeting ID: [b6]

Passcode: [b6]

Find your local number: <https://nih.zoomgov.com/u/ae3D0njKJ>

Invitation from Google Calendar

You are receiving this courtesy email at the account [b6] because you are an attendee of this event.

To stop receiving future updates for this event, decline this event. Alternatively you can sign up for a Google account at <https://calendar.google.com/calendar/> and control your notification settings for your entire calendar.

Forwarding this invitation could allow any recipient to send a response to the organizer and be added to the guest list, or invite others regardless of their own invitation status, or to modify your RSVP. [Learn More](#).

Organizer: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Meeting [b6] to discuss COVID Vaccine Allergic Reaction
Location: Zoom
Start Time: 2021-07-30T15:00:00Z
End Time: 2021-07-30T15:30:00Z
Attendees: [b6]

Topic: Meeting [b6] to discuss COVID Vaccine Allergic Reaction
Time: Jul 30, 2021 11:00 AM Eastern Time (US and Canada)

Join ZoomGov Meeting
<https://nih.zoomgov.com/j/> [b6]

Meeting ID: [b6]
Passcode: [b6]
One tap mobile
+16692545252 [b6] US (San Jose)
+16468287666 [b6] US (New York)

Dial by your location
+1 669 254 5252 US (San Jose)
+1 646 828 7666 US (New York)
+1 551 285 1373 US
+1 669 216 1590 US (San Jose)

Meeting ID: [b6]
Passcode: [b6]
Find your local number: <https://nih.zoomgov.com/u/ae3D0njKJ>

From: [b6]
Sent: 7/27/2021 5:36:11 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
CC: Brown, Warren (NIH/NINDS) [C] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=bef0730648434bb69542199fca79f67e [b6]
Subject: [b6]
Re: COVID Vaccine Allergic Reaction - Paresthesias

Hi Dr. Nath and Mr. Brown,

Thank you for your response and for offering to talk to us about this. I am copying [b6] here. Please let us know when a good time to meet would be.

We can prepare a timeline of symptoms and diagnostics to send to you to inform our discussion.

Thank you,

[b6]

On Mon, Jul 26, 2021 at 11:07 PM Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

I am sorry to hear of [b6] illness. I would be willing to talk to her to see what we can do to assist. I have copied Warren who can help schedule a meeting.

Avi

Avindra Nath MD

Chief, Section of Infections of the Nervous System

Clinical Director,

National Institute of Neurological Disorders and Stroke

National Institutes of Health, Bethesda, MD

[b6]

From: [b6]
Date: Monday, July 26, 2021 at 8:20 AM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: COVID Vaccine Allergic Reaction - Paresthesias

Hi Dr. Nath,

My name is [b6] and I'm [b6] whose [b6] has been suffering from paresthesias in arms and legs and face and has been not doing well overall since having an allergic reaction to polyethylene glycol in one dose of the Pfizer COVID vaccine, given [b6]. Since then, we have been working with her PCP, allergist and neurologist to try to diagnose and treat her symptoms through many diagnostic tests, with little success so far.

We have found support groups online for other people who have had similar reactions and trouble getting sufficient care from their providers due to the newness and complexity of their symptoms caused by the experimental vaccine. We heard your and Dr. Safavi's name from the NIH from [b6] [b6] in one of the groups who is also suffering similar symptoms. She suggested that I contact you.

[b6] and I have been wondering if you would be willing to offer any support or advice to us, or possibly offer guidance to her providers for her treatment, given your expertise in neuroimmunology. Please let us know either way. If so, I can write up a more detailed timeline of [b6] symptoms. Thank you for taking the time to read this - we look forward to hearing from you.

Best,

[b6]

From: [b6]
Sent: 7/14/2021 2:53:00 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: RE: long-term neurologic sequellae from vaccine

Dear Avi –
Thank you so much.
Best,

[b6]

From: Nath, Avindra (NIH/NINDS) [E] [b6]
Sent: Tuesday, July 13, 2021 10:01 PM
To: [b6] Patterson, Amy (NIH/NHLBI) [E] [b6] Wright, Clinton (NIH/NINDS) [E] [b6]
Subject: Re: long-term neurologic sequellae from vaccine

Dear [b6]
I am terribly sorry to hear of these illnesses. Unfortunately, the intramural program at NINDS has not received any funding for COVID research. I have copied Drs. Patterson and Wright who are managing the portfolio and would be in a better position to respond to your concerns.
With best wishes.
Avi
Avindra Nath MD
Chief, Section of Infections of the Nervous System
Clinical Director,
National Institute of Neurological Disorders and Stroke
National Institutes of Health, Bethesda, MD

[b6]

From: [b6]
Date: Tuesday, July 13, 2021 at 2:56 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: long-term neurologic sequellae from vaccine

Dear Dr. Nath –

Hello! I'm a [b6] and have two acquaintances who have had persistent and debilitating neurologic symptoms that seem to be in response to the COVID-19 vaccine. Apparently there are many others out there with similar symptoms and folks have started forming groups, such as <https://www.vaxlonghaulers.com/>. The symptoms seem to be similar to those of Long COVID, with the exception of respiratory symptoms. As a [b6] I am well aware that many of these symptoms can be due to depression, anxiety, and a whole host of other causes, both organic and non, but I am struck by the case of a colleague, a bright and highly successful [b6] who has been completely debilitated since her vaccination with exhaustion,

weakness, vestibular dysfunction, trouble with word-finding, problem-solving, and memory. She was a true champion for science and mitigation measures at her school this past year and happily received her vaccine. Unfortunately, not only has she been debilitated since then, but multiple attempts to seek answers or assistance from V-SAFE, VAERS, FDA, Janssen, and CDC have been unsuccessful. In fact, it's been a comedy (more of a tragedy) of errors, with lost case numbers, disconnected phone calls, CISA consults that were cancelled without her knowledge, and more dead ends and frustration than you can imagine.

I'm writing to you today to ask that NIH begin to seriously study these potential neurologic adverse reactions to vaccine. I know you have a lot on your plate, with acute and long-COVID and their neurologic manifestations being very important, and the meeting the next two days. But these folks are also suffering, and we owe it to them to first recognize and acknowledge what is happening, and then try to figure out why it's occurring and what therapeutics may be useful. We also owe it to medical professionals and citizens to gather good data to help us understand this phenomenon and then communicate about it, so that these poor folks will no longer be dismissed out of hand and told that they're imagining it all.

I would also appreciate any efforts you could make to send the message that the V-SAFE system and other safety measures we've put in place do not seem to be working as intended or as promised to the public.

Thank you so much for all of your excellent work. Good luck with the meeting this week. I'll hope to see some investigation into potential long-term neurologic sequelae of COVID-19 vaccines in the very near future.

Sincerely,

b6

b6

From: [b6]
Sent: 12/18/2020 12:27:51 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: update on the vaccine

No. Just a heavy sensation. They going to give me [b6]

[b6]

From: Nath, Avindra (NIH/NINDS) [E] [b6]
Sent: Friday, December 18, 2020 8:15 AM
To: [b6]
Subject: Re: update on the vaccine

Sorry, any sign of a Bell's palsy?
Avi

From: [b6]
Date: Friday, December 18, 2020 at 6:46 AM
To: "Nath, Avindra (NIH/NINDS) [E]" [b6]
Subject: Re: Re: update on the vaccine

Dear Avi,
Got some reaction after the vaccine. Eye and lip swelling and left side of face paresthesias and heavy sensation. Came to ER and I'm in observation. Feeling a little better although concern.
Best,

[b6]

[b6]

From: Nath, Avindra (NIH/NINDS) [E] [b6]
Sent: Thursday, December 17, 2020 7:56 PM

REL0000229212

To: [b6]

Subject: Re:

Terrific!

No vaccine is available at NIH yet. But can't wait to get it.

All the best.

Avi

From: [b6]

Date: Thursday, December 17, 2020 at 6:55 PM

To: "Nath, Avindra (NIH/NINDS) [E]" [b6]

Subject: <no subject>

Dear Avi,

Got the vaccine [b6]

Got yours?

Best,

[b6]

[b6]

From: [b6]
Sent: 6/11/2021 9:31:40 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Concerns of a Study Participant
Attachments: Nath NIH CC 6_11_21.pdf

Dr. Nath,

Please see the attached letter.

Thank you, [b6]

June 11, 2021

Avindra Nath, MD
Clinical Director
Office of Clinical Services
National Institute of Neurological Disorders and Stroke, NIH

Dear Dr. Nath:

I am writing to express concerns about my research participation and interactions with members of one of your research teams. This letter provides a non-exhaustive summary highlighting some of my experiences and perspectives.

Background:

Within 2 hours after receiving a first dose of the Pfizer COVID-19 vaccine, I developed neurological symptoms. Dr. Mark Hallett heard of some of the symptoms, contacted me, and invited me to NIH for an assessment. I was subsequently enrolled into an NINDS protocol entitled Diagnosis and Natural History Protocol for Patients with Different Neurological Conditions (PI: Mark Hallett). During that assessment on [b6] a previous NIH fellow (Dr. Farinaz Safavi) was in attendance. Dr. Safavi, in consultation with Dr. Hallett, suggested that I switch to a different study protocol that addresses covid vaccine reactions. There was no mention of the exact protocol. Dr. Safavi did the latter portion of my physical assessment during that visit and advised at that time that I find a general neurologist in the community for her to communicate with. I thereafter met with 2 non-NIH neurologists, in-person, based on that recommendation. On March 24, Dr. Safavi contacted me by phone and I specifically asked for the study protocol, which I assumed would include the informed consent. Dr. Safavi replied that it was being worked on. A few weeks passed and I did not receive a copy, and the afternoon prior to my in-person visit scheduled with Drs. Nath and Safavi, when the Research Coordinator (RC) called for covid screening, I asked for the protocol. While on the phone, the RC sent it in an encrypted email and informed her I was unable to open the email.

I attended the intake visit on [b6] when you performed the informed consent process. The meeting did not start until 9:20-9:25am (after the intake nurse had gone through questions and measurements) and you seemed a bit rushed. I had the impression you may have thought I had already seen the consent form, although that was not the case. I nonetheless signed the consent form, in part because Dr. Safavi had assured me in previous emails that all study procedures were entirely voluntary. A signed copy of the consent form for the study was not provided to me at the time I signed the original. The next day, I called the RC and requested she send an unencrypted copy. Upon receiving an unsigned copy of the form, Natural History of

Inflammatory and Infectious Disease of the Nervous System (PI: Dr. Avindra Nath), via email, I noticed that certain procedures, including a lumbar puncture, are not optional for study participants. I immediately called back the RC for clarification, and the RC confirmed that the LP and various other procedures were mandatory. I soon thereafter emailed my concerns about the consenting process to Dr. Safavi, her previous claims that nothing was mandatory, and explained I would need to withdraw if the LP was indeed a protocol requirement. She replied that I had been sent the protocol 3 times, but did not say in what manner. Her email ended conveying that you had determined I should not have a LP based on my medical history. I responded that I had no motivation to tell her anything other than what I experienced, and as an investigator, I would want to know if study participants were not receiving materials. I had, by the way, received Dr. Hallett's protocol materials with no issues.

At the same visit on [b6] after you left the examination room, Dr. Safavi informed me that she would now be my primary neurologist. Dr. Safavi advised me to "slow down", in reference to my outside care. She specifically advised me to discontinue other therapeutic procedures I had scheduled, namely [b6] scheduled with a non-NIH anesthesiologist later that week to reduce the nerve pain in my lower extremities. I canceled the [b6] at Dr Safavi's request, although regretted I had to tolerate pain and limited mobility for an unknown period of time. Dr. Safavi also informed me of what treatments she was planning for me: [b6]
[b6]
[b6] She commented that left untreated, inflammation could flare in the future, and added that she preferred the efficacy of an IV.

Prior to the [b6] appointment, I woke one day with peripheral diplopia and headaches that prompted non-NIH providers to recommend a brain MRI. I contacted Dr. Safavi and she encouraged me to get a MRI at NIH, and said if I did so and enrolled in the study, NIH could treat me. She hoped to have the MRI done [b6] but no appointments were available, and as it turned out, it would be another week beyond then before I could be tested at NIH. A non-NIH imaging facility was able to do the MRI within a week of my cranial symptoms' onset. [b6]
[b6] I informed her that I had received the MRI outside, yet expressed I was willing to do a brain MRI at NIH.

Days after my visit with you and Dr. Safavi, I developed uncharacteristic, severe shoulder pain that was suggestive of either cervical radiculopathy, and later -- brachial neuritis. Non-NIH providers documented the extent of my discomfort. Because the symptoms prevented me from lying in a supine position, I asked Dr. Safavi if she could accept the brain MRI completed in the community (several other study participants were participating by telehealth and have brain MRIs completed in the community.) Or, postpone the 75+ minute NIH MRI until late May or early June, reflecting what my pain management anesthesiologist predicted for my recovery and personal circumstances. Dr. Safavi responded that the brain MRI done in the community was

not performed consistent with the study protocol and was missing images. (Non-NIH providers stand-by the conclusions from the images and wondered if some imaging might not have been copied to the CD I gave Dr. Safavi). In an attempt to address pain, and get the NIH MRI, I also asked Dr. Safavi about the length of time needed between [b6] and the MRI so I could try to reduce my discomfort and get the imaging done. She did not respond to that question. Instead, I received an ultimatum from her: complete a brain MRI at NIH in the "very near future" or be dismissed from the protocol. Dr. Safavi's secretary called and gave me up to 9 business days to schedule and complete the MRI. I was unaware of any study protocol deadlines and the protocol continues to enroll new patients. It is now early June, and Dr. Safavi has not as yet discussed the MRI that I completed at NIH on May 6. Relatedly, the written test results of the NIH MRI referenced a protocol investigating long-term COVID-19, which raised concerns that I may be enrolled in a different study. I never received a copy of the signed consent from the study team.

My first blood work was drawn [b6]. The second MRI, additional bloodwork, and a pregnancy test was completed at NIH on [b6]. I have not received any information from or interpretation by Dr. Safavi about any of my test results, nor clinical status. When I had the sudden symptom onset of severe shoulder pain, Dr. Safavi emailed me that I should seek medical care from community providers for my "ongoing disease". She and I had not discussed a "disease". Hence, I thought the ongoing disease she was referring to was cervical radiculopathy which had been the content of recent emails. I replied to her that the symptoms were also thought to be consistent with [b6] [b6] and asked if NIH would evaluate. Dr. Safavi briefly responded that a neuro exam and EMG was needed to confirm [b6]. She did not offer to do the neuro exam or an EMG test at NIH. This left me confused and I commented to her that I could go outside NIH to evaluate [b6]. But as I thought about it more, if I sought an EMG in the community, only to have Dr. Safavi later insist (like the brain MRI) that the test be repeated at NIH – it would be a poor use of my time and resources, plus uncomfortable to repeat an EMG. I have sought clarification from her in 2 additional emails to determine NIH's role in my care, plus clarification of what diagnosis she was referring to. Dr. Safavi has provided no responses to date.

Some Conclusions and Other Noteworthy Issues:

I was not properly or accurately informed of the protocol prior to consent. This became a larger issue because Dr. Safavi previously emailed that "absolutely nothing is mandatory" and I signed a consent form believing that to be true, only to discover the opposite. It alarmed me and concerned my non-NIH providers about a LP requirement, and was unsettling that she had provided me with contradictory information prior to the consent. This seemed avoidable had she been truthful, and I received an advance copy of the form.

I had already agreed, via email, to repeat the brain MRI at NIH. With no known deadlines or urgency for the MRI, she nonetheless had a knee-jerk reaction to my having a repositioned shoulder and scapula, and intense pain. The demand to rush completion of the imaging while I was in pain or be expelled from the protocol if I could not tolerate the haste, seemed harsh.

Dr. Safavi stated in writing and verbally that I could be treated by NIH, with one offer seemingly hinged to my doing a brain MRI at NIH. The only reason I got a repeat brain MRI at NIH, and while in pain, was because I was led to believe if I did so, I would have the option of receiving treatment at NIH. Why would I otherwise have repeated a test that I was certain would not reveal the cause of b6 symptoms? As a study participant, I feel I was coerced into participation, only for Dr. Safavi to (seemingly) withdraw the intent by ceasing communication with me.

After reading the signed consent provided to me in the past week, I realized a side effect I experienced from the NIH brain MRI is not mentioned in the consent form: tinnitus. The covid vaccine instigated tinnitus in my left ear, yet it was tolerable. After the lengthy brain MRI in the robust NIH machine, my left ear worsened... now sounding like an angry train whistle blowing in my head. It is difficult to sleep. My right ear developed tinnitus for the first time ever the day after the NIH MRI. It is unfortunate the MRI's potential for worsening tinnitus, given my post-vaccine medical symptoms, was not noted or recognized. I reported to you during the intake interview that I did not have hearing loss since the vaccine. But I did report tinnitus. I hope the potential side effect of tinnitus is noted on your consent form in the future to inform and help guide future decisions.

Currently I am seeking treatment for tinnitus and incurring the costs for medical care to address an issue that a NIH test provoked. Ironically, the medical care I am receiving is from a clinician who provides treatment at the NIH CC, to outpatients on NIH protocols. He advised me to have my NIH physician send him a note to start treatment with him at NIH. I had to inform him my NIH physician does not respond to my emails. I am now being treated in his private practice at my expense.

Dr. Safavi's changing her mind -- two, maybe three times -- about who should be my primary neurologist has been problematic. The day she announced she would be my primary neurologist, I told her she had a scheduled appointment with a new neurologist that very afternoon and she shrugged. It could not be cancelled on such short notice. During my appointment with him, I could not encourage him to provide care for me as Dr. Safavi had declared that role. Now Dr. Safavi is "ghosting" me and not clarifying which "ongoing disease" she has referred to and how I fit in the NIH protocol. And I have little to provide non-NIH clinicians in terms of information from my time spent as a study participant at NIH.

Since I brought the consent process and her contradictory claims about the study requirements to Dr. Safavi's attention, she has been disrespectful, and seems hostile towards me. A small yet perhaps telling example... the schedule for my last MRI and bloodwork stated, "... go to phlebotomy to have your non-fasting labs drawn." After I arrived at the Phlebotomy Department, the lab technician said I had to provide a urine sample for a pregnancy test. I had just voided -- ready only for bloodwork and then onto the MRI. The laboratory technician advised me not to strain to provide a urine sample. I asked the Phlebotomy Lab to call Dr. Safavi to request clarification about the pregnancy test. Dr. Safavi, the physician who said nothing was mandatory, firmly replied that pregnancy test was a protocol requirement. She was unrelenting. The protocol requires "a urine pregnancy test for women and girls who are able to get pregnant." Her clinical judgement about who is able to get pregnant is questionable. I drank water to provide a urine sample, and subsequently was even more uncomfortable during the 75+ minutes of MRI imaging.

I planned to report my experiences with Dr. Safavi to other sources, but some senior staff at NIH, plus the CC, encouraged me to write directly to you. b6

b6

b6

With this background, it is an understatement to express that my being a study participant with a physician in your group went horribly wrong. And from chatter on social media, it appears Dr. Safavi is confusing other future and current study participants she interacts with, but those are their tales to tell.

Thank you for your attention to this matter. Hearing from you about any of the foregoing would be helpful and appreciated -- particularly my test results and clinical status, role in the study protocol, and NIH's intent to treat me. Please advise if I can answer any questions or provide additional information.

Sincerely,

b6

From: [b6]
Sent: 12/30/2021 6:22:41 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: [EXTERNAL] Re: Covid vaccine neurological issues
Attachments: A Possible Role for Anti-idiotypic Antibodies in SARS-CoV-2 Infection and Vaccination NEJM.pdf

CAUTION: This email originated from outside of the organization. Do not click links or open attachments unless you recognize the sender and are confident the content is safe.

How about this theory? It is from the nejm from November. I have been in contact with Dr Murphy and they may do some more research after the holidays.

[b6]

Sent from my iPhone

On Dec 26, 2021, at 9:20 AM, [b6] wrote:

Dr. Nath,

Sorry to keep bothering you. I hope your holiday season is well. I am wondering if you have any answers as to why my symptoms are worse in the morning upon waking and are mostly if not all the way gone by evening? I read that inflammation can be worst upon waking due to the body's circadian rhythm. Is this a possible answer? I really need to get better. My own PCP and one of the neurologists I saw won't do anything to treat symptoms unless there are studies that prove something works. I asked about IVIG, plasmaphoresis, high does vitamin C and other things. I know I said I'm [b6] so I can seek whatever treatment I may be able to get. I'm hoping you and [b6] will be able to help me.

Regards,

[b6]

Sent from my iPhone

On Dec 21, 2021, at 8:26 AM, Nath, Avindra (NIH/NINDS) [E]
[b6] wrote:

Yes, I will be glad to talk to [b6] should be fine. I do not see any reasons for concern.

Avi

From: [b6]
Date: Tuesday, December 21, 2021 at 9:23 AM
To: Nath, Avindra (NIH/NINDS) [E]; [b6]
Subject: [EXTERNAL] Re: Covid vaccine neurological issues

CAUTION: This email originated from outside of the organization. Do not click links or open attachments unless you recognize the sender and are confident the content is safe.

Dr. Nath,

I am going to be seeing [b6] The immunologist I saw there had said that [b6] is familiar with you. Is there any way you and [b6] could collaborate on a care plan for me? I'm desperate to get back to a normal life with my family. Also, I was [b6] when I got the shot on recommendation by CDC, ACOG, SMFM. Also, [b6] approved etc. I asked many providers when I was having an abnormal response to the vaccine if I should [b6] and all said [b6] so we have been. Is [b6] going to have issues from this then? I'm really worried about this whole situation. I did have EMG done recently and it was [b6] Thanks. Happy holidays.

Regards,

[b6]

Sent from my iPhone

On Nov 15, 2021, at 9:08 PM, Nath, Avindra (NIH/NINDS) [E]

[b6] wrote:

Dear [b6]

Sorry, that you have not been able to get adequate care.

Avi

From: [b6]

Date: Monday, November 15, 2021 at 2:25 PM

To: Nath, Avindra (NIH/NINDS) [E]; [b6]

Subject: Re: Covid vaccine neurological issues

Dr. Nath,

I contacted the doctors whom you mentioned. Most didn't reply and one (the male doctor) responded and didn't seem to know much about these reactions. I see on your profile you are a neuro-immunologist for the nih. I am begging and pleading for these issues to be researched further. I have been in contact from others around the world who have had the same symptoms I have had and no one has answers. My neurologist wants to label me with [b6] I don't buy that for one second. I am [b6] and I have [b6] I am giving you a link to an online forum so you can read these people's posts. I'm begging for anyone to look into this and to not give this Pfizer shot to kids! We need to know why these neurological issues are happening. I read an online article with you quoted in it regarding a reaction that was similar when these shots were in trials and it was a concern then. What does the nih plan to do about this or the United States for that matter?

<https://vestibular.org/forum/symptoms/tingling-numbness-in-body/paged/54/>

REL0000229230

Please help us.

Regards,

b6

Sent from my iPhone

On Oct 23, 2021, at 8:25 PM, **b6**

b6 wrote:

Thank you so much for this information. I don't live in New York but will travel anywhere to feel better. Will I be able to get around New York if I haven't been fully vaccinated? I have been advised to not get the second shot. My doctor would give me an exception letter too. Thank you so much for replying! You are a blessing. Have a great weekend!

Regards,

b6

Sent from my iPhone

On Oct 23, 2021, at 8:12 PM, Nath,
Avindra (NIH/NINDS) [E]

b6 wrote:

Dear **b6**

Sorry to hear of your illness. If you live in the NY area, I would suggest seeing any of the following:

b6

They are all well versed in these complications and will investigate and treat you.

Avi
Avindra Nath MD
Chief, Section of Infections of the
Nervous System
Clinical Director,
National Institute of Neurological
Disorders and Stroke
National Institutes of Health, Bethesda,
MD

b6

From: b6

b6

Date: Friday, October 22, 2021 at 11:36 AM

To: Nath, Avindra (NIH/NINDS) [E]

b6

Subject: Covid vaccine neurological issues

Good morning,

I'm writing to you today out of desperation. I'm looking for anyone who can help me recover after my first Pfizer vaccine. Almost immediately after receiving it I had lightening bolt of pain on the left side of my brain and after that I have had a multitude of symptoms. I felt electrical sensations all over my body with a revved up feeling internally. I had very deep sleep but also was not my normal sleep. I was having lucid nightmares. At one point I almost felt like I was losing my mind when I would go to sleep. That has gotten better but I am still having vivid dreams. I developed diarrhea, tinnitus, sensitivity to sound/light/touch, paresthesias in all limbs and numbness in limbs, headaches unlike any I have ever felt before, brain fog or difficulty concentrating, skin feeling sensitive and burnt but I haven't been in the sun, random areas of intermittent pain on my skin as well. I saw Dr. Thakur as an author of a review in a neurology journal and he mentioned talking with you. I got your email off of the internet. I have reached out to many others as well as Mayo Clinic and come up short. Please help me or point me in a direction of someone that can. I have 3 kids to care for that are:

b6

b6

Thanks so much.

REL0000229230

Regards,

b6

Sent from my iPhone



A Possible Role for Anti-idiotypic Antibodies in SARS-CoV-2 Infection and Vaccination

William J. Murphy, Ph.D., and Dan L. Longo, M.D.

November 24, 2021

Editors

DOI: 10.1056/NEJMcibr2113694

Mary Beth Hamel, M.D., M.P.H., Editor

Article

Figures/Media

Metrics

11 References

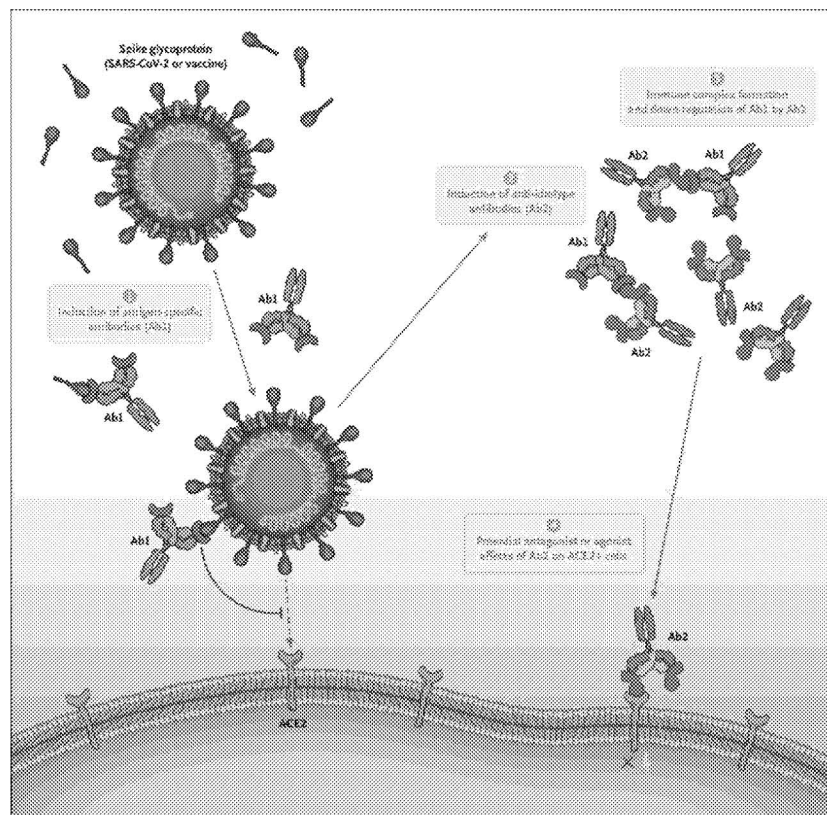
Article



The Clinical Implications of Basic Research series has focused on highlighting laboratory research that could lead to advances in clinical therapeutics. However, the path between the laboratory and the bedside runs both ways: clinical observations often pose new questions for laboratory investigations that then lead back to the clinic. One of a series of occasional articles drawing attention to the bedside-to-bench flow of information is presented here, under the Basic Implications of Clinical Observations rubric. We hope our readers will enjoy these stories of discovery, and we invite them to submit their own examples of clinical findings that have led to insights in basic science.

THE PATHOGENESIS OF SEVERE ACUTE RESPIRATORY SYNDROME CORONAVIRUS 2 (SARS-CoV-2) infection is incompletely understood, with its effects on multiple organ systems¹ and the syndrome of “long Covid” occurring long after the resolution of infection.² The development of multiple efficacious vaccines has been critical in the control of the pandemic, but their efficacy has been limited by the appearance of viral variants, and the vaccines can be associated with rare off-target or toxic effects, including allergic reactions, myocarditis, and immune-mediated thrombosis and thrombocytopenia in some healthy adults. Many of these phenomena are likely to be immune-mediated.³ How can we understand this diversity in immune responses in different persons?

Figure 1.



Anti-idiotypic Antibodies and SARS-CoV-2.

One way of thinking about the complexity of the immune response is through the lens of anti-idiotypic immune responses. The Network Hypothesis, formulated in 1974 by Niels Jerne, described a mechanism by which the antibody responses to an antigen themselves induced

downstream antibody responses against the antigen-specific antibody.⁴ Every antibody that is induced and specific for an antigen (termed “Ab1” antibody) has immunogenic regions, particularly in their variable-region antigen-binding domains, that are unique as a result of genetic recombination of immunoglobulin variable, diversity, and joining (VDJ) genes; VDJ recombination results in new and therefore immunogenic amino acid sequences called idiotopes, which are then capable of inducing specific antibodies against Ab1 antibodies as a form of down-regulation. A similar paradigm has been proposed for T cells. However, these regulatory immune responses are also capable of doing much more. The paratopes, or antigen-binding domains, of some of the resulting anti-idiotype (or “Ab2”) antibodies that are specific for Ab1 can structurally resemble that of the original antigens themselves. Thus, the Ab2 antigen-binding region can potentially represent an exact mirror image of the initial targeted antigen in the Ab1 response, and Ab2 antibodies have even been examined for potential use as a surrogate for the antigen in vaccine studies. However, as a result of this mimicry, Ab2 antibodies also have the potential to bind the same receptor that the original antigen was targeting (Figure 1). Ab2 antibodies binding to the original receptor on normal cells therefore have the potential to mediate profound effects on the cell that could result in pathologic changes, particularly in the long term — long after the original antigen itself has disappeared.

This aspect of regulation of immune-cell responses was postulated by Plotz in 1983 as a possible cause of autoimmunity arising after viral infection⁵ and has since been supported experimentally by direct transfer of anti-idiotype antibodies. Ab2 antibodies generated against the enterovirus coxsackievirus B3 in mice can bind myocyte antigens, resulting in autoimmune myocarditis,⁶ and anti-idiotype responses can act as acetylcholine receptor agonists, leading to myasthenia gravis symptoms in rabbits.⁷ In addition, by displaying the mirror image of the viral antigen, Ab2 alone can even mimic the deleterious effects of the virus particle itself, as has been shown with bovine viral diarrhea virus antigen.⁸

For SARS-CoV-2 infection, attention centers on the spike (S) protein and its critical use of the angiotensin-converting-enzyme 2 (ACE2) receptor to gain entry into the cell. Given its critical role in regulating angiotensin responses, many physiological effects can be influenced by ACE2 engagement.⁹ The S protein itself has a direct effect on suppressing ACE2 signaling by a variety of mechanisms and can also directly trigger toll-like receptors and induce inflammatory cytokines.¹⁰ Anti-idiotype responses may affect ACE2 function, resulting in similar effects. However, preclinical and clinical assessments of antibody responses to SARS-CoV-2 vaccines have focused solely on Ab1 responses and virus-neutralizing efficacy. The delineation of potential anti-idiotype

responses has inherent difficulties because of the polyclonal nature of responses, dynamic kinetics, and the concurrent presence of both Ab1 and Ab2 antibodies. Furthermore, ACE2 expression within cells and tissues can be variable. The different vaccine constructs (RNA, DNA, adenoviral, and protein) are also likely to have differential effects on Ab2 induction or in the mediation of vaccine effects that differ from responses to infection. Some off-target effects may not be directly linked to Ab2 responses. The association of thrombotic events with some SARS-CoV-2 vaccines in young women and the etiologic role of anti-platelet factor 4–polyanion antibodies may be the result of the adenoviral vector. However, the reported occurrence of myocarditis after vaccine administration bears striking similarities to the myocarditis associated with Ab2 antibodies induced after some viral infections.⁶ Ab2 antibodies could also mediate neurologic effects of SARS-CoV-2 infection or vaccines, given the expression of ACE2 on neuronal tissues, the specific neuropathologic effects of SARS-CoV-2 infection,¹¹ and the similarity of these effects to Ab2-mediated neurologic effects observed in other viral models.

It would therefore be prudent to fully characterize all antibody and T-cell responses to the virus and the vaccines, including Ab2 responses over time. Using huACE2 transgenic mice and crossing them with strains that are predisposed to autoimmunity or other human pathologic conditions can also provide important insights. An understanding of potential Ab2 responses may also provide insights into Ab1 maintenance and efficacy and into the application of antibody-based therapeutic agents. However, much more basic science research is needed to determine the potential role idiotype-based immunoregulation of both humoral and cell-mediated responses may play both in antiviral efficacy and in unwanted side effects of both SARS-CoV-2 infection and the vaccines that protect us from it.

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Disclosure forms provided by the authors are available at NEJM.org.

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Author Affiliations



From the Departments of Dermatology and Internal Medicine, Division of Hematology and Oncology,

Supplementary Material

▼

Disclosure Forms

PDF

132KB

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▼

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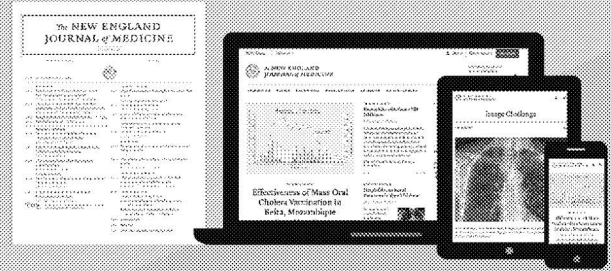
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From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 [b6]
Sent: 7/24/2021 1:08:01 AM
To: [b6]
Subject: Re: Ongoing health issues post Pfizer Covid vaccine

Dear [b6]

It was good to meet you. Looks like the Neurologist is well qualified and since he treats patients with MS, he should be very comfortable with immune therapies. But let me see what my group says about bringing you to NIH. I will let you know on Monday.

Best.

Avi

From: [b6]
Date: Friday, July 23, 2021 at 7:04 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Re: Ongoing health issues post Pfizer Covid vaccine

Dear Dr.Nath,

Words cannot express my gratitude to you for spending the time to chat with me today and discuss potential treatment options which have worked for others. It was a very encouraging and uplifting conversation. Here is the information for the neurologist that I have seen twice this year: [b6]

[b6] Also, as an update on my health from the end of my initial email to you to aid with Monday's case discussion: I continue to struggle with vertigo, paresthesias, brain fog, profound fatigue, chest pain, palpitations/tachycardia on a daily basis. I had another episode of muscle weakness earlier this week and also a few times this week have felt dyspneic and presyncopal. Symptoms worsen with the more activity that I do and seem to be slowly worsening since [b6] I have struggled greatly working [b6] this week to the point where it affected [b6]
[b6] This past Monday I had a [b6] I have a cardiac MRI scheduled for early September.

Thank you again,

[b6]

On Mon, Jul 19, 2021 at 9:49 PM Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

I am terribly sorry to hear of your illness. I will be glad to talk to you. I have copied Warren who maintains my calendar and can help set it up.

Best wishes.

Avi

Avindra Nath MD

Chief, Section of Infections of the Nervous System

Clinical Director,

REL0000229443

National Institute of Neurological Disorders and Stroke

National Institutes of Health, Bethesda, MD

b6

(Office)

(cell)

b6

From: **b6**

Date: Monday, July 19, 2021 at 4:51 PM

To: Nath, Avindra (NIH/NINDS) [E] **b6**

Subject: Ongoing health issues post Pfizer Covid vaccine

Hi Dr.Nath,

I received your email from **b6** of whom was helped immensely from her treatment at the NIH, as I have been having difficulty reaching out to Dr.Safavi and she thought you may be able to help me. Below is the email that I sent Dr.Safavi of which I have not received a response. Any advice or recommendations that you could provide me with would be greatly appreciated.

Thank you,

b6

----- Forwarded message -----

From: **b6**

Date: Fri, Jul 9, 2021 at 1:05 AM

Subject: Ongoing health issues post Pfizer Covid vaccine

To:

b6

Cc:

Hi Dr.Safavi,

My name is **b6** and I'm a **b6**

b6 I have been suffering from an ongoing Pfizer vaccine reaction since **b6** I was previously healthy and never missed time off work before the vaccine. I can't seem to recover from my vaccine induced illness and I wanted to

REL0000229443

reach out to you to see if you could potentially help me. I received your information from [b6] of whom you have helped immensely, and I hope you don't mind me reaching out.

Here is my story: I received the second dose of Pfizer on [b6] 13 hours after receiving the vaccine, I started with flu like symptoms (HA, neck pain, body aches, fever, restless, nausea, vomiting). 36 hours post-vaccine, I had profound fatigue, still felt feverish, scattered hives, headache and neck pain, and had intermittent dizziness. Day 3 and until this day I have had vertigo. That first week I had chest pain and dyspnea that would come and go, lasting until 2-3 weeks (ish) post-vaccine before seemingly resolving (more on this later). I was hospitalized [b6] had extensive testing, and was diagnosed with [b6] from the vaccine. Headache and neck pain lasted through [b6] The weekend of [b6] I had paresthesias of my hands, feet, L forearm and L cheek that seemingly resolved. The vertigo was the main symptom (with the exception of hives that would occur nightly on my chest/back/neck for about 30 minutes (ish) and would self resolve) from [b6] The vertigo slowly improved over this time [b6] My husband and I would notice that I had issues with short term memory and word finding at times, with making easy decisions, and crowds would flare up all symptoms. PT reported that [b6] [b6] don't know if this is important or not, but I started having hair loss in [b6] and my menstrual cycles were irregular for [b6] In [b6] things unexpectedly progressed.

[b6] I started with tinnitus which is still present to this day. [b6] I suddenly had a return of paresthesias, this time ascending, starting from hands/feet that progressed up my entire arms and legs bilaterally. I also developed weakness in my legs and arms where it was difficult to go upstairs and brush my hair. I saw my pcp, had a [b6] neuro exam, and was referred to neurology. I also had a return of chest pain this day which was largely ignored in my appt with my pcp and starting having issues with intermittent brain fog. I saw neurology on [b6] The weakness was coming and going, not frequently, but the paresthesias persisted. I had a [b6] EMG on [b6] and was diagnosed with [b6] No further work up or medications recommended by my neurologist. Since [b6] I've had 4 discreet episodes of muscle weakness where walking any significant distance/up steps is difficult as noted above, lasting half a day to 48 hours when it comes. The paresthesias have been persistent since [b6] [b6] It's mainly in my hands/feet, forearms, and mid shins. Intensity waxes and wanes, sometimes I can't sleep due to the intense burning sensation. Sometimes I have issues where my hands feel clumsy such as with texting or some of the procedures I perform at work.

[b6] I again had another progression of symptoms while at work. I had worsening vertigo and paresthesia first, followed by intense chest pain with intermittent dyspnea, and later in the afternoon brain fog. I had been having intermittent chest pain since the [b6] but this was worse than I had ever had, and I also noted I was having intermittent palpitations/tachycardia. I blew off the issue until I went home and found my HR 100-120s for an hour while at rest. The tachycardia at rest did normalize after that hour. What I've had since then is intermittent tachycardia with standing/short walking and persistent frequent episodic chest pain both at rest and with exertion, long episodes (rare that I don't have pain), worse with exertion. Have been profoundly fatigued since this started. I woke up Sunday around 4am with intense chest pain and rapid HR and confusion, I think it lasted for a few minutes before I went back to sleep. Sunday daytime I had to stop in the middle of a flight of steps due to chest pain and dyspnea which is unusual for me. [b6] I was essentially confined to my couch due to feeling unwell/lightheaded/weak with any light activity (such as walking from the living room to the kitchen). Today my symptoms were slightly better, I was able to go to work for 3 hours administratively but again worsening symptoms with activity. I did see my pcp today, have a [b6] [b6] and an echocardiogram to be scheduled.

I'm not sure if you have the availability to help me, if I'm too late in asking for help in terms of effectiveness of potential treatments, or if I'm not sick enough to be considered. I've been praying that this would all go away and working with my local physicians for months now and I'm still not doing well. My fear is that I have some sort of smoldering demyelinating illness that would explain my ongoing and progressive symptoms but this is just a guess. I thank you for reading my email and for your time and consideration.

Sincerely,

b6

b6

b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 [b6]
Sent: 6/15/2021 1:58:18 AM
To: [b6]
Subject: Re: Concerns of a Study Participant

Thanks.
Avi

From: [b6]
Date: Monday, June 14, 2021 at 9:47 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Re: Concerns of a Study Participant

Hello Dr. Nath,

This may be more information than you need.

I had never previously had tinnitus in my right ear. Tinnitus started in my right ear on [b6] the day after my brain MRI at NIH.

Left ear tinnitus was noticeable the second week after my J&J shot on [b6]. After the brain MRI at NIH, it gradually began to increase in intensity to the high level it is now. I started to call for treatment appointments for the left ear the end of [b6] if that helps.

Thank you for the consult request. Kymani contacted me today and I have a ENT consult this Wednesday at the Clinical Center.

Best, [b6]

On Jun 14, 2021, at 9:09 PM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

You may have mentioned it but I cannot recall when did you notice the increase in tinnitus after the MRI? I need to include this information in the AE report. The ENT consult request has been placed.

Thanks.

Avi

From: [b6]
Date: Sunday, June 13, 2021 at 4:58 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Re: Concerns of a Study Participant

Thank you.

Best, [b6]

On Jun 12, 2021, at 7:25 PM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

It was a pleasure to talk to you. Thank you for your understanding. I am summarizing our action plan below. Hope I did not miss anything.

1. We will request an ENT consult for tinnitus
2. We will report the tinnitus to the IRB as an adverse reaction to MRI and seek their guidance about amending our consent form accordingly.
3. With regards to ongoing neurological symptoms you will seek help from your outside neurologist and PCP
4. If and when we publish our research findings we will share them with you.

With best wishes.

Avi

From: [b6]

Date: Saturday, June 12, 2021 at 10:49 AM

To: Nath, Avindra (NIH/NINDS) [E] [b6]

Subject: Re: Concerns of a Study Participant

Will plan to call your cell today at 3pm. I look forward to talking with you then.

Thanks, [b6]

On Jun 12, 2021, at 7:22 AM, Nath, Avindra (NIH/NINDS) [E]

[b6] wrote:

Let's talk at 3 pm today. My cell is [b6]

Thanks

Avi

On Jun 11, 2021, at 11:18 PM, [b6]

[b6] wrote:

Dr. Nath,

I appreciate your prompt and empathetic response. I'm available Saturday and Sunday this weekend anytime after 2pm, or next week. For example, Monday or Tuesday between 10am and 1pm, or Wednesday afternoon or Thursday morning. Please let me know if any of those days or times might work for you.

Am sorry to hear of [b6] I emailed her April 29 and 30, and June 1 with questions.

Thank you, [b6]

On Jun 11, 2021, at 9:14 PM, Nath,
Avindra (NIH/NINDS) [E]

b6

wrote:

Dear b6

Thanks for reaching out to me. I am
terribly sorry for the experience you
have had and for the symptom that you
are experiencing. I will be glad to talk to
you and see what I can do to help. I am
available this weekend or anytime next
week. Please let me know what might
be most convenient. b6

b6

With apologies.

Avi

Avindra Nath MD
Chief, Section of Infections of the
Nervous System
Clinical Director,
National Institute of Neurological
Disorders and Stroke
National Institutes of Health, Bethesda,
MD

b6

(Office)
(cell)

b6

From: b6

b6

Date: Friday, June 11, 2021 at 5:31
PM

To: Nath, Avindra (NIH/NINDS) [E]

b6

Subject: Concerns of a Study
Participant

Dr. Nath,

Please see the attached letter.

Thank you, b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 [b6]
Sent: 7/30/2021 3:40:32 PM
To: [b6]
CC:
Subject: Re: COVID Vaccine Allergic Reaction - Paresthesias

Dear [b6]

It was good to meet you. Sorry to hear of your illness. Hopefully, I was able to address the issues. If there are any additional questions for me, please feel to contact me again.

With best wishes

Avi

From: [b6]
Date: Thursday, July 29, 2021 at 4:58 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Cc: [b6]
Subject: Re: COVID Vaccine Allergic Reaction - Paresthesias

Hi Dr. Nath,

Thank you again for agreeing to talk to us about [b6] symptoms. I have copied [b6] here, in case she wants to add or edit the HPI/timeline below of her reaction to her only dose of the Pfizer vaccine:

Pfizer vaccine administered on [b6] Started to experience near-syncope, swelling near eyes after 30 mins. On [b6] several episodes of near-syncope, paresthesias in arms and legs, leg weakness, urticaria in bilateral legs - went to ER via ambulance to [b6] The visit was very traumatic for [b6] reason for visit listed as only anxiety, likely due to paramedics giving incomplete HPI and no sufficient intake interview with [b6] despite us telling paramedics that this was an allergic reaction to C19 vaccine. Incident with RNs who refused to take off blood pressure cuff on left arm when [b6] pleaded for them to stop due to extreme pain. CMP showed [b6] [b6] On the notes, the neuro exam showed [b6] felt like her legs were starting to buckle when asked to stand, and the resident MD had a hard time getting ankle and patellar DTRs (Her PCP also had a hard time getting lower limb DTRs at her follow up 3 days later). Only given water by mouth and prescribed [b6] and discharged same night. She had to be sent out in a wheelchair out of the ED. It was five days later that [b6] doctor prescribed [b6] At this time, her symptoms still included paresthesias in arms/legs, leg weakness, involuntary vibrations in her hands when she opens them after being closed, shakiness in her legs, and fatigue. In addition, she was having trouble sleeping through the night and started to have occasional night sweats.

We also found that polyethylene glycol was in the Pfizer vaccine - she had a severe reaction to [b6] and did not tolerate [b6] afterwards. I deeply regret that I did not look up the ingredients of the Pfizer vaccine beforehand, as I would have noticed that PEG was used and I would have prevented [b6] from taking the vaccine and she would not have been suffering like this for the past four months.

During this time, [b6] consulted with PCP, which made referral to neurology, and established care with allergist MD at [b6] who has been working with her on figuring out [b6]

b6 Allergist labs on b6 showed b6
b6

On b6 established care with neurologist at b6 at initial telehealth interview the neurologist only focused on incident with BP cuff from ED visit. Head MRI/MRV ordered b6
b6

On b6 paresthesias and weakness became very severe along with facial flushing and tongue swelling, and b6 took a few days of b6 also started to feel that her heart was beating harder than normal, when at rest, and was sometimes awoken from sleep with faster heart beat and palpitations- PCP notified. b6 was suggested after b6 experienced jitteriness and palpitations after taking one dose, and was discontinued after one dose.

b6 Allergist ordered b6
b6

b6 Completed PCP ordered b6
b6

Throughout these two months, all blood labs b6
b6
b6 which left b6 at home with b6
b6 as she is primary caretaker, and we do not have family closeby that are able to watch
b6

b6 continued to have paresthesias in arms and legs. Started to have facial numbness and tingling b6 Since her paresthesias were getting worse, and had spread to her face, we were starting to get more concerned that something had been missed, and we notified neurologist. He was dismissive of her leg weakness, and has minimized her symptoms. We have had to advocate strongly for her to get her symptoms taken more seriously. During this time, b6 was also informed by dentist that she will need b6
b6 Upon consultation with periodontist and informing him about this vaccine reaction b6 was told that we need to diagnose and resolve the neurological issues before surgery can be undertaken. When we informed the neurologist of this new urgency, he finally started to think about this being issues with autonomic nervous system and small fiber neuropathy.

b6 Seen by only other neurologist at office, due to assigned neurologist not being available for appointments. We were in contact with assigned neurologist about concerns for GBS, since b6 found support group online started by b6 who had asimilar reaction and symptoms as b6 after getting the COVID Vaccine. In this support group, there were several cases of patients being told that they didn't have GBS due to "no clinical signs" but then were confirmed to have GBS weeks/months later after getting a spinal tap. The neurologist that b6 saw in the office this day, after giving her a physical exam, told her that she does not have GBS, but needs EMG and nerve studies to test her autonomic nervous system, as well as cervical MRI. Blood tests, including b6
b6

Around this same week, b6 started to wake up early each morning (around 4am on average) with her tongue thrusting involuntarily to the roof of her mouth, and her tongue slightly swollen. This symptom has persisted throughout each day, to the present day.

b6 Allergist suggested b6
b6 She has only been able to tolerate one daytime dose per day since then. When we tried a nighttime dose, she woke up repeatedly in the night. The b6 has only slightly decreased her tongue swelling and paresthesias, but has not treated her tongue thrusting at all. We are still working with allergist to titrate b6 and when to fold in b6. In addition, we are working with him to possibly rule out Mast Cell Activation Syndrome. b6 We are instructed to try to do a repeat 24hr urine test during a "flare up" to see if any biomarkers there suggest MCAS.

b6 Since the EMG and nerve studies could only be scheduled as early as August 18, and since b6 symptoms were progressively getting worse, neurologist performed b6
b6 He doesn't think she has b6 and but told her to keep August 18 appointment as a consultation appointment. Blood tests, including b6
b6
b6

b6 her tongue thrusting has felt much more severe, and her paresthesias have felt worse as well, despite taking b6

We are considering keeping cervical MRI test date. We got a reschedule of her ANS tests to August 12 - table test, QSART, deep breathing, and one other test that I cannot recall at this point.

Throughout these four months, b6 has tried to take at least one 30min-1hour walk per day, despite how challenging it is with her symptoms.

I apologize if this is more detail than you need, but I thought it would be helpful to get a sense of the progression of her symptoms, because of your neuroimmunology expertise, and to help guide our discussion tomorrow.

We are very thankful that you are taking time out of your busy schedule to meet with us on Friday morning on Zoom. We look forward to speaking with you.

Thank you,

b6

On Mon, Jul 26, 2021 at 11:07 PM Nath, Avindra (NIH/NINDS) [E] b6 wrote:

Dear b6

I am sorry to hear of b6 illness. I would be willing to talk to her to see what we can do to assist. I have copied Warren who can help schedule a meeting.

Avi

Avindra Nath MD

Chief, Section of Infections of the Nervous System

Clinical Director,

National Institute of Neurological Disorders and Stroke

National Institutes of Health, Bethesda, MD

b6

From: **b6**

Date: Monday, July 26, 2021 at 8:20 AM

To: Nath, Avindra (NIH/NINDS) [E]: **b6**

Subject: COVID Vaccine Allergic Reaction - Paresthesias

Hi Dr. Nath,

My name is **b6** and I'm **b6** whose **b6** has been suffering from paresthesias in arms and legs and face and has been not doing well overall since having an allergic reaction to polyethylene glycol in one dose of the Pfizer COVID vaccine, given **b6**. Since then, we have been working with her PCP, allergist and neurologist to try to diagnose and treat her symptoms through many diagnostic tests, with little success so far.

We have found support groups online for other people who have had similar reactions and trouble getting sufficient care from their providers due to the newness and complexity of their symptoms caused by the experimental vaccine. We heard your and Dr. Safavi's name from the NIH from **b6** in one of the groups who is also suffering similar symptoms. She suggested that I contact you.

b6 and I have been wondering if you would be willing to offer any support or advice to us, or possibly offer guidance to her providers for her treatment, given your expertise in neuroimmunology. Please let us know either way. If so, I can write up a more detailed timeline of **b6** symptoms. Thank you for taking the time to read this - we look forward to hearing from you.

Best,

REL0000229446

b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6] b6
Sent: 12/30/2021 8:00:36 PM
To: b6
Subject: Re: [EXTERNAL] Re: Covid vaccine neurological issues

It is just a hypothesis not a theory!

From: b6
Date: Thursday, December 30, 2021 at 1:25 PM
To: Nath, Avindra (NIH/NINDS) [E] b6
Subject: Re: [EXTERNAL] Re: Covid vaccine neurological issues

CAUTION: This email originated from outside of the organization. Do not click links or open attachments unless you recognize the sender and are confident the content is safe.

How about this theory? It is from the nejm from November. I have been in contact with Dr Murphy and they may do some more research after the holidays.

b6

Sent from my iPhone

On Dec 26, 2021, at 9:20 AM, b6 wrote:

Dr. Nath,

Sorry to keep bothering you. I hope your holiday season is well. I am wondering if you have any answers as to why my symptoms are worse in the morning upon waking and are mostly if not all the way gone by evening? I read that inflammation can be worst upon waking due to the body's circadian rhythm. Is this a possible answer? I really need to get better. My own PCP and one of the neurologists I saw won't do anything to treat symptoms unless there are studies that prove something works. I asked about IVIG, plasmaphoresis, high doses vitamin C and other things. I know I said I'm b6 b6 so I can seek whatever treatment I may be able to get. I'm hoping you and b6 will be able to help me.

Regards,

b6

Sent from my iPhone

On Dec 21, 2021, at 8:26 AM, Nath, Avindra (NIH/NINDS) [E] b6 wrote:

Yes, I will be glad to talk to b6 should be fine. I do not see any reasons for concern.

Avi

From: [REDACTED] b6
Date: Tuesday, December 21, 2021 at 9:23 AM
To: Nath, Avindra (NIH/NINDS) [E] [REDACTED] b6
Subject: [EXTERNAL] Re: Covid vaccine neurological issues

CAUTION: This email originated from outside of the organization. Do not click links or open attachments unless you recognize the sender and are confident the content is safe.

Dr. Nath,

I am going to be seeing [REDACTED] b6 The immunologist I saw there had said that [REDACTED] b6 is familiar with you. Is there any way you and [REDACTED] b6 could collaborate on a care plan for me? I'm desperate to get back to a normal life with my family. Also, I was [REDACTED] b6 when I got the shot on recommendation by CDC, ACOG, SMFM. Also [REDACTED] b6 approved etc. I asked many providers when I was having an abnormal response to the vaccine if I should [REDACTED] b6 and all said [REDACTED] b6 so we have been. Is [REDACTED] b6 going to have issues from this then? I'm really worried about this whole situation. I did have EMG done recently and it was [REDACTED] b6 Thanks. Happy holidays.

Regards,

[REDACTED] b6

Sent from my iPhone

On Nov 15, 2021, at 9:08 PM, Nath, Avindra (NIH/NINDS) [E]
[REDACTED] b6

Dear [REDACTED] b6

Sorry, that you have not been able to get adequate care.
Avi

From: [REDACTED] b6
Date: Monday, November 15, 2021 at 2:25 PM
To: Nath, Avindra (NIH/NINDS) [E] [REDACTED] b6
Subject: Re: Covid vaccine neurological issues

Dr. Nath,

I contacted the doctors whom you mentioned. Most didn't reply and one (the male doctor) responded and didn't seem to know much about these reactions. I see on your profile you are a neuro-immunologist for the nih. I am begging and pleading for these issues to be researched further. I have been in contact from others around the world who have had the same symptoms I have had and no one has answers. My neurologist wants to label me with [REDACTED] b6 I don't buy that for one second. I am [REDACTED] b6 and I [REDACTED] b6 I am giving you a link to an online forum so you can read these people's posts. I'm begging for anyone to look into this and to not give this Pfizer shot to kids! We need to know why these neurological issues are happening. I read an online article with you quoted in it regarding a reaction that was similar when these shots

were in trials and it was a concern then. What does the nih plan to do about this or the United States for that matter?

<https://vestibular.org/forum/symptoms/tingling-numbness-in-body/paged/54/>

Please help us.

Regards,

b6

Sent from my iPhone

On Oct 23, 2021, at 8:25 PM, **b6**

b6 wrote:

Thank you so much for this information. I don't live in New York but will travel anywhere to feel better. Will I be able to get around New York if I haven't been fully vaccinated? I have been advised to not get the second shot. My doctor would give me an exception letter too. Thank you so much for replying! You are a blessing. Have a great weekend!

Regards,

b6

Sent from my iPhone

On Oct 23, 2021, at 8:12 PM, Nath, Avindra (NIH/NINDS) [E]

b6 wrote:

Dear **b6**

Sorry to hear of your illness. If you live in the NY area, I would suggest seeing any of the following:

b6

They are all well versed in these complications and will investigate and treat you.

Avi
Avindra Nath MD
Chief, Section of Infections of the
Nervous System
Clinical Director,

National Institute of Neurological
Disorders and Stroke
National Institutes of Health, Bethesda,
MD

b6

From: b6

b6

Date: Friday, October 22, 2021 at
11:36 AM

To: Nath, Avindra (NIH/NINDS) [E]

b6

Subject: Covid vaccine neurological
issues

Good morning,
I'm writing to you today out of
desperation. I'm looking for anyone
who can help me recover after my first
Pfizer vaccine. Almost immediately
after receiving it I had lightening bolt of
pain on the left side of my brain and
after that I have had a multitude of
symptoms. I felt electrical sensations all
over my body with a revved up feeling
internally. I had very deep sleep but
also was not my normal sleep. I was
having lucid nightmares. At one point I
almost felt like I was losing my mind
when I would go to sleep. That has
gotten better but I am still having vivid
dreams. I developed diarrhea, tinnitus,
sensitivity to sound/light/touch,
paresthesias in all limbs and numbness
in limbs, headaches unlike any I have
ever felt before, brain fog or difficulty
concentrating, skin feeling sensitive and
burnt but I haven't been in the sun,
random areas of intermittent pain on
my skin as well. I saw Dr. Thakur as an
author of a review in a neurology
journal and he mentioned talking with
you. I got your email off of the internet.
I have reached out to many others as
well as Mayo Clinic and come up short.
Please help me or point me in a
direction of someone that can. I have 3

kids to care for that are

b6

b6

Thanks so

much.

Regards,

b6

Sent from my iPhone

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246- b6]
Sent: 12/19/2021 12:25:11 PM
To: b6
Subject: Re: [EXTERNAL] Re: b6

Hi b6

I am sorry to hear that. You need to discuss b6
b6 with your PCP or by presenting in local ED.
please let me know if I can be any help to discuss it with your health care providers.
Hope you feel better soon.
Best

Farinaz

From: b6
Sent: Sunday, December 19, 2021 5:54:52 AM
To: Safavi, Farinaz (NIH/NINDS) [E] b6
Subject: Re: [EXTERNAL] Re: b6

CAUTION: This email originated from outside of the organization. Do not click links or open attachments unless you recognize the sender and are confident the content is safe.

Hi Dr. Safavi,

b6 I have the predicted symptoms of cough, low grade fever, congestion, headache, myalgias and arthralgias. Would you be able to refer me to b6
Thanks
b6

On Mon, Dec 13, 2021 at 6:21 PM b6 wrote:
<https://www.fda.gov/news-events/press-announcements/coronavirus-covid-19-update-fda-authorizes-new-long-acting-monoclonal-antibodies-pre-exposure>

Another link

On Mon, Dec 13, 2021 at 6:08 PM b6 wrote:
Hi,
Here is the article.

<https://www.empr.com/home/news/evusheld-authorized-for-pre-exposure-prophylaxis-of-covid-19-in-certain-individuals/>

b6

On Mon, Dec 13, 2021 at 6:04 PM Safavi, Farinaz (NIH/NINDS) [E] b6 wrote:
Hi b6
Can you please send me the original information and FDA link about this statement.
Thanks

REL0000230891

Farinaz

From: [REDACTED] b6

Sent: Monday, December 13, 2021 5:55:45 PM

To: Safavi, Farinaz (NIH/NINDS) [E] [REDACTED] b6

Subject: [EXTERNAL] Re: [REDACTED] b6

CAUTION: This email originated from outside of the organization. Do not click links or open attachments unless you recognize the sender and are confident the content is safe.

Dr. Safavi,

On December 8th the FDA authorized new long acting monoclonal antibodies for pre exposure prevention on covid 19 for people with severe adverse reactions to the covid 19 vaccine. [REDACTED] b6

[REDACTED] b6

Thank you

[REDACTED] b6

On Fri, Nov 26, 2021 at 10:10 PM Safavi, Farinaz (NIH/NINDS) [E] [REDACTED] b6 wrote:

Hi [REDACTED] b6

Based on discussions among our team, the consensus is not taking the booster shot since you had adverse events after the vaccine. Of course, we defer the final decision to you since our suggestion is based on anecdotal experience and there is no solid epidemiological data.

I cc Dr. Nath for further comments.

Hope it helps.

Farinaz

From: [REDACTED] b6

Sent: Friday, November 26, 2021 9:06:07 PM

To: Safavi, Farinaz (NIH/NINDS) [E] [REDACTED] b6

Subject: [REDACTED] b6

Hi, Dr. Safavi,

I hope you had a great Thanksgiving. I have a question for you concerning if I should get a booster shot for Covid considering my previous reaction. Should I attempt to get a pediatric dose? What are your thoughts?

Feel free to call me to discuss.

Thank you.

[REDACTED] b6

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246; **b6**
Sent: 5/19/2021 1:56:43 AM
To: **b6**
Subject: Re: neurological complications of Pfizer vaccine

Perfect!
I will send you MS teams link shortly.
Best

Farinaz

From: **b6**
Sent: Tuesday, May 18, 2021 5:09:37 PM
To: Safavi, Farinaz (NIH/NINDS) [E]; **b6**
Subject: Re: neurological complications of Pfizer vaccine

Dr. Safavi,

Yes, I can do Sunday at 2-3 EST. Just let me know how we are to meet.

Best,

b6

b6

From: Safavi, Farinaz (NIH/NINDS) [E]; **b6**
Sent: Tuesday, May 18, 2021 3:42 PM
To: **b6**
Subject: RE: neurological complications of Pfizer vaccine

CAUTION: External Sender

Hi,
Do you think Sunday works for you. I am flexible about time. Best will be 2-3pm ET? If not we can find a different weekday next week.
Best

Farinaz Safavi MD, PhD
Division of Neuroimmunology and Neurovirology
NINDS, NIH, Bethesda, MD

REL0000230915

From: [b6]
Sent: Tuesday, May 18, 2021 4:36 PM
To: Nath, Avindra (NIH/NINDS) [E]; Safavi, Farinaz (NIH/NINDS) [E]
Subject: Re: neurological complications of Pfizer vaccine

Dear Dr. Nath,

I appreciate your response very much and look forward to speaking with Dr. Safavi.

Thank you again, and best wishes,

[b6]

[b6]

From: Nath, Avindra (NIH/NINDS) [E] [b6]
Sent: Tuesday, May 18, 2021 11:00 AM
To: [b6] Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Re: neurological complications of Pfizer vaccine

CAUTION: External Sender

Dear [b6]
Sorry to hear of your illness. I have copied Dr. Safavi, who is a neurologist working with me. She has kindly agreed to discuss your symptoms with you and see what we can do to help.

With best wishes.

Avi
Avindra Nath MD
Chief, Section of Infections of the Nervous System
Clinical Director,
National Institute of Neurological Disorders and Stroke
National Institutes of Health, Bethesda, MD

[b6]

(Office)
(cell)

[b6]

From: [b6]
Date: Monday, May 17, 2021 at 8:09 AM
To: [b6] Nath, Avindra (NIH/NINDS) [E]
[b6]
Subject: neurological complications of Pfizer vaccine

Dear Drs. Das and Nath,

I hope this finds you well.

REL0000230915

I write to you because of your connection with the *Annals of Neurology* podcast of March 12, 2021 ("ANA Investigates: Neurological Complications of COVID-19 Vaccines"). The podcast write-up was one of the few places where I have seen a clear statement* that some of the symptoms I've been experiencing have been associated with the vaccines. I hope that you will not mind my sharing my experience.

I received dose 1 of the Pfizer vaccine on [b6] On [b6] I began experiencing muscle twitching in the arch of my foot. Fairly quickly the muscle twitches/spasms spread over the whole of my body, and I also began to experience vibration sensations (especially in my feet but also in a few other places). Unfortunately, I did not immediately connect these strange new occurrences with the vaccine because no one else I knew had experienced them. This meant that I ended up getting dose 2 of Pfizer on [b6] The muscle twitches/spasms and vibrations continue to this day, [b6] One day last week, one of my big toes twitched while also vibrating for about 30 minutes. Since the condition is worse when I lie down or when my legs are outstretched, I have not slept in a bed for several days. Sometimes the twitches and sensations are visible to the eye, and sometimes they are not. Occasionally, I will also have shooting burning sensations and perhaps mild pins and needles sensations (though with the heightened awareness of my body it is hard to tell whether the latter are psychosomatic or real). My GP--the only doctor I have seen--also diagnosed [b6] [b6] Otherwise, he said he thinks I am merely anxious. I am [b6] right now, but the idea that these symptoms are primarily rooted in anxiety is rubbish. (Incidentally, I have reported my symptoms to VAERS, and I do not pretend that they are the worst neurological symptoms.)

I understand that correlation is not causation, and in five years, I expect to read that a large-scale epidemiological study shows that the neurological effects allegedly associated with these vaccines cannot be definitively linked to them because the incidence was no greater than what one would expect to see in the general population, or something to that effect. Again, I do think this is rubbish in some cases.

Besides a general concern about a push to vaccinate young children for what is by no means a "childhood illness" like polio or the measles, I am of course concerned about whether the vaccine has done some sort of lasting damage to my body or prompted some horrific autoimmune disease. Unlike some vaccine neurology patients, I do not seem to be in the midst of an emergency, and I have been unable to get an in-network neurology appointment prior to September. I do know that my physical state could change for better or worse quite quickly.

I know that you are both incredibly busy men, so thank you for reading this long note. Any advice or suggestions you have would be most appreciated.

Best,

[b6]

*"The most common neurological symptoms included dizziness, headache, pain, muscle spasms, myalgia, and paresthesias, which are expected to occur as acute, transient effects of the vaccination. Rare cases of tremor, diplopia, tinnitus, dysphonia, seizures, and reactivation of herpes zoster have been reported."

[b6]

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From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246: **b6**
Sent: 11/27/2021 3:05:58 AM
To: **b6**
Subject: Re: **b6**

From: **b6**
Sent: Friday, November 26, 2021 9:06:07 PM
To: Safavi, Farinaz (NIH/NINDS) [E]: **b6**
Subject: **b6**

Hi, Dr. Safavi,
I hope you had a great Thanksgiving. I have a question for you concerning if I should get a booster shot for Covid considering my previous reaction. Should I attempt to get a pediatric dose? What are your thoughts? Feel free to call me to discuss.
Thank you.

b6

From: [b6]
Sent: 3/9/2021 8:59:31 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: ResponseSummary.pdf
Attachments: ResponseSummary.pdf

This is an extensive questionnaire listing some medical history of pre-existing conditions as well as dates and duration of my ongoing symptoms. This data may or may not be of use to you.

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From: [b6]
Sent: 3/9/2021 7:32:42 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246] [b6]
Subject: Re: 1 Year Covid Long Hauler

Dr Safavi,

Here are screenshots of work-ups from the 5 ER visits, 2 urgent care visits, as well as labs from my various providers. These may come in several emails. I will include a .pdf of a symptom questionnaire I filled out last night for your reference.

My write up on the course of my illness is as follows. I am not certain where I was exposed to the virus. I suspect several possibilities but am not certain. I first felt symptoms on [b6] It began with a sore throat on the right side with an ear ache in the right ear accompanied with a fever for several days. I felt massive all-body muscle pain and a fearful/bad feeling. Those symptoms subsided and [b6] I began feeling shortness of breath the following week. I was swabbed at an urgent care on [b6] Symptoms worsened and I went to the ER on [b6] That doctor did not swab me again, but informed me that she didn't need to because she was convinced symptomatically that [b6] Looking at my blood work and from her patients she had been admitting and treating, that was her conclusion.

I was not admitted but sent home. My symptoms worsened then moving to the heart. Tachycardia and bradycardia continued such as drastic spikes in pulse while laying down. Oxygen levels would drop to the 70s and swing back up. Massive chest pain. I went to the ER a few more times until August, when I began to experience more heart issues and scary neurological symptoms. A flushing feeling and hot/cold feeling at the base of the brain, flushing through temporal and frontal lobes. Followed by shaking for hours. I could not respond to family members speaking to me for stretches of time. I would stare off, my mouth would water and I felt like doom overwhelming me as I experienced sudden and extreme exhaustion and crying. Those episodes spontaneously went away several months after. The EEG taken a couple of months later [b6] although my PCP suspected the previous shaking episodes and brain sensations could have been [b6] I saw a cardiologist, pulmonologist. I [b6] during Covid, from [b6] Later was prescribed [b6] in the fall due to ongoing [b6] that worsened after a reaction to [b6] I felt my cardiac, pulmonary and neurological manifestations significantly improve quickly due to [b6] Although there were occasional neurological episodes that ensued that eventually dissipated until recently.

My primary residual symptoms after 1 year post Covid is massive chronic fatigue. Brain fog, not being able to focus on simple tasks.

I received the Pfizer vaccine. 1st dose on [b6] 2nd dose [b6] 24 hours following I spiked a 102 fever with sweating, dizziness and headache. The sensations in the brain came back worse and with a vengeance coupled with the seizure like activity. The myoclonic like jolts go down all limbs, and now include a jerking of the head to the right. I feel these episodes before they happen from an increased sensation in the brain. Movements include full body at its worst. Most of time lately it involves only the left arm and leg along with the head jerking to the right. These episodes last anywhere from 8-20 hours. I tried getting help from the ER. They did not have access to an EEG. The MRI showed [b6] [b6] This has been going on since [b6] I took [b6] and saw symptoms reduce the past few days with [b6]

This is not a complete account of all of my symptoms, as it is extensive and a good place to start.

I look forward to our visit tomorrow.

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> On Mar 6, 2021, at 9:08 PM, [b6] wrote:

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> Dr. Safavi,

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> Thank you for your correspondence. That time will work for me.

>

> I will collect my medical records for you to review.

>

> [b6]

>

>> On Mar 5, 2021, at 7:43 PM, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

>>

From: [REDACTED] b6
Sent: 3/9/2021 8:24:08 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group
(FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246] [REDACTED] b6
Subject: Re: 1 Year Covid Long Hauler

Attachments cont.

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> On Mar 6, 2021, at 9:08 PM, [REDACTED] wrote:

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> Dr. Safavi,

>

> Thank you for your correspondence. That time will work for me.

>

> I will collect my medical records for you to review.

>

> [REDACTED]

>

>> On Mar 5, 2021, at 7:43 PM, Safavi, Farinaz (NIH/NINDS) [E] [REDACTED] wrote:

>>

From: [b6]
Sent: 3/9/2021 8:55:23 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246] [b6]
Subject: Re: 1 Year Covid Long Hauler

Attachments cont.

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From: [REDACTED] b6
Sent: 3/9/2021 7:43:14 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246- [REDACTED] b6
Subject: Re: 1 Year Covid Long Hauler

Attachments cont.

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> On Mar 6, 2021, at 9:08 PM, b6 wrote:
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