
From: [REDACTED] b6
Sent: 1/28/2022 11:30:36 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [REDACTED] b6
Subject: [EXTERNAL] [REDACTED] b6
Attachments: [REDACTED] b6

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So I sent for the [REDACTED] b6 I'm glad I have been shattered by this free vaccine.
These need to be taken off the market now.

[REDACTED] b6

Sent from my iPhone

b6

From: [b6]
Sent: 2/1/2022 3:55:17 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: [EXTERNAL] Vaccine Reaction?

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Dr. Nath,

I appreciate the follow up. It is certainly a puzzling reaction, and the impact on her and our family has been significant. We are happy to participate in a survey, especially if the goal is to determine why this happened and to prevent this from occurring in other patients. I contacted your team regarding this.

Thank you

[b6]

From: Nath, Avindra (NIH/NINDS) [E] [b6]
Sent: Monday, January 31, 2022 8:40 PM
To: [b6]
Cc: NINDSPostCovid19 <nindspostcovid19@ninds.nih.gov>
Subject: Re: [EXTERNAL] Vaccine Reaction?

Dear [b6]

I am terribly sorry to hear of your wife's illness. Currently, we do not have any treatment protocols, but we are very interested in collecting information about such adverse reactions. I have copied our team who would gather the information.

With best wishes.

Avi

Avindra Nath MD

Chief, Section for 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: Monday, January 31, 2022 at 1:28 PM
To: "Nath, Avindra (NIH/NINDS) [E]" [b6]
Subject: [EXTERNAL] Vaccine Reaction?

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REL0000229252

Dr. Nath,

I am a [b6] in [b6] and am aware of your research through my attempts to find any assistance and explanation for the suffering my wife has experienced following receipt of the Moderna vaccine. I am contacting you with her consent.

She is a [b6] previously healthy and active mother and wife who received the Moderna series of vaccinations in [b6]. She has subsequently suffered a series of profoundly life altering symptoms, the details of which I am happy to provide.

We have pursued local evaluation with multiple physicians (ENT, neurology, immunology, gastroenterology, primary care, dentistry), and she has been hospitalized twice, but a definitive medical explanation for her symptoms has, to date, not been determined.

If you are currently involved with the evaluation and/or management of patients who have suffered similar reactions we would greatly appreciate any and all assistance.

Thank you

[b6]

From: [b6]
Sent: 2/21/2022 3:18:24 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [EXTERNAL] Science Magazine article

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Hello Dr. Nath,

I found the Science Magazine article that interviewed you:

[In rare cases, coronavirus vaccines may cause Long Covid-like symptoms | Science | AAAS](#)

Are there studies underway yet for neurological injury following COVID-19 vaccination? Alternately, has data been collected on those who have come to NIH for help following vaccination presenting with neurological and PASC-like symptoms with negative nucleocapsid and all other medical tests showing no underlying conditions?

It looks like NIH website still hasn't been updated to acknowledge known neurological conditions post COVID-19 vaccination: [Coronavirus and the Nervous System | National Institute of Neurological Disorders and Stroke \(nih.gov\)](#)

What timeframe might that information be updated?

Thank you,

[b6]

From: [b6]
Sent: 2/27/2022 11:38:24 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [EXTERNAL] Re: Reaction after pfizer vaccine

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Thank you i don't see anything attached though

Sent from my T-Mobile 5G Device
[Get Outlook for Android](#)

From: Nath, Avindra (NIH/NINDS) [E] [b6]
Sent: Sunday, February 27, 2022 3:10:52 PM
To: [b6] NINDSPostCovid19 <nindspostcovid19@ninds.nih.gov>
Subject: Re: Reaction after pfizer vaccine

Dear [b6]

I am terribly sorry to hear of your illness. We have a study at NIH, that will be collecting data on patients who have such symptoms. I have copied them on this email.

Also I will forward you to others at NIH to see if they can provide you additional information.

Best wishes.

Avi

From: [b6]
Date: Sunday, February 27, 2022 at 3:44 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: [EXTERNAL] Reaction after pfizer vaccine

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Good afternoon,

I am searching high and low for answers for what's happened to me after pfizer vaccine.
I read an article your name was attached to and not sure if you can help but I'm desperate!

I completely lost my sense of hunger and fullness.

I lost all feelings of emotions

Lost my taste and smell not covid related

Never feel tired, exhausted, or relaxed anymore constantly awake!

There's more but these are my most concerning. I feel like the senses have been shut off in my brain.

Do you think you might know what's going on or can point me in a direction to get this figured out?

Thanks,

b6

Sent from my T-Mobile 5G Device
Get [Outlook for Android](#)

From: [b6]
Sent: 3/9/2022 2:02:44 AM
To: [b6] Nath, Avindra
(NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group
(FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [EXTERNAL] Vaccine reaction please help

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.

Hello my name is [b6] I recently came across your article in science magazine and wanted to reach out to you. I received the first shot on [b6] and had a bad reaction to it. It started with a headache then chest pain I then started having sharp pains throughout my body. My skin started feeling like it was on fire then half of my face was cold the other half was hot and then had a sharp pain in the right side of my neck and a few seconds later my head felt like it exploded with pain. I went to the er and they thought I had a hyper immune response to the vaccine. Since that day I have had a constant headache my blood pressure and pulse fluctuates and I have a burning pain in my legs if I stand to long. We have tried several medications I have had [b6]
[b6] I just completed [b6]
[b6] I wanted to try and contact you to see if you had any tests or medications to try. I just trying to figure out where to go from here to get relief and get back to my normal life. I can be reached at [b6] if you have any questions.

Thank you

[b6]

From: [b6]
Sent: 1/24/2022 8:13:20 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
CC: [b6]
Subject: [EXTERNAL] Pfizer Vaccine Death Confirmed Via Autopsy Report
Attachments: [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.

Dear Dr. Avindra Nath,

Greetings. My name is [b6] along with [b6] We are emailing to discuss my [b6] who passed away on [b6] We have received an extensive autopsy report and the findings concurred that his death was caused directly due to the Pfizer booster vaccine that he had received on [b6] The pathologist performed scans of his heart and gathered 22 slides which confirmed that [b6] had severe myocarditis from the Pfizer booster vaccine that led to his death.

Please give us answers and follow up to why this occurred. We are devastated.

Lot #'s

Pfizer 1st dose

Pfizer 2nd dose

Pfizer booster -

[b6]

Autopsy, death certificate, vaccine cards, and apple watch heart rate data are attached

Thank you,

[b6]

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From: [b6]
Sent: 8/12/2021 12:37:53 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Neuropathy getting worse, numbness spreading
Attachments: YouCut_20210726_145831144.mp4; Screenshot_20210812-073054_MyChart.jpg; Screenshot_20210812-072702_MyChart.jpg; Screenshot_20210812-065545_WhatsApp.jpg

Dr. Nath good morning,

I hope you have been doing fine. Unfortunately, Im not improving, I am getting worse, and Im not getting help here. The type of insurance I have HMO limits me tremendously. I am please begging you to please help me. My numbness is worse and is spreading and I wake up with my hands asleep and now my left leg. I'm having increased weakness, my legs and arms quiver. My heart rate [b6]
[b6] I have chest stabbing pains, tinnitus, fatigue, brain fog, palpitations, joint pain, internal vibrations, to name a few.

I gave [b6] your email because her doctors were dismissive [b6] she is my friend and we have similar symptoms, dysautonomia and neuropathy, she told me you kindly replied to her and she is getting treatment at the NIH at the end of the month.

I'm attaching a video of my hands problem and also my diagnosis [b6]
[b6]

I would not be bothering you if I had other alternative doctor, please, I have been struggling since February and only getting worse. I had to dictate to the phone to type this email because I have problems with my fingers.

Thank you so much for being the only light to many of us during these dark times in our life. God bless you,

[b6]

b6

b6

b6

From: [b6]
Sent: 3/30/2022 12:26:15 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [EXTERNAL] [b6] Diagnosis after Receiving Pfizer Vaccine

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Hello [b6]

My name is [b6] and I have followed your work on neurological conditions associated with COVID-19.

My brother, an otherwise healthy [b6] started experiencing a muscle fasciculation in his left deltoid (same arm as vaccine administration) 2 days after receiving his second dose of the Pfizer vaccine. He had [b6]
[b6] Roughly [b6] post-vaccine, this fasciculation has not stopped and the disruption to his quality of life has led him to seek medical treatment.

Sadly, the first neuromuscular physician he saw gave him a diagnosis of [b6] He has had a [b6] diagnosis on a second opinion. There has been [b6] and no other signs of [b6]

Obviously, the death sentence given to him has been tragic to his mental and emotional health as we search for answers.

Would it be possible for us to connect? Are there any trials with your team he may be eligible for? Looking forward to hearing from you as we investigate this further.

Best Regards,

[b6]

From: [b6]
Sent: 5/1/2022 4:53:04 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [EXTERNAL] question on long covid like symptoms after the vaccine

Hello Dr Avindra

I hope you don't mind me emailing you and I hope that you might be able to help me.

I unfortunately am one of the rare people that react to the COVID vaccines. Last year... Astra Zenica and this year Pfizer.

Last year I suffered from 5 months of fatigue and pain and then was well again. I then had the Pfizer booster [b6] [b6] and have suffered since then with pain, fatigue, skin changes (skin peeling off if squeezed and moles peeling off) and headaches. I had [b6] [b6] I believe I am just turning the corner again and starting to get better.

I read an article in Science that seemed to suggest you might be looking into this area (which is why I am reaching out to you). I am wondering if you have found anything that might be helpful in my quest to get well. In this country there has been discouragement for doctors to report adverse events from vaccines as there is a desperate need to get everyone vaccinated... [b6] I totally understand this (am definitely not anti vaccine). Unfortunately this position means that there is little data out there for those of us who do react and need medical help.

From all of my research it seems that the reaction I (and others from the science article I read) have is very similar to the symptoms of those who experience long COVID. I am wondering if this is an over inflammatory reaction of cytokines? Have you or your colleagues come across anything else that may help? I have been tested for [b6] [b6] The fact that I seem to recover eventually suggests that it might be something other than an underlying autoimmune disease. I have requested [b6]

hoping you can help me or point me to any research article or researcher that may be able to help

thanking you in anticipation of a reply

regards

[b6]

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From: [b6]
Sent: 5/12/2022 11:26:38 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [EXTERNAL] [b6] needs help..

Please help. [b6] has suffered from a serious reaction to the mRNA and has given up on finding help. This past week she has suffered extreme pain in her leg- moved to her foot (swelling/redness/pain shooting through her toes), then 2 days later suffered acute coughing fit unable to catch her breath- today, she blacked out and her entire right side is feeling numb/pain- shooting pain in her head.

She has never had [b6]
[b6] do you know anyone [b6] who understands those with these types of injuries who can help? I found your name mentioned by a few others who suffered adverse reactions. I'm just a friend, but I [b6]

[b6]
[b6] I am desperate to help [b6] find help- she's been through so much [b6] since her 2nd shot. Please help if you can,

[b6]

Sent from my iPhone

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REL0000229342

From: [b6]
Sent: 12/22/2020 11:11:45 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: PEG

Dear Avi,

This sounds encouraging. The reaction although not life threatening, but was scary and still had symptoms yesterday. Today I feel much better without antihistamines. Does moderna vaccine has PEG?

The infection with COVID is frightening. If there an alternative for a vaccine without PEG, I will consider it.

Best,

[b6]

[b6]

From: Nath, Avindra (NIH/NINDS) [E] [b6]
Sent: Monday, December 21, 2020 11:12 PM
To: [b6]
Subject: PEG

Dear [b6]

The speculation is that the PEG (polyethelyne glycol) in the vaccine is what triggers the allergic reaction. It will become evident soon if that is true. So, would be good to know if any of the others have PEG as well. If so, you could choose the second dose with a vaccine that does not have PEG.

What do you think?

Avi

From: [REDACTED] b6
Sent: 5/31/2022 3:26:21 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6] b6
Subject: [EXTERNAL] COVID - Article - Support

Hi and good morning,

I was reading an article where you were working on why vaccines may cause adverse reactions for some and wondered if there is any programs to help. I

live in [REDACTED] b6 and received one doze of Pfizer and have had life changing, and deliberating reactions.

I have burning, numbness, muscle weakness, severe thirst (drink about 100 oz of water a day), weight loss, mouth is changing and many other symptoms that make doing normal life tasks almost impossible.

I read some articles where they are doing [REDACTED] b6 and just wanted to see if you had any places I could turn to for help.

I wondered if a transfusion from a person that did not have the vaccine would work?

Please let me know if there is anything out there to support of help as I know it is new but for us that are having this happen very scary.

Thank you [REDACTED] b6

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From: [b6]
Sent: 6/12/2022 1:25:45 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [EXTERNAL] Please help me recover from my vaccine injury

Dear Dr. Nath,

My name is [b6] I'm desperate for help to recover from my Pfizer Vaccine Injury. My life has been turned upside down and I've been seeing doctors since [b6] just 36 hours after my second dose of the Pfizer vaccine. I'm begging you to please help me. I see that you have helped others who are injured and I just want to be a normal active [b6] again without being bedridden, to be a [b6] a [b6] [b6] I just want to be better. At this point, I'm not even worried about trying to prove it was from the vaccine, I just want help. Even if you could call my primary and tell her what to do to help, or if you could see me I'd be more than willing to come to Maryland.

[b6] was like any other day, felt completely normal and went to receive my second dose. Upon receiving my second dose I noticed a very strange taste in my mouth, and my arm began to tingle down to my wrist. I did let them know while waiting the 15 minutes in the waiting area after the injection. I entered my car and told my mom, who was waiting for me to run her to the store that I had this nasty taste and my arm felt strange. She said she knew others who said their arms felt strange and then they were fine. A little bit later the taste and the tingly feeling went away. [b6] I was watching tv and got up to use the restroom. Upon washing my hands I had this horrible feeling come over me, my heart racing, dizzy, trouble speaking, I turned on the light and looked in the mirror and my entire right side of my face was drooping. I called my parents to tell them I loved them and that I was having a stroke and if I die to please take care of [b6] Next thing I knew I was at the hospital and being swarmed by many doctors and nurses. They told me I was having a stroke but I'd be okay. The next afternoon after hours and hours of tests, they discharged me and said I had a ministroke. A couple of hours after being home, it happened again and back to the hospital I went again. I went a little over a week without being in the hospital until it was each and every day after being sent home, I'd have more ministrokes. Then one neurologist said that he felt the Pfizer Covid Vaccine caused a mutation (in regards to stress on the body triggering a mutation) and diagnosed me with a rare but serious disorder [b6]

[b6] As the months went on I received a diagnosis of [b6]
[b6] and have multiple suspected diagnoses that are trying to be confirmed. Those are [b6]
[b6] The only medical conditions I had prior are [b6]

I suffer with memory loss, speech impairment, cognitive decline, numbness, swelling of random lymph nodes, weakness, pain, shortness of breath, shooting pains in random places (toes, tips of fingers, etc). racing heart, heat intolerance, passing out, exercise intolerance, vision issues, loss of hot/cold sensation in parts of my body, dizziness, nausea, and the list is actually 5 pages long of symptoms.

In the last [b6] I have received [b6]
[b6] I do have doctors that believe and have written letters that my injuries are from the vaccine, but no one knows how to help. My primary care physician is willing to work with anyone who is willing to help me.

I truly am desperate. It's been [b6] of suffering. I am truly exhausted from trying to find help, answers, and solutions. I just need help. Can you please help me? I can send you more information if needed.

Please help me. Thank you so much for your time.

b6

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From: [b6]
Sent: 8/19/2022 1:30:48 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [EXTERNAL] Neuropathic symptoms with SARS-CoV-2 vaccination

Dear Dr. Nath,

I followed this study with great interest, as someone who was diagnosed with [b6] [b6] after the J&J vaccine, alongside extreme vascular pain and moderate POTS symptoms. I later contracted COVID, and became quite debilitated with POTS. I was finally offered [b6] [b6] I have not recovered from either experience, [b6] later.

My question is about future prevention of COVID in people like myself. What does your study team recommend, should we try another vaccine? Perhaps a lower dose? I feel my body is going to react poorly to both vaccine and COVID, but there is no official guidance on this, and my team of doctors is either not well informed on the matter, or worse, refuse to discuss it with me (neurologist even refused to read your study)

If you could, please point me to more information on prevention, or treatment options if I contract COVID again, or react poorly to another vaccine. I was wearing an N95 when I got COVID (outside), so nowhere feels safe. I am trapped in my house and in a body I no longer trust.

Thank you for your time, and thank you for the study.

Best,

[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.

From: [b6]
Sent: 8/30/2022 2:21:35 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: [EXTERNAL]; [b6]

Hi Dr. Nath,

Physicians have no idea. My rheumatologist [b6] does not know how to treat this systemic immune disorder. Neither does my neurologist not immunologist.

I reached out not because I am asking for treatment, you made it very clear you are not going to help me. I am reaching out to ask how the other patients you have seen are doing with [b6] because you're one of the few places that has seen at least a few people with vaccine injuries. There is no place we can all go to that is collecting data on our condition and treatments, so you're the only source to have any kind of knowledge on how we are doing and what is working.

I am just trying to get my life back and understand if I should go through the process of trying [b6] which, as you know, is quite daunting.

Thanks,

[b6]

On Mon, Aug 29, 2022 at 9:38 PM Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

I am terribly sorry to hear that. The symptoms you are experiencing are beyond our area of expertise. We are at a loss to how to investigate or treat it. We would suggest that you continue to follow up with your physicians and maybe consider seeing a rheumatologist since they specialize in systemic immune disorders.

Best wishes.

Avi

From: [b6]
Date: Monday, August 29, 2022 at 2:31 PM
To: Safavi, Farinaz (NIH/NIAID) [E] [b6] Nath, Avindra (NIH/NINDS) [E]
[b6]
Subject: [EXTERNAL]; [b6]

Hello Dr. Safavi and Dr. Nath,

I am sad to report that my post-vaccine symptoms have once again become quite intense - malaise, fatigue, very painful sore throat, rash, night sweats, weight loss and appetite loss, internal tremors, muscle quivering, weakness and debilitating fatigue.

REL0000229369

I am wondering if this is the case because it has now been [b6] I was wondering, of the patients you saw and ones that [b6] have they been able to recover or do they keep improving? I have now tried [b6]
[b6]

I am still quite desperate to get to my pre-vaccine state and it does not seem whatever it caused is getting better with time.

I appreciate any thoughts you have.

Thank you,

[b6]

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From: [b6]
Sent: 9/4/2022 9:54:38 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [EXTERNAL] Injured

Hello Dr. Nath,

I hope you are doing well and always appreciate everything you are doing and your prompt response giving me names of doctors to help the injured in the past. I fortunately am still doing remarkably well despite how sick I was. Because I made such a huge turnaround [b6] people are reaching out to me for help and I can't handle the volume. Do you foresee a study anytime in the future on these reactions? At [b6] the cardiologists, neurologists and radiology department are talking about it very hush hush because they are afraid of getting in trouble. I feel like we need to study this sooner than later because I'm a believer in vaccines saving lives but with this one, the injuries are just so many and it's creating hesitancy. I have people terrified contacting me especially after reading substacks like Steve Kirsch's. Is there any truth in his work as he is not a doctor? Also groups on FB are growing by the tens of thousands everyday with injuries. I have hope that if we can figure out what is causing it we can find a way of identifying who may not be a candidate or prevent these serious reactions. We have the best medical team in the world and I have faith we can figure this out but it needs to be soon because many people are barely hanging on. I also wanted to pass on to you [b6] He's a neurologist in the autonomic department. He was in charge of the long covid clinic but now is treating the vaccine injured as well. He is treating so many of us and he's amazing if you ever want to reach out to him with what he is seeing. I see him monthly and on my last visit he said he has just as many vaccine injuries as he does long haulers so we definitely have a problem. He's a wonderful neurologist and might be able to provide some insight as well as add him to your list of referrals. I thank you once again for all you do.

Sincerely,

[b6]

Sent from my iPhone

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REL0000229370

From: [REDACTED] b6
Sent: 9/4/2022 1:31:12 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6] b6
Subject: [EXTERNAL] In need of post vaccine reaction support

Dear Dr. Nath,

I just read an article online about long-haul Covid symptoms and Covid vaccines in Science from January of this year and learned about your work. I have been struggling with ongoing symptoms from Covid that were improving until I received a Covid vaccine. I'm looking for help and I'm not sure where to go from here or where I should start.

I would be interested in learning about studies that may be ongoing or that I could take part in. Would you consider a meeting or phone call? I would greatly appreciate any assistance you can provide.

Be well-live well-give well,

[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.

From: [b6]
Sent: 10/3/2022 5:58:26 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: [EXTERNAL] Referral for Adverse Rxn to Covid 19 Vaccine

Thank you.

Sent from my iPhone

On Oct 3, 2022, at 1:39 PM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

Sorry to hear of your illness. Not sure why they would refuse to take referrals. This is outside my area of expertise, but you could try other major medical centers such as Hopkins, UCSF or Yale. It sounds like you need some multidisciplinary care.

Best.

Avi

From: [b6]
Date: Monday, October 3, 2022 at 12:57 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: [EXTERNAL] Referral for Adverse Rxn to Covid 19 Vaccine

Dr. Nath,

I am located in [b6] I have not been able to get medical referrals from my rural healthcare location to diagnose or treat the adverse reaction that I had due to the covid-19 vaccine. Despite being hospitalized for [b6] [b6] there has been no follow up care for my severe edema in hands and feet, joint pain everywhere, reactivated neuropathy, stiffness. I can no longer perform daily tasks because my hands are stuck in a claw position and my skin is cracking from being pulled so tightly with the edema. Rheumatology providers have refused referrals from my GP, as have [b6] [b6] No one will diagnose me or treat me. Before this, I was a healthy [b6] regularly practicing yoga, active and 10 years out cancer survivor from breast cancer with minimal long term side effects (migraines).

I saw your work reported in Science mag. I am writing on the off-chance that you know of anyone taking cases like mine in the United States, who could see me, diagnose me and treat me. I am miserable and getting no help. Any advice is appreciated. Please help.

Best regards,

[b6]

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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.

REL0000229373

From: [b6]
Sent: 10/21/2022 3:30:46 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6] Safavi, Farinaz (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: [EXTERNAL] Please help me / Post-COVID-Vaccination Adverse Events

Dear Sir/Madam,

I apologize for contacting you both out of the blue and I acknowledge that it may be both inappropriate for me to seek your assistance and also unlikely that I will receive a reply. However, my circumstances dictate that I must try to begin somewhere. I will try to be as brief as possible in describing my problems.

I learned of your names in relation to this matter in an [article](#) on [science.org](#). I found this article because of extensive research I have been doing in relation to health issues surrounding vaccination for COVID-19.

I am a regular, [b6] US citizen who has now received her fourth COVID vaccination (two primary Moderna, one Moderna booster, one Pfizer booster). I received the Pfizer bivalent booster on [b6]. My husband and I have always taken the COVID pandemic with the utmost seriousness and have done everything within our powers to avoid contracting the illness, including taking all shots indicated. We also both experience acute side effects from the shots lasting 24-48 hours including high fever, exhaustion, muscle aches, nausea and malaise. These generally resolve within 48 hours. All symptoms were reported using the V-Safe check-in system in both our cases.

However, while my husband's acute side effects after vaccination subside and he experiences no other ill effects, I have become *extremely* concerned about my own experience. Indeed, I am now beginning to wonder if the vaccines have been affecting my health over the past [b6] to a greater degree than confounding issues surrounding [b6] that I have been experiencing. The time elapsed between my two boosters was almost 12 months [b6] and during this time (and in particular during the last couple of months) I have seen an uptick in my general health and wellbeing.

I am now [b6] post-bivalent-booster. I am noticing with great alarm the return of symptoms that I had almost forgotten about, and research is now (in October 2022) bringing up the concerning possibility that some of what I am experiencing may be related to the vaccines I have been so gladly receiving.

A small snapshot of the diffuse symptoms that have returned to me since obtaining my bivalent booster include:

- Significant exacerbation of tinnitus/hearing issues/some ear pain (it should be noted that after my second primary vaccine, my acute reaction symptoms ended with pain in my ears, which seemed very bizarre)
- Intermittent headaches which are much different from 'normal' headaches in the past
- Extreme brain fog combined with short-term memory issues
- Trouble sleeping and exhaustion
- Unusual chest sensation such as tightness/band constriction and a dry cough/desire to cough/feeling of "wheeziness"
- Depression - most likely as a result of the above-mentioned symptoms returning

I had absolutely no indication that these symptoms may be attributable to a somewhat unique reaction to the vaccines. However, the more I research and read, the more concerned I am becoming that I could possibly be experiencing the long-COVID mimicry as a result of vaccination that some others have brought to the attention of your good selves as well as others in positions of significance within the medical community.

I understand from my extensive research that there are a few mechanisms proposed to cause such long-lasting side effects, such as microclots that can damage the cells that line blood vessels, and possibility of the presence/manufacture of autoantibodies to the ACE2 receptor.

I am writing you both to plead with you to share any resources that may be available to me and/or referral to any specialists who may be able to assist me. I live in [b6] and have had very little involvement with the medical system. I do not believe there would be a way for me to approach a primary care physician about this matter - at least without having some professional advice from individuals such as yourselves as to where to begin looking for a diagnosis, and also advice on possible solutions and/or treatments - such as [b6] [b6]. There are no specialists in any field even adjacent to this that I know of anywhere near where I live. Your input could well offer some hope that I can return to fully functioning status rather than live a half-life with no help or assistance for a year or years longer before this finally begins to wear off.

Yours, hopefully,

b6

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From: [b6]
Sent: 1/5/2021 7:30:25 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Question

Dear Avi,

So so sorry to disturb you. But I need your advice as a friend who knows medicine... I am scared and worried. I finally got a consult with an immunologist.

She says that my reaction to the vaccine was [b6] Therefore, she is

[b6]

[b6] She thinks it may be [b6]

[b6]

[b6] She recommends [b6]

[b6]

Do you think this is OK? Should I be more relaxed and confide that it will be OK?

[b6]

[b6]

From: [b6]
Sent: 1/7/2021 7:51:22 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: Re:



b6

From: Nath, Avindra (NIH/NINDS) [E] [b6]
Sent: Thursday, January 7, 2021 3:05 PM
To: [b6]
Subject: Re:

OK. Glad you are still alive!
Keep me posted
Avi

From: [b6]
Date: Thursday, January 7, 2021 at 2:03 PM
To: "Nath, Avindra (NIH/NINDS) [E]" [b6]
Subject: <no subject>

Dear Avi,
Got the vaccine [b6] Went well. Had the lips paresthesias and slight swelling and bilateral face paresthesias mostly lower face. Milder than the first one. It happened 20 mins after and lasted 20 mins. Still have some weird sensations but very mild.
Have a bad headache than doesn't respond to [b6]
Sounds good put last time my symptoms began 10 hour after, so waiting. Hope it doesn't get worse.
Thank you for everything, it help me a lot. Was more relaxed.
All the best,

[b6]

b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 [b6]
Sent: 6/17/2021 12:55:51 AM
To: [b6]
Subject: Re: Pfizer vaccine Reaction Study

Dear [b6]

I am terribly sorry to hear of your illness. You have done the right thing by seeking help from a neurologist. He/She would be the best person to investigate your symptoms. Although we have heard from and talked to several patients with post-vaccine complications, we currently do not have a study for this purpose.

Wishing you all the best.

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: Wednesday, June 16, 2021 at 3:19 PM

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

Subject: Pfizer vaccine Reaction Study

Hello,

My name is [b6] I am a [b6] living in [b6] I received the Pfizer vaccine on [b6] 3 days after I got the vaccine I started to have severe flare up on [b6] I had fainting episodes in the shower, cluster headache, [b6] Chronic Fatigue, chronic muscle weakness, chronic muscle and joint pain, daily headaches, muscle spasms, SEVERE tremors and intermittent loss of motor function. I am SCARED FOR MY LIFE! [b6]
[b6] I have an appointment with my Neurologist today and am hoping to get a referral to be in the study for vaccine side effects. I am willing to participate in any way I can to find a diagnosis, find treatment and save others from suffering as I have.

Thank you for your time.

[b6]

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6] b6
Sent: 8/4/2021 9:37:49 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246] b6
Subject: Re: b6 Consent

Hi b6

The epidemiological data have not yet been generated. These data should eventually become available from CDC. This is a good conversation to have with your PCP, to develop a plan for treatment in case you do develop COVID infection. They would be the ones treating you so, best to discuss in advance with them.

Best
Avi

From: Safavi, Farinaz (NIH/NINDS) [E] b6
Date: Wednesday, August 4, 2021 at 4:40 PM
To: b6 Nath, Avindra (NIH/NINDS) [E] b6
Subject: Re: b6 Consent

Unfortunately I do not know answer of your questions. I cc Dr.Nath to comment.
Best

From: b6
Sent: Wednesday, August 4, 2021, 4:31 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Re: b6 Consent

Got it, I will get working on that.

I was wondering if you could elaborate on the percentages of post vax patients having Covid complications and how severe it was. Also would this prioritize me to receive b6 upon a positive diagnosis?

Thank you

b6

Sent from my iPhone

On Aug 4, 2021, at 12:55 PM, Safavi, Farinaz (NIH/NINDS) [E] b6 wrote:

Hi b6

Please find the scale as attached. If you can give us an estimate score when your symptoms at peak and one for now that would be great.

I also would like to see all your records including b6

b6

Thank you!

Farinaz

From: [b6]
Sent: Friday, May 28, 2021 5:14 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Re: [b6] Consent

Hi Dr Safavi,

My vascular issue is starting to concern me.. I'm becoming very sensitive. For example I [b6]
[b6]
[b6] I'm also having issues with my veins looking swollen/ purple with just light house work. I'm waiting to get into rheumatology, [b6] thought that it was [b6] do you have any idea what this might be or what I should be looking to get tested for?

Thank you

[b6]

Sent from my iPhone

On May 25, 2021, at 12:03 PM, Safavi, Farinaz (NIH/NINDS) [E] [b6]
wrote:

My fault.You already sent both
Thanks

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

From: [b6]
Sent: Tuesday, May 25, 2021 2:59 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Re: [b6] Consent

I'm not sure which form you are referring to, those were the only 2 forms Amanda sent me.

Sent from my iPhone

On May 25, 2021, at 7:50 AM, Safavi, Farinaz (NIH/NINDS) [E]
[b6] wrote:

Thanks: [b6]

Can you please sign and send us your medical release form as well?
Amanda will send you a kit and instruction to draw blood and send it to us.

Thanks again.

Please keep me updated about treatment plan with [b6]

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

From: [b6]

Sent: Tuesday, May 25, 2021 12:12 AM

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

Subject: [b6] Consent

Attached are my consent forms.

[b6]

Sent from Outlook

<WHO scale post-COVID.docx>

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6] b6
Sent: 8/26/2021 12:28:14 AM
To: b6
Subject: Re: COVID vaccine adverse reaction

Dear b6
Sorry to hear of your illness. I will be glad to review your records.
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: Wednesday, August 25, 2021 at 5:46 PM
To: Nath, Avindra (NIH/NINDS) [E] b6
Subject: COVID vaccine adverse reaction

Dear Dr. Nath,

Greetings. I discovered your name in a recent Medscape article, "Federal Vaccine Program Hasn't Helped Those Whose Lives Were Altered by COVID Shot" during my daily search for answers to my current situation. I am a b6 at b6 in b6 I received the second dose of the Pfizer vaccine. Within 30 hours, I began to experience rapid onset neurological complications. I developed left facial numbness and severe vertigo, and disequilibrium. I could not walk without assistance and was bedridden for weeks. b6 b6 My neurologist, b6 diagnosed me with b6 b6 Since that time, I have made only modest improvements, and have run out of options for treatments. Although we have tried many treatments, I still have b6 I have extreme fatigue, am not back to work, driving or participating in my normal activities.

I am reaching out to see if you would be willing to review my case. b6 is willing to send a detailed referral letter with all b6 Possibly, you would have some suggestions for different treatments.

Respectfully,

b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6] b6
Sent: 8/28/2021 4:30:17 PM
To: b6
Subject: Re: post covid vaccination reaction.

Dear b6

Sorry to hear of your illness. All of this is still quite new to us. But I have heard from several patients who have symptoms suggestive of dysautonomia and peripheral neuropathy. Some of them have been treated with b6. Any possibility of giving it a try? Of course all treatment decisions would have to be made by your physicians. Hard to practice medicine via email. Further, NIH is a research organization and not a patient care facility.
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, August 26, 2021 at 5:21 PM
To: Nath, Avindra (NIH/NINDS) [E] b6
Subject: post covid vaccination reaction.

Dr. Nath good afternoon

My Name is b6 I am b6 work at b6 I saw the article about you doing research on post covid vaccination reactions, though you may help me. Please reply at your convenience. I am from b6
b6

I received Pfizer covid vaccination, I am having multiple symptoms since received the vaccination. I am seeing neuromuscular specialist at b6 I am with multiple symptoms. Seen Immunologist, Rheumatologist, Hematologist and going to see Urologist and dermatologist too.

I am having autonomic dysfunction also. Having dizziness and nausea all the time.

b6

b6

Since got the vaccination, I am b6

My phone number is b6

Thank you

b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 [b6]
Sent: 8/12/2021 5:36:21 PM
To: [b6]
Subject: Re: Neuropathy getting worse, numbness spreading

Our studies will take a long time to enroll. If interested, you can contact the following email address:
Nindspostcovid19@ninds.nih.gov

The fastest way to get treatment is to get something locally.
Avi

From: [b6]
Date: Thursday, August 12, 2021 at 1:17 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Re: Neuropathy getting worse, numbness spreading

Doctor Nath,

Thank you so much for replying.

I would like to please know how is the criteria for the NIH to admit us, please? I gave my friend [b6] your information and we have similar symptoms, same diagnosis. She is getting admitted to the NIH and I am not. I'm happy that you can help her, I would just like to know why I'm not getting the same opportunity as [b6] and other patients. [b6] and myself have dysautonomia and neuropathy. What else do I need to show you, please? I'm asking humbly and genuinely. I am diagnosed with [b6] [b6] and I am getting worse.

Thank you so much for your understanding.

[b6]

On Thu, Aug 12, 2021, 11:41 AM Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Sorry to hear about your ongoing symptoms. [b6] Can you PCP prescribe it. If they would like to talk to us, we can do so.

Best.

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

b6

From: b6
Date: Thursday, August 12, 2021 at 8:40 AM
To: Nath, Avindra (NIH/NINDS) [E] b6
Subject: Neuropathy getting worse, numbness spreading

Dr. Nath good morning,

I hope you have been doing fine. Unfortunately, I'm not improving, I am getting worse, and I'm not getting help here. The type of insurance I have HMO limits me tremendously. I am please begging you to please help me. My numbness is worse and is spreading and I wake up with my hands asleep and now my left leg. I'm having increased weakness, my legs and arms quiver. My heart rate b6 I have chest stabbing pains, tinnitus, fatigue, brain fog, palpitations, joint pain, internal vibrations, to name a few.

I gave b6 your email because her doctors were dismissive b6 she is my friend and we have similar symptoms, dysautonomia and neuropathy, she told me you kindly replied to her and she is getting treatment at the NIH at the end of the month.

I'm attaching a video of my hands problem and also my diagnosis b6
b6

I would not be bothering you if I had other alternative doctor, please, I have been struggling b6 and only getting worse. I had to dictate to the phone to type this email because I have problems with my fingers.

Thank you so much for being the only light to many of us during these dark times in our life. God bless you,

b6

REL0000229465

1

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6] b6
Sent: 9/1/2021 12:58:47 AM
To: b6
CC: Jones, Antoinette (NIH/CC/OD) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=668563213d304055953d974bcd8a269d] b6

Dear b6

As agreed, you are not on our protocol and none of your data will be published.

Best wishes.

Avi

From: b6
Date: Tuesday, August 31, 2021 at 3:06 PM
To: Nath, Avindra (NIH/NINDS) [E] b6
Cc: Jones, Antoinette (NIH/CC/OD) [E] b6
Subject: Thank you

Dear Dr. Nath,

Thank you for your time and our discussion yesterday about my participation in your protocol, "Natural History of Inflammatory and Infectious Diseases of the Nervous System."

I appreciate that we came to a common understanding I am withdrawn from the protocol and (my data) will not be included in any publications.

I wish you all the best in your investigation of covid vaccine side effects.

Sincerely yours,

b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6] b6
Sent: 1/26/2022 8:55:36 PM
To: b6 Patterson, Amy (NIH/NHLBI) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=afad1ca74b3e449d8b4f3191d65bb70f] b6
Subject: Re: [EXTERNAL] Pfizer Vaccine Death Confirmed Via Autopsy Report

Dear b6

I am copying Dr. Patterson who might be able to guide you.

Avi

From: b6
Date: Wednesday, January 26, 2022 at 3:12 PM
To: "Nath, Avindra (NIH/NINDS) [E]" b6
Subject: Re: [EXTERNAL] Pfizer Vaccine Death Confirmed Via Autopsy Report

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.

Good afternoon. Checking in again, thank you again for your response. I appreciate the communication.

Would you be able to refer me to someone within the NIH whose expertise is myocarditis or cardiac-related issues? I have already spoken to numerous physicians who have all confirmed my b6 died from the myocarditis he experienced after receiving Pfizer's COVID vaccine, but they are not providing the sort of answers that physicians/scientists at the NIH can hopefully provide. I would like to speak with whoever is researching these issues, as the CDC is not following up on my b6 death.

Please. And thank you.

b6

On Mon, Jan 24, 2022 at 3:19 PM b6 wrote:

We understand. Thank you for responding and please forward this to anyone you feel who would be more appropriate.

Thank you

b6

On Mon, Jan 24, 2022 at 2:49 PM Nath, Avindra (NIH/NINDS) [E] b6 wrote:

Dear b6

I am terribly sorry to hear of your b6 death. My deepest sympathies. The literature shows an association of myocarditis with the COVID vaccines however, that is not an area of my expertise. A cardiologist might be in a better position to provide answers. I am very very sorry.

Avi

Avindra Nath MD

REL0000229487

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: [REDACTED] **b6**
Date: Monday, January 24, 2022 at 3:14 PM
To: Nath, Avindra (NIH/NINDS) [E]; [REDACTED] **b6**
Cc: [REDACTED] **b6**
Subject: [EXTERNAL] Pfizer Vaccine Death Confirmed Via Autopsy Report

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.

Dear Dr. Avindra Nath,

Greetings. My name is [REDACTED] **b6** along with [REDACTED] **b6** We are emailing to discuss my [REDACTED] **b6** who passed away on [REDACTED] **b6** [REDACTED] **b6** We have received an extensive autopsy report and the findings concurred that his death was caused directly due to the Pfizer booster vaccine that he had received on [REDACTED] **b6** The pathologist performed scans of his heart and gathered 22 slides which confirmed that [REDACTED] **b6** had severe myocarditis from the Pfizer booster vaccine that led to his death.

Please give us answers and follow up to why this occurred. We are devastated.

Lot #'s
Pfizer 1st dose [REDACTED] **b6**

REL0000229487

Pfizer 2nd dose
Pfizer booster -

b6

Autopsy, death certificate, vaccine cards, and apple watch heart rate data are attached

Thank you,

b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6] b6
Sent: b6
To: b6
Subject: Re: second vaccine dose

Sounds very reasonable.
Wishing you all the best.
Keep me posted.
Avi

From: b6
Date: b6
To: "Nath, Avindra (NIH/NINDS) [E]" b6
Subject: Re: second vaccine dose

Just picked them up!

b6

What do you think?

b6

From: Nath, Avindra (NIH/NINDS) [E] b6
Sent: b6
To: b6
Subject: Re: second vaccine dose

b6

Avi

From: b6
Date: b6
To: "Nath, Avindra (NIH/NINDS) [E]" b6
Subject: second vaccine dose

Dear Avi,

Liked your talk today at the meeting!

I have my second dose of the COVID vaccine on

b6

b6

What do you think?

Best,

b6

b6

b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 b6]
Sent: 2/6/2021 7:44:53 PM
To: b6
Subject: Re: Referred by b6 regarding immunologic complications of vaccination

Dear b6

I agree with you and your doctors that b6

b6

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: Saturday, February 6, 2021 at 1:31 PM

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

Subject: Referred by b6 regarding immunologic complications of vaccination

Dear Dr.Nath,

b6 suggested my neurologist or myself contact you regarding the matter below.

I suffered right brachial plexopathy from the 1st injection of the Pfizer Covid vaccine. I am seeking knowledge/advice regarding risk of repeat plexopathy from potential future Covid vaccination or possibly other vaccinations (Flu, pneumovax, varicella) that I expect to receive.

I suffered right brachial plexopathy as a result of 1st injection of the Pfizer Covid vaccine on b6 I recognized the neurologic symptoms and found help and was b6

b6

My symptoms began two days after 1st dose of Covid vaccine and consisted of 6 days of severe right periscapular muscle spasms followed by right arm ulnar paresthesias and moderate right wrist/hand weakness with very mild upper arm weakness. Minimal transient symptoms of my left arm. I had received the vaccine in my left arm contralateral to side of my symptoms.

Given that brachial plexopathy reportedly 15% of time results from vaccination; by my calculations, it seems approximately 30X more likely that my symptoms were related to the vaccination than simply a random event serendipitously temporally related to the vaccination.

Although I have partial and limited duration of immunologic protection from Covid from the single vaccination, I desire to more adequately protect myself especially with the Covid variants. I am **b6**
b6 Wondering should I be concerned about a repeat neurologic event, possibly more severe, from subsequent vaccination (Covid or other type). **b6**

b6

I was hoping you would be willing to offer your thoughts or advice on this matter.

Kindly,

b6

b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 b6]
Sent: 5/18/2021 4:00:29 PM
To: b6 Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 b6]
Subject: Re: neurological complications of Pfizer vaccine

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.

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 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, four weeks 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

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

From: Jones, Antoinette (NIH/CC/OD) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=668563213D304055953D974BCD8A269D: b6]
Sent: 8/30/2021 2:35:47 PM
To: b6; Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6: b6]
Subject: 15-N-0125
Location: Microsoft Teams Meeting
Start: 8/30/2021 7:00:00 PM
End: 8/30/2021 7:30:00 PM
Show Time As: Tentative

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

Microsoft Teams meeting

Join on your computer or mobile app

[Click here to join the meeting](#)

Or call in (audio only)

b6 United States, Bethesda

Phone Conference ID: b6

[Find a local number](#) | [Reset PIN](#)

[Learn More](#) | [Meeting options](#)

From: [b6]
Sent: 8/21/2021 6:13:24 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: please add my vaccine reaction to your study

Dr. Natha,

I found out about your study of the reactions people have to the vaccine from the woman in this article who personally told me about it. <https://www.latimes.com/science/story/2021-08-17/severe-covid-vaccine-injuries-help-federal-vaccine-court>

I have had the same issue when I took the Pfizer a 3rd time 3 weeks after the 2nd vaccine. Within 3 days it created a horrible chain of reactions in my body that has not stopped to this day. It was an allergic reaction to it.

[b6]

[b6]

From: [b6]
Sent: 7/14/2021 3:01:02 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Automatic reply: long-term neurologic sequellae from vaccine

Thank you for your email. I am not on contract for the summer months and so will only be checking email intermittently.

[b6]

Thank you.

From: [b6]
Sent: 7/25/2022 5:15:03 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: [EXTERNAL] [b6] follow up

Thank you so much for this referral. I will help him try and get it with these physicians. I appreciate it very much.

Sent from my iPhone

On Jul 24, 2022, at 9:19 PM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

Sorry to hear of this patient's illness. I might suggest [b6]
[b6] They are all outstanding and experts in neuroimmunology.

Best.

Avi

From: [b6]
Date: Sunday, July 24, 2022 at 10:17 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: [EXTERNAL] [b6] follow up

Hello Dr. Nath,

I want to thank you for communicating with me in the past. I am [b6] who was hospitalized after my covid vaccine and you were so kind to respond and refer me to [b6]
[b6] Unfortunately he didn't see vaccine injured but I appreciated the effort. This problem isn't going away and because I am a vaccine injured [b6] are reaching out to me needing help. I'm doing my best to try and help as many as I can but [b6]
[b6] I need help with a referral for this particular case. [b6] was a normal healthy [b6] who developed tremors and seizures 2 hours after his second dose of moderna. He was a very intelligent college student and unfortunately now he spends his days [b6]

b6

[b6] It's been awhile since we have communicated. Do you still think it's the same etiology of being immune mediated neuro inflammation or is there new data I may be unaware of? I appreciate your help as these parents that are reaching out to me are beyond devastated. Please take a look at the videos below of [b6] and let me know if there is anywhere I can send him. Unfortunately he is one of so many kids like this. I would also be happy to get you in touch with all these parents. Since their videos all look so similar and their reactions happened right after the vaccine it might be good data for the NIH to study.

Sincerely,

[b6]

b6

Sent from my iPhone

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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.

From: [b6]
Sent: 11/8/2022 9:26:25 PM
To: Gavin, Angelique (NIH/NINDS) [C] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=6e97392e947e4f7ebb17eeb8ac87c5d5; [b6]
Subject: Information Request: Clinical Center Study PI000089-N

LastName :

FirstName :

Organization :

Building Mail Stop:

Street Addresss:

City/State/Zip:

Phone:

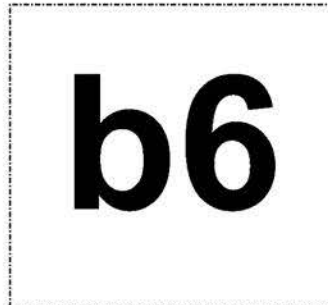
Fax:

Patient's First Name(if different
from sender name):

Patient's Last Name((if different
from sender name):

Comments :

Is NIH doing any data gathering or clinical research on post-COVID
vaccine adverse responses? I am interesting in participating.



From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 b6]
Sent: 8/30/2021 4:11:18 PM
To: b6 NINDSPostCovid19 [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=7288bc48d86f4f5fb796620bda298e7f-nindspostco]
Subject: Re: Pfizer Vaccine Reaction - Dysautonomia/POTS Syndrome

Dear b6

Sorry to hear of your illness and thanks for your interest in participating in our research study. We are currently gathering data to better understand the symptoms. I have copied our research team who can guide you on how to participate in our online 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: Monday, August 30, 2021 at 11:41 AM
To: Nath, Avindra (NIH/NINDS) [E] b6
Subject: Pfizer Vaccine Reaction - Dysautonomia/POTS Syndrome

Dear Dr Nath, I saw an article about your work regarding the rare reactions some are having to the COVID vaccine and wanted to reach out to you. I am a b6 I'm a patient of b6

b6

I had 1st Pfizer shot on b6 No immediate reaction, upper arm pain x1 day. However, the morning of b6 I started to experience severe symptoms: weakness & lightheadedness, fatigue, hot/cold flashes, drenching night sweats, decreased appetite, increased GERD symptoms, sleep disturbance (only 2-4 hr/night), bad waves of nausea, kept me down for the count in bed and in need of care from my husband. I lost 6 lbs in the week. No fever or flu-like symptoms. It was two weeks before I was well enough to shower and be out of bed in recliner but was still having hot flashes with sweating and then freezing cold hourly or more frequently and waves on nausea every couple of hours. On b6 I had my 2nd dose of the vaccine. Within a few days I again had severe worsening of the above symptoms with extreme fatigue/weakness, bedridden other than bathroom visits. I was feeling better by b6 b6 including starting a walking routine, adding 1 min ea day. I started the walking b6 I had gotten up to 36 minutes at very slow pace. On that day it was as if I'd hit a wall. Extreme weakness, dizziness, no appetite, sweats, sleep disturbance, severe brain fog, pounding heart when standing. I saw my primary physician and rheumatologist the 2nd week of June and was diagnosed with b6 and was experiencing POTS symptoms. I was referred to an endocrinologist, cardiologist, and finally neurologist, and b6 Cardiologist and neurologist confirmed diagnoses and all agree the vaccine was the cause. Although they are hopeful I will slowly recover, it will be 6 months or more before we know better what level of recovery I will have neurologically.

To my knowledge no one has reported my case to the NIH or any other organization.

REL0000229726

Thank you for the work you are doing. Feel free to reach out to me.

b6

From: [REDACTED] b6
Sent: 8/31/2021 7:59:25 PM
To: Gavin, Angelique (NIH/NINDS) [C] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=6e97392e947e4f7ebb17eeb8ac87c5d5] b6
Subject: RE: NIH COVID-19 vaccine study

Of course. Please include me in any post-vaccine research. Thank you for doing this work.

I also know a group with 900+ people post vaccine and another person just reached out to me who is part of a group of over 2,000 post vaccine. When the information is ready for the online survey, I can get the information to them as well.

I've learned in the last several months that things that seemed unrelated on the surface have links back (at least in J&J) to known mechanisms with injectable adjuvants.

I've also been in direct contact with [Cynthia M. Magro, M.D. | Dermatopathology \(cornell.edu\)](#), who is working on this: [The Histologic And Molecular Correlates Of Covid-19 Vaccine Induced Changes In The Skin \(nih.gov\)](#).

And directly in contact with Dr. Patterson published here [Frontiers | Immune-Based Prediction of COVID-19 Severity and Chronicity Decoded Using Machine Learning | Immunology \(frontiersin.org\)](#), who has several hundred seeking help for post vaccine reaction.

I have over 200 pages of my labs, results, journaling across time, medical research journals and mechanism that separate out so many mediating variables to help narrow down mechanisms.

b6

I've been able to identify corroborating evidence from published studies with adenovirus vector vaccines that existed prior to COVID-19, studies pointing to molecular mimicry, and studies pointing to the two main pathways of injury from wild/natural COVID-19 (1) virus, and 2) spike protein in the absence of viral load). With that information, in the absence of other confounds (in me at least), it has made it possible to narrow down mechanism.

- I have never smoked
- I have never used drugs
- I don't drink coffee or caffeinated beverages
- I have never used/taken any form of birth control
- I've been on no prescription medications (before or since vaccination)
- I worked out/highly active
- Mediterrean diet/low saturated fat
- Very low sugar intake
- No underlying health conditions prior and [REDACTED] b6

b6

Very few clinical studies even have this much data on a single person to sift out confounds. I want to help, because if it is possible to compare parallel symptoms from wild/natural COVID-19 and parallel symptoms post-vaccine, it can give

researchers a chance to separate out the mechanisms of injury leading to a constellation of symptoms that are parallel to those seen with COVID-19 as a vascular injury. Remove the virus (vaccines) and still seeing the parallel of vascular injury showing up in the constellation of symptoms, and it is possible to then focus on the mechanism of the virus itself to crack the code of a virus that keeps mutating.

Brute force looking at separate symptoms from specializations is missing the chance to see the parallel vascular symptoms seen with spike protein and endothelial cells. Localized inflammatory responses and vascular inflammation seems to be able to evade traditional systemic inflammatory blood work, which is perplexing clinicians and specialists, and resulting in many people being told "it's just anxiety" and "there's nothing wrong with you."

That's leading to a public health crisis that is not being acknowledged and impacting healthcare coverage (denials), mental health (so many are becoming suicidal because they are not being believed, the severity of symptoms parallel to COVID-19 and long haul but without the virus), and because there are people losing their jobs because it is as debilitating as COVID-19 (but without the virus and without being recognized as such).

b6

From: Gavin, Angelique (NIH/NINDS) [C]

Sent: Tuesday, August 31, 2021 11:36 AM

To: b6

Subject: NIH COVID-19 vaccine study

Dear b6

Thank you for your interest in our research. I received your information from Dr. Avindra Nath. We are currently developing an online survey system to collect stories about people's complications after receiving COVID vaccines. At this time, if you are willing, we can take your name and contact information. We will reach back out to you when the survey system is completed to see if you are willing to volunteer in our on-line study.

Thanks,

Angelique

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

b6

(office)

(cell)

(301) 480-5368 (efax)

b6

<https://clinicaltrials.gov> - study number 000089

REL0000229728

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 b6]
Sent: 9/21/2021 6:44:30 PM
To: b6 NINDSPostCovid19 [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=7288bc48d86f4f5fb796620bda298e7f-nindspostco]
Subject: Re: Allergic reaction to Moderna Covid-19 vaccine

Dear b6

Sorry to hear of your illness. Currently we are collecting data on these adverse effects. I have copied our research team, who can guide you on how to provide us with the information.

Thanks

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, September 21, 2021 at 2:20 PM
To: Nath, Avindra (NIH/NINDS) [E] b6
Subject: Allergic reaction to Moderna Covid-19 vaccine

Hi Dr. Nath,

I am a b6 I am by no means anti-vaccine and was excited to receive my first dose of Moderna on b6 I experienced some sort of an allergic reaction to the vaccine, and have been experiencing odd neurological symptoms since. I read an article in the LA Times about women experiencing similar reactions to my own, and they noted that you have been doing some research on the phenomenon. The doctors that I have seen here have not really known how to move forward, and I'm honestly desperate for some answers at this point.

I am b6 I have never had an allergic reaction to any vaccines before and have no known allergies to medications. I have a history of skin sensitivity to sunscreens and lotions, but have not known the common ingredient causing the sensitivity. I received my first Moderna vaccine b6 and felt perfectly fine, so I left after 15 minutes. On the drive home I started to experience some flushing in my cheeks that I attributed to having a mask on for a while. By the time I arrived at home about 25 minutes after the vaccine was given, I started to feel some burning around my lips and across my forehead. My face was also very flushed and appeared somewhat swollen. About 45 minutes after my shot, I started with some tightness in my chest, my throat felt like it was swelling, and I had some short lived stomach discomfort. The symptoms would last about 5 minutes and then resolve, but return about every 15 minutes. I called my Dr. because I was unsure of what to do. She advised me to b6 b6 I also drank a lot of water throughout the next few days hoping that it would help in some way. I went to the Dr the day after my vaccine for a follow up and my BP and vitals were stable. I was feeling well enough to b6 However, later that evening I felt something that I would describe as fire across my hairline and then a feeling of ice water rushing through my extremities followed by uncontrollable shaking. I felt like I was going to pass out so I immediately laid down and put my feet up and asked my husband to call 911. The squad arrived about 10 minutes later and my vital signs were stable enough that we

decided not to transport to the hospital. I continued to just feel "off" for the next couple of weeks and developed a widespread rash. Approximately 2 weeks after my vaccine I was cooking dinner and my throat started to swell as I was sauteeing zucchini [REDACTED] b6

[REDACTED] b6 but all of a sudden was reacting to everything it seemed. I wasn't comfortable inside or outside of my home-I felt constant burning in my face, tingling and "buzzing" under my skin in my extremities, tongue swelling and tingling, and a soap taste in my mouth. I took [REDACTED] b6

[REDACTED] b6 I've been able to tolerate symptoms [REDACTED] b6 throughout July and most of August, but have noticed chest tightness, tingling in my extremities, and facial burning has returned with the start of fall allergy season

[REDACTED] b6 It honestly feels as though the vaccine triggered some sort of flare up in my immune system causing me to react to any sort of allergen for the past 6 months.

[REDACTED] b6

I'm writing to you in hopes that a study will be completed to help those of us that have experienced such strange reactions to the vaccine. I'm still recommending the vaccine to my family and friends, and my husband was able to get both doses of Moderna with no issues other than the expected side effects of fatigue and arm soreness.

I appreciate you taking the time to read my email and would be happy to discuss the details of my situation with you further if that would be helpful.

Sincerely,

[REDACTED] b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 [b6]
Sent: 10/11/2021 3:28:14 PM
To: [b6] NINDSPostCovid19 [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=7288bc48d86f4f5fb796620bda298e7f-nindspostco]
Subject: FW: Referral from [b6] / request for [b6]
Attachments: [b6]

Dear [b6]

I am sorry to hear of the adverse effects from the vaccination. Currently, we are collecting information on these side effects. We do not have any ongoing clinical trials. I have copied our research team and would be most appreciative if you would be willing to share the information with us.

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: Monday, October 11, 2021 at 10:23 AM
To: Nath, Avindra (NIH/NINDS) [E] <avindra.nath@nih.gov>
Subject: Referral from [b6] / request for [b6]

Hi Dr. Nath--

I had an appointment last week with [b6] a neurologist in [b6] for [b6] of adverse neurological effects following an AstraZeneca vaccination. He referred me to you, and I am following up with you in the hopes that you might be willing to consult with me.

By way of background and introduction, I am attaching the letter I sent to [b6] here.

Thanks in advance for any help you can provide.

Regards,

[b6]

Hi [b6]

Thank you for seeing me. I'm a [b6] who has recently returned to the [b6]. The short story: I have had [b6] of severe headaches, mild peripheral neuropathy, and debilitating fatigue in the wake of my first AstraZeneca vaccine injection. I thought it would be worthwhile to provide a synopsis in advance of our appointment next week.

On [b6] in the UK, I received my first AZ jab, and only had a day or two of feeling poorly: the customary reaction. But on day 12-13 after the jab (when antibodies start to emerge and humoral immunity begins to kick in), I was hit with agonizingly severe headaches. [b6] [b6] These headaches did *not* arrive as a thunderclap, but came on strong within a day or two. They were mostly in my temples, sinuses, and behind my eyes, although they sometimes shifted to my crown and the base of my skull. My neck was incredibly stiff too, and I had strange little coat-hanger tender spots on my shoulder blades. It felt like my brain was going to explode within the cage of my skull; it felt like inflammation of my brain. [b6] did nothing to touch the unrelenting, constant headaches.

[b6]

This was around the time of emerging worries over the deadly VITT/TTS clotting syndrome, associated with the AstraZeneca jab (prevalence perhaps as high as 1-in-25,000). I went to the ER, where they [b6]

[b6]

I was discharged from the ER with [b6]. My headaches didn't go anywhere, although they fell from their terrifying peak. Wait times to see an NHS neurologist were a year or more. So I saw a private neurologist [b6] after the jab. I attach his notes [b6] and a letter intended to help me pursue an mRNA jab for my second dose [b6]. He offered [b6] for my symptoms, but I declined at the time, hoping to deal my pain without adding more side effects to contend with. He [b6]

[b6] I was definitely opposed to getting a 2nd AZ jab (something he suggested was sensible), and somewhat reluctant to get a Pfizer/Moderna for my 2nd jab, and in any case I couldn't convince the UK system to allow an alternate for my 2nd.

Meanwhile, other worrying symptoms emerged. Around [b6] I experienced a burst of spasms and twitching and pain in my lower legs, mostly in my calves. I have continued to experience strange pains, paresthesias, and fasciculations in my arms and legs and wrists and ankles and hands and feet. Last week, my left eye started twitching out of nowhere, for a day or two. The pains and tremors are more upsetting than disabling; they are mild compared to many other people I know. Accompanying the pains and tremors are fatigue

and muscle weakness. I have no strength or energy whatsoever, and 'pushing it' seems to make things worse. The post-exertional malaise seems awfully similar to the fatigue of ME/CFS and Long Covid patients. I haven't noticed any heart trouble per se. [b6]

[b6]

I moved back to the U.S. [b6] Now, I'm [b6] post jab, still sick, and still only partially vaccinated. The headaches are still a constant, although they are not as severe as they were at the start. They are like a dull ever-present hangover in my temples or crown that occasionally flares to crippling levels with exertion, or in the heat, or with lack of sleep. I can work, and I can soldier on as [b6] but life has become a slog. Like many others with my symptoms, [b6]

[b6]

[b6] My neck is still stiff, all the time. The mild neuropathy and fatigue are also ever-present, receding and flaring without rhyme or reason. They have altered my life significantly. I can walk just fine, but if I walk too far, or overextend myself in any way, I crash. Running or exercise of any sort is out of the question.

Early on, this was all hard to talk about with friends and family, for fear of sounding like a crazy antivaxxer. And it was hard for doctors to take seriously, with many more people sick from Long Covid, or Covid itself. At the outset, my NHS GP in the UK dismissed my symptoms as being due to anxiety. But I have found some solace knowing I am definitely not alone: I am in a few Facebook support groups, where there are thousands suffering from extremely similar (and sometimes more severe) long term vaccine side effects, with eerily similar timelines. The anecdotal data is now beyond doubt; the problem is we have no idea of prevalence -- are our reactions a 1 in 25,000 thing, like VITT, or are they far more common? Another problem is that there are no biomarkers, and no one knows anything about the root cause. Doctors have been left to try and help manage symptomatic pain, while hoping that time will lead to recovery. I know a few patients who have been seen here at the NIH by Avindra Nath and Farinaz Safavi, who have tried more experimental interventions [b6] with potentially promising results. But most patients cannot get any help, and many are turning in their desperation to all sorts of kooky dietary regimens and supplements. Some have been seduced by fringe doctors advocating fringe treatments like ivermectin, etc.

I am just beginning to establish a network of medical providers here in the U.S. My GP is [b6] [b6] who is supporting me in my request for a medical exemption from a vaccine mandate instituted by my employer. [b6] I have also had a consultation with an immunologist [b6]

[b6]

I don't have high expectations for a magical treatment: some in my groups have recovered with time, but many are now at 8 months and beyond with few signs of their symptoms lessening.

But I am hoping you might provide advice and counseling for diagnostics

b6

b6

symptomatic treatments if my pain gets worse

b6

b6 and any more foundational treatments b6 that might seem more sensible with or emerging evidence. I also wonder about your experience with these reactions: are you treating anyone else in my situation? Also: do you know any research-oriented colleagues who are trying to think about root causes?

Thank you for your time and consideration. Talk to you soon.

Regards,

b6

From: [b6]
Sent: 11/29/2021 2:46:20 PM
To: Gavin, Angelique (NIH/NINDS) [C] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=6e97392e947e4f7ebb17eeb8ac87c5d5; [b6]
CC: [b6]
Subject: Study # 000089 Long Haul COVID
Attachments: covid long haul study referral.pdf

Hi Angelique,

I am writing regarding a referral from my daughter's neurologist, [b6] requesting participation in the long haul COVID study, #000089. I do have HIPPA authorization to assist in my daughter's behalf. My daughter, [b6] contact information is included and she is cc'd on this email.

b6

She developed a pervasive stutter 24 hours after her second Pfizer vaccine which was administered 2 weeks after her diagnosis of COVID-19 on the recommendations of [b6] This is one reason I assist as a contact for her.

She has been symptomatic since her diagnosis of COVID-19 in March of 2020 with constant headaches, memory problems, mild aphasia, inability to sleep, new onset hypertension and tachycardia, new onset asthma with exercise intolerance, persistent loss of taste and smell, anxiety, depression, and intermittent nausea. She has been under the care of her PCP, neurologist, cardiologist, psychiatry and sleep specialist. She is now on multiple medications when before COVID she was healthy on no medications.

b6

Her neurologist [b6] recommends that she participate in a long haul COVID study as she has not made any progress.

Thank you for your consideration,

b6

Sent from Mail for Windows

b6

b6

b6

From: [b6]
Sent: 10/22/2021 3:36:18 PM
To: Gavin, Angelique (NIH/NINDS) [C] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=6e97392e947e4f7ebb17eeb8ac87c5d5; [b6]
Subject: Re:

I'd be happy to do so, Angelique. What contact information do you need?

Thank you,

[b6]

On Fri, Oct 22, 2021, 11:26 AM Gavin, Angelique (NIH/NINDS) [C] [b6] wrote:

Dear [b6]

Thank you for your interest in our research. We are currently developing an online survey system to collect stories about people's complications after receiving COVID vaccines. At this time, if you are willing, we can take your name and contact information. We will reach back out to you when the survey system is completed to see if you are willing to volunteer in our on-line study.

Thanks,

Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

10 Center Drive

Building 10, Room 3B19, MSC 1251

Bethesda, MD 20814-9692

[b6]

(office)

(cell)

(301) 480-5368 (efax)

[b6]

<https://clinicaltrials.gov> - study number 000089-N

REL0000229738

From: [REDACTED] b6

Sent: Thursday, October 21, 2021 10:48 PM

To: Gavin, Angelique (NIH/NINDS) [C] [REDACTED] b6

Subject:

Dear Ms. Gavin,

I've been informed you are in the process of coordinating an online study for severe adverse events connected to vaccines/Covid vaccines. Thank you! I understand you are currently assembling a waitlist. I'd be happy to be part of the study, just let me know what you need.

Sincerely,

[REDACTED] b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 [b6]
Sent: 3/7/2022 4:55:17 PM
To: [b6] NINDSPostCovid19 [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=7288bc48d86f4f5fb796620bda298e7f-nindspostco]
Subject: Re: [EXTERNAL] Neurological reactions to COVID vaccine

Dear [b6]

Sorry to hear of your illness. Thanks for the very detailed information. I have copied our research team who are compiling all this information.

Best.

Avi

From: [b6]
Date: Monday, March 7, 2022 at 11:20 AM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: [EXTERNAL] Neurological reactions to COVID vaccine

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.

Dear Dr. Nath,

I got your name from the [science.org](https://www.science.org) article on COVID vaccine recipients also getting the neurological symptoms of long haul COVID. The information from my VAERS report may be useful to your research. Having lived through it, it does seem to be an autoimmune reaction to the spike protein no matter the source, [b6]

[b6] It was as if my immune system "remembered" to attack the spike protein, but also the same nerves as before, suggesting a new autoimmune reaction from the vaccine. I did not have anything like that previously.

[b6]

In my case, my vaccine reaction at [b6] so I am very glad my doctor did not push me to get another shot (although being banned from things I loved for not being "fully vaccinated" has been very frustrating, as I tried to do the right thing for others by getting the shot, and that's what happened on top of everything else, including the medical bills). As I'm under 65, it appears a second shot would not have boosted my immunity much anyway.

Like Brienne Dressen in the article, I noticed the symptoms between COVID long haul and vaccine long haul were extremely similar while it was happening to me. Anecdotally, it also appeared that others in online communities had their symptoms repeat themselves as well, whether vaccine symptoms repeated themselves during COVID [b6] [b6] or long haul COVID symptoms repeated themselves after the vaccine.

Here is the timeline from the report. I'm happy to answer any other questions you may have that would assist you in your research.

[b6]

received Pfizer vaccine in upper left arm
stiff left elbow; was more mild by [b6] check-in on CDC's V-Safe.

b6 left lymph node swollen, "pins and needles" from left shoulder to left ring and pinky finger, muscle aches. Coincidentally had annual OB/GYN exam that day and described symptoms; she recommended b6

b6 left arm paresthesia continued. Regular PCP was not available, so visited other healthcare provider, who prescribed b6 for arm pain. Afterwards, chills, body aches, fatigue, faster heart rate, random muscle twitches spread from left arm to rest of body, neurological "pinpricks" or "zaps" throughout body.

b6 paresthesia and fasciculations throughout body (but mostly left arm and leg), rapid heart rate, muscle and body aches, and fatigue continued. Fever, night sweats; did not take temperature. Felt shaky in the morning. Stiffness on left side of body upon waking; did not sleep on left side.

b6 sudden shooting pain in back of left thigh to the point of limping. Telehealth and urgent care advised going to ER if medication did not improve symptoms; b6 Although the shooting pain faded to a dull ache, went to emergency room as instructed. In hospital, left leg tested; b6

b6 Advised follow-up appointment with PCP.

b6 Described symptoms at follow-up appointment. Left leg felt better, but other symptoms continued. b6

b6 Woke up in pain. For past few days, had new symptoms of stiff, sore arms in mornings, heart palpitations especially when trying to sleep, chest pain, shortness of breath, and occasionally a sore stomach in mornings (may have been due muscle spasms at night). Neuropathy and fasciculations continuing. Inability to walk in mornings. Limbs feel heavy and hard to move for several hours. b6

b6 b6 Also, menstrual period unusually late. Follow-up appointment and b6 Some symptoms improving after deciding to go on anti-inflammatory diet. Still taking; b6 Leg pain gone, muscle twitches still exist, peripheral neuropathy primarily in right fingers, foot, and left thigh. Cramping in left arm. Right arm numbness persists. Left hand feels cool to the touch but not in pain. Fewer muscle twitches, but intermittently persist in right lower rib cage. b6

b6 More severe symptoms mostly resolved, but left eye often twitches and left arm does not feel normal. Still getting random occasional muscle twitches; they persist to this day, especially after eating inflammatory foods. Left arm still weaker than right.

b6 Started having cold-like symptoms. Cold-like symptoms continued off and on. Additionally, new tingling down to ring and pinky fingers of left arm, as they did after the vaccine. Due to this, b6 During quarantine, besides a cough, mild cold-like symptoms, and temporary loss of smell, had a (fortunately milder) replay of vaccine side effects, with paresthesia in left arm down to the same fingers, left leg feeling weak, more muscle fasciculations, fever, and tachycardia, but for a much shorter duration. It was as if my immune system attacked the spike protein, but also the same nerves as before, suggesting a new autoimmune reaction from the vaccine.

Additional information for Item 19:

b6

b6

b6

Please let me know if you have any questions.

Thank you,

b6

From: [b6]
Sent: 3/31/2022 1:57:16 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6; [b6] NINDSPostCovid19 [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=7288bc48d86f4f5fb796620bda298e7f-nindspostco]; [b6]
Subject: [b6]
Re: [EXTERNAL] Re: [b6] Diagnosis after Receiving Pfizer Vaccine

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.

Thank you, Dr. Nath.

[b6] please let us know what is needed from our end.

Best Regards,

[b6]

From: "Nath, Avindra (NIH/NINDS) [E]" [b6]
Date: Wednesday, March 30, 2022 at 11:02 PM
To: [b6] NINDSPostCovid19
<nindspostcovid19@ninds.nih.gov>; [b6]
Subject: Re: [EXTERNAL] Re: ALS Diagnosis after Receiving Pfizer Vaccine

Dear [b6]
I have copied our COVID research team and [b6] They can guide you and your brother.
Best
Avi

From: [b6]
Date: Wednesday, March 30, 2022 at 7:28 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: [EXTERNAL] Re: [b6] Diagnosis after Receiving Pfizer Vaccine

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.

Hello Dr. Nath,

Thank you for reaching out. We would definitely be interested in your clinical studies for [b6]

Additionally, do you currently have any open clinical studies looking at COVID-19 and neurological conditions?

Best Regards,

b6

On Mar 30, 2022, at 3:35 PM, Nath, Avindra (NIH/NINDS) [E] b6 wrote:

Dear b6

Not sure about the association of the vaccine and b6 but if you are interested in our clinical studies on b6 we can see if you meet our inclusion criteria.

Avi

From: b6

Date: Wednesday, March 30, 2022 at 8:27 AM

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

Subject: [EXTERNAL] b6 Diagnosis after Receiving Pfizer Vaccine

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.

Hello Dr. Nath,

My name is b6 and I have followed your work on neurological conditions associated with COVID-19.

My brother, an otherwise healthy b6 started experiencing a muscle fasciculation in his left deltoid (same arm as vaccine administration) 2 days after receiving his second dose of the Pfizer vaccine. He had b6 Roughly one year post-vaccine, this fasciculation has not stopped and the disruption to his quality of life has led him to seek medical treatment.

Sadly, the first neuromuscular physician he saw gave him a diagnosis of b6

b6

b6

Would it be possible for us to connect? Are there any trials with your team he may be eligible for? Looking forward to hearing from you as we investigate this further.

Best Regards,

b6

From: [b6]
Sent: 7/19/2022 5:51:35 AM
To: Gavin, Angelique (NIH/NINDS) [C] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=6e97392e947e4f7ebb17eeb8ac87c5d5; [b6]
CC: [b6]
Subject: Re: [EXTERNAL] RE: NIH Vaccine Study

Wonderful, Angelique. We appreciate that and look forward to participating.

Sincerely,

[b6]

Sent from my iPhone

On Jul 14, 2022, at 7:21 AM, Gavin, Angelique (NIH/NINDS) [C] [b6] wrote:

Thank you [b6] is on the wait list and we will contact her soon. Have a great day!

Angelique

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

[b6] (office)
[b6] (cell)
(301) 480-5368 (efax)

[b6]
<https://clinicaltrials.gov> - study number 000089-N

From: [b6]
Sent: Wednesday, July 13, 2022 10:59 PM
To: Gavin, Angelique (NIH/NINDS) [C] [b6]
Cc: [b6]
Subject: [EXTERNAL] RE: NIH Vaccine Study

Hello Angelique,

Thank you so much for letting me know the status of the study and I heard from Elizabeth Bartrum today regarding it getting started. I just wanted to make sure that [b6] also receives the informational, encrypted email from Ms. Bartrum's group. I've included her email again above and she may reach out to you via phone in the morning.

We're both so pleased that the severe health issues after vaccination will be looked at as they continue to this day for us and I know many others are also struggling. We can't wait to learn what has happened to us and to be a part of helping others.

Sincerely,

b6

b6

From: Gavin, Angelique (NIH/NINDS) [C] **b6**

Sent: Wednesday, June 29, 2022 11:07 AM

To: **b6**

Subject: NIH Vaccine Study

Hi **b6**

I am responding to your recent phone mail message inquiring about our vaccine study here at the NIH. We certainly appreciate your patience! We are in the process of finalizing all details of the study and anticipate just a few more weeks until we start. Thanks for checking in. You are on our wait list and will be contacted as soon as we are ready to go.

Sincerely,
Angelique

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

b6

(office)

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b6

<https://clinicaltrials.gov> - study number 000089-N

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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.

REL0000229801

From: [b6]
Sent: 8/31/2021 6:36:12 PM
To: Gavin, Angelique (NIH/NINDS) [C] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=6e97392e947e4f7ebb17eeb8ac87c5d5 [b6]
Subject: Automatic reply: NIH COVID-19 vaccine study

Thank you for your patients as I continue a long recovery process. For the first time in [b6] there is a plan forward to hopefully help my vaccine injury. We have scientific data now, bio markers that show the severity of my symptoms are parallel to those of severe Covid-19 and long haul (but without ever having the virus).

If you're interested in finding out more, or you know someone suffering from long haul, find out more about Dr. Patterson's work here:

<https://covidlonghaulers.com/>

<https://www.frontiersin.org/articles/10.3389/fimmu.2021.700782/full> [b6]
[b6]

I have still not been cleared to drive or work.

I took the Johnson and Johnson vaccine on [b6] and have been experiencing severe adverse reactions since. [b6]
[b6]

If the message is related to [b6] and you need a response soon, please call [b6]
[b6]

From: Gavin, Angelique (NIH/NINDS) [C] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=6E97392E947E4F7EBB17EEB8AC87C5D5] [b6]
Sent: 8/17/2021 2:23:19 PM
To: [b6]
Subject: RE: Long vaccine study with Dr. Nath?

Thank you [b6] I will keep your information on hand and will contact you when we're ready.

Sincerely,
Angelique

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

[b6] (office)
[b6] (cell)
(301) 480-5368 (efax)

[b6]
<https://clinicaltrials.gov> - study number 000089

From: [b6]
Sent: Tuesday, August 17, 2021 10:22 AM
To: Gavin, Angelique (NIH/NINDS) [C] [b6]
Subject: Re: Long vaccine study with Dr. Nath?

Hi Angelique--

Yes, I'd be grateful if you kept me on a wait list and let me know about the study if it is approved.

Regards,

[b6]

On Mon, Aug 16, 2021 at 3:43 PM Gavin, Angelique (NIH/NINDS) [C] [b6] wrote:

Thank you [b6] for reaching out to us. The study is not yet underway and is in the infancy of development. I can keep your information on a wait list and contact you once we have approval. Let me know if you are interested. We do not currently have study information that we can share.

Sincerely,
Angelique

Angelique Gavin, MS

Clinical Operations Manager

Contractor, PSG

National institutes of Health

10 Center Drive, Building 10

Room 3B19, MSC 1251

Bethesda, MD 20814

b6-phone

301-451-7352-fax

From: **b6**

Sent: Monday, August 16, 2021 3:36 PM

To: Gavin, Angelique (NIH/NINDS) [C] **b6**

Subject: Long vaccine study with Dr. Nath?

Hi Angelique--

My name is **b6** I recently moved **b6** After receiving my first AstraZeneca jab in **b6** I have been suffering from persistent long-term headaches, peripheral neuropathy and parasthesia, and fatigue.

My friend **b6** who participated in past studies with Dr. Nath, mentioned that he is planning a trial for people suffering from "long vaccine" symptoms, and that you might be collecting a list of possible participants.

Can you tell me anything more about the study? I'm eager to try anything that might help with my symptoms.

Regards,

b6

From: Gavin, Angelique (NIH/NINDS) [C] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=6E97392E947E4F7EBB17EEB8AC87C5D5 [b6]
Sent: 8/17/2021 4:49:21 PM
To: [b6]
Subject: RE: NIH Study Inquiry

Thank you [b6] for your response. This upcoming study is entirely on-line through questionnaires. We are not offering treatment at this time. I will keep your information on file and will contact you when the study is available. At that time, we can determine if you are eligible to participate and can offer you more specific information about what the study will entail. You will then have the option to participate if you so desire.

Sincerely,
Angelique

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

[b6] (office)
[b6] (cell)
(301) 480-5368 (efax)

[b6]
<https://clinicaltrials.gov> - study number 000089

From: [b6]
Sent: Tuesday, August 17, 2021 11:42 AM
To: Gavin, Angelique (NIH/NINDS) [C] [b6]
Subject: Re: NIH Study Inquiry

Yes please, what all do you need?

I was told some people actually get appointments with a Dr at NIH. Mine would have to be virtual but definitely willing.. Nobody in my area really knows what to do. One Dr is trying to treat me with [b6]
[b6]
[b6] I would appreciate any help, thank you.

Sent from Yahoo Mail on Android

On Tue, Aug 17, 2021 at 9:12 AM, Gavin, Angelique (NIH/NINDS) [C]
[b6] wrote:

Dear [b6]

Thank you for your interest in our research. We are currently developing an online survey system to collect stories about people's complications after receiving COVID vaccines. At this time, if you are willing, we can take your name and contact information. We will reach back out to you when the survey system is completed to see if you are willing to volunteer in our on-line study.

Thanks you,

Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

10 Center Drive

Building 10, Room 3B19, MSC 1251

Bethesda, MD 20814-9692

b6 (office)
(cell)

(301) 480-5368 (efax)

b6

<https://clinicaltrials.gov> - study number 000089

-

From: Gavin, Angelique (NIH/NINDS) [C] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=6E97392E947E4F7EBB17EEB8AC87C5D5] [b6]
Sent: 9/21/2021 8:45:51 PM
To: [b6]
Subject: RE: NIH COVID Vaccine study

Thank you [b6] Will do!

Angelique

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

[b6] (office)
[b6] (cell)
(301) 480-5368 (efax)

[b6]
<https://clinicaltrials.gov> - study number 000089-N

From: [b6]
Sent: Tuesday, September 21, 2021 3:58 PM
To: Gavin, Angelique (NIH/NINDS) [C] [b6]
Subject: Re: NIH COVID Vaccine study

Hi Angelique,

Thank you so much for your email. I would be happy to participate in the online survey, so please do keep my contact info on file. Thank you!

Sincerely,

[b6]

On Sep 21, 2021, at 2:09 PM, Gavin, Angelique (NIH/NINDS) [C] [b6] wrote:

Dear [b6]

Thank you for your interest in our research. We are currently developing an online survey system to collect stories about people's complications after receiving COVID vaccines. At this time, if you are willing, we can take your name and contact information. We will reach back out to you when the survey system is completed to see if you are willing to volunteer in our on-line study. Let me know if you remain interested.

Sincerely,
Angelique

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

b6

(office)

(cell)

(301) 480-5368 (efax)

b6

<https://clinicaltrials.gov> - study number 000089-N

From: Gavin, Angelique (NIH/NINDS) [C] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=6E97392E947E4F7EBB17EEB8AC87C5D5 [b6]
Sent: 10/28/2021 1:45:06 PM
To: [b6]
Subject: RE: Injured vaccine

Thank you [b6] for following up with us! I have your information from the email you sent in August. The study you are interested in is currently not active and is waiting to be approved. Once underway and recruiting, the study team will contact you. All my best to you!

Sincerely,
Angelique

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

[b6] (office)
[b6] (cell)
(301) 480-5368 (efax)

[b6]
<https://clinicaltrials.gov> - study number 000089-N

From: [b6]
Sent: Thursday, October 28, 2021 12:51 AM
To: NINDSPostCovid19 <nindspostcovid19@ninds.nih.gov>
Subject: Injured vaccine

I emailed months ago and was told that you were getting a study for those of us that have had issues and would be hearing from you. Now I hear there is a study ready but I've heard nothing.. Can you please respond is if there is another study?

Sent from Yahoo Mail on Android

From: Gavin, Angelique (NIH/NINDS) [C] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=6E97392E947E4F7EBB17EEB8AC87C5D5 [b6]
Sent: 11/29/2021 4:07:13 PM
To: [b6]
Subject: RE: Study # 000089 Long Haul COVID

You are very welcome.

Sincerely,
Angelique

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692
[b6] (office)
[b6] (cell)
(301) 480-5368 (efax)
[b6]
<https://clinicaltrials.gov> - study number 000089-N

From: [b6]
Sent: Monday, November 29, 2021 10:58 AM
To: Gavin, Angelique (NIH/NINDS) [C] [b6]
Subject: RE: Study # 000089 Long Haul COVID

Thank you Angelique! You have no idea how much this means to us! [b6]

Sent from [Mail](#) for Windows

From: Gavin, Angelique (NIH/NINDS) [C]
Sent: Monday, November 29, 2021 10:35 AM
To: [b6]
Subject: RE: Study # 000089 Long Haul COVID

Thank you [b6] for your interest in our COVID-19 study here at the NIH. Liz Bartrum, NP, from my team will be contacting your daughter to arrange an eligibility interview. All my best to you and your daughter.

Sincerely,
Angelique

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive

REL0000229903

Building 10, Room 3B19, MSC 1251

Bethesda, MD 20814-9692

b6

(office)

(cell)

(301) 480-5368 (efax)

b6

<https://clinicaltrials.gov> - study number 000089-N

From: **b6**

Sent: Monday, November 29, 2021 9:46 AM

To: Gavin, Angelique (NIH/NINDS) [C] **b6**

Cc: **b6**

Subject: Study # 000089 Long Haul COVID

Hi Angelique,

I am writing regarding a referral from my daughter's neurologist, **b6** requesting participation in the long haul COVID study, #000089. I do have HIPPA authorization to assist in my daughter's behalf. My daughter,

b6

contact information is included and she is cc'd on this email.

b6

She developed a pervasive stutter 24 hours after her second Pfizer vaccine which was administered 2 weeks after her diagnosis of COVID-19 on the recommendations of **b6** This is one reason I assist as a contact for her.

She has been symptomatic since her diagnosis of COVID-19 in March of 2020 with constant headaches, memory problems, mild aphasia, inability to sleep, new onset hypertension and tachycardia, new onset asthma with exercise intolerance, persistent loss of taste and smell, anxiety, depression, and intermittent nausea. She has been under the care of her PCP, neurologist, cardiologist, psychiatry and sleep specialist. She is now on multiple medications when before COVID she was healthy on no medications.

b6

Her neurologist, **b6** recommends that she participate in a long haul COVID study as she has not made any progress.

Thank you for your consideration,

b6

Sent from Mail for Windows

REL0000229903

From: Gavin, Angelique (NIH/NINDS) [C] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=6E97392E947E4F7EBB17EEB8AC87C5D5] b6
Sent: 2/1/2022 4:40:47 PM
To: b6
Subject: RE: NIH Vaccine Study Inquiry

Thank you, b6 The study is not yet underway. However, you would not be able to participate on behalf of your wife. It sounds like she is too ill at this time. I don't anticipate it will begin for another 2-3 months. Have her contact me in a couple of months if she is feeling better and is still interested. In the meantime, I have reached out to a physician here to see if there are any therapeutics or local physicians he might recommend. I will get back to you soon.

Sincerely,
Angelique

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

b6 (office)
b6 (cell)
(301) 480-5368 (efax)

b6
<https://clinicaltrials.gov> - study number 000089-N

From: b6
Sent: Tuesday, February 1, 2022 10:53 AM
To: Gavin, Angelique (NIH/NINDS) [C] b6
Subject: [EXTERNAL] Re: NIH Vaccine Study Inquiry

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.

I am happy to participate, if it helps other patients. In her current state, I may have to fill this out for her. Would that be possible?

b6

From: Gavin, Angelique (NIH/NINDS) [C] b6
Sent: Tuesday, February 1, 2022 8:59 AM
To: b6
Subject: NIH Vaccine Study Inquiry

Dear b6

Thank you for your interest in our research. We are currently developing an online survey system to collect stories about people's complications after receiving COVID vaccines.

REL0000229911

If your wife is interested in participating, please have her contact me at this email address. We will reach back out to her when the survey system is completed to see if she is willing to volunteer in our on-line study.

Thank you,
Angelique

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

b6

(office)

(cell)

(301) 480-5368 (efax)

b6

<https://clinicaltrials.gov> - study number 000089-N

-

From: Gavin, Angelique (NIH/NINDS) [C] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=6E97392E947E4F7EBB17EEB8AC87C5D5 [b6]
Sent: 2/1/2022 5:04:29 PM
To: [b6]
Subject: RE: NIH Vaccine Study Inquiry

Hello [b6]

I have listed some information below that I hope will be helpful. Please check out this site for all info regarding our vaccine studies. All my best to you and your wife.
It is possible they have better answers to such questions than we do.

<https://www.niaid.nih.gov/about/vrc>

Sincerely,
Angelique

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

[b6] (office)
[b6] (cell)
(301) 480-5368 (efax)

[b6]
<https://clinicaltrials.gov> - study number 000089-N

From: [b6]
Sent: Tuesday, February 1, 2022 10:35 AM
To: Gavin, Angelique (NIH/NINDS) [C] [b6]
Subject: [EXTERNAL] Re: NIH Vaccine Study Inquiry

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.

Thank you for the follow up. A survey is nice, but direction on therapeutics would be greatly appreciated. Are you aware of any effective treatments that have been utilized. Could I be directed to a local physician that might help?

Thank you

[b6]

REL0000229913

From: Gavin, Angelique (NIH/NINDS) [C] [b6]
Sent: Tuesday, February 1, 2022 8:59 AM
To: [b6]
Subject: NIH Vaccine Study Inquiry

Dear [b6]

Thank you for your interest in our research. We are currently developing an online survey system to collect stories about people's complications after receiving COVID vaccines.
If your wife is interested in participating, please have her contact me at this email address. We will reach back out to her when the survey system is completed to see if she is willing to volunteer in our on-line study.

Thank you,
Angelique

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

[b6] (office)
[b6] (cell)
(301) 480-5368 (efax)

[b6]
<https://clinicaltrials.gov> - study number 000089-N

-

From: Wiebold, Amanda (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=4491EE2AE9804610899C741100150540] b6
Sent: 5/17/2021 12:22:53 PM
To: b6
CC: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246] b6
Subject: RE: covid vaccine reaction

Hello b6

I am so sorry to hear about the difficulties you are experiencing. I know it must be incredibly frustrating to not be able to get answers from doctors. I will pass along your email to Dr. Safavi. She has received a huge response from the community and I know it is taking her some time to get back to people.

Thank you,
Amanda

From: b6
Sent: Saturday, May 15, 2021 11:37 AM
To: Wiebold, Amanda (NIH/NINDS) [E] b6
Subject: covid vaccine reaction

Hello Amanda,

I was emailing Dr. Safavi but I realize she is very busy. I got the other emails that I have sent confused with you all at NIH. I am hoping to be involved in your study so that I can get some help for my covid vaccination reaction. I haven't been able to get any help locally and have done a ton of leg work to try to get it.

A quick breakdown of events: b6 I was vaccinated and had an immediate adverse reaction with numbness, weakness, dizziness, chest pains, I felt like my BP and HR dropped and blurred vision. Then had digestive issues. Over the course of weeks the dizziness and weakness persisted as well as digestive issues. I went to the doctor for my symptoms and they found b6 I felt ignored when they told me it was b6 I started to realize that eating certain foods made my symptoms worse and gave me diarrhea. So intuitively I cut back on high allergenic foods and high histamine foods. Within a week I was feeling more stable. The dizziness seemed to get less as well as the weakness.

I thought since I felt mostly better that I must be recovering finally. That's when things got way worse. On b6 b6 I was so weakened I could barely stand up for weeks. Upon standing, I was very winded and felt like I was going to pass out. My HR would shoot up upon standing, so much muscle weakness in legs and core muscles, and I would have palpitations when laying. I then noticed I was reacting to other things like the shower, foods like sweet potato, oatmeal, and onion, b6 b6

I can finally stand up today but I can not walk far at all without becoming very winded and weak. I walked to the end of my street yesterday which is not a long street and then today I slept all day. I am beyond exhausted, the fatigue is disabling. My diet is restricted because I'm scared to eat more foods and slide back to where I was.

My possible/probable neuro symptoms now seem to come and go along with the long list of other symptoms but the ones I have and do experience is: burning feeling, confusion, mentally slower than normal, at times slurred speech when having a reaction, exhaustion when talking, lethargy, muscle weakness, nausea, digestive problems, b6 b6 short of breath, and vision changes/color halos around light. I am sure there is more too because a lot has happened over the last b6

My immunologist says I have [b6] but I am in a group on FB where others just like me talk about reaching out to NIH for help.

Other health issues, I am diagnosed with [b6] and my endo thinks [b6]
[b6] But all this happened in the middle of that testing so I am holding off for now.

All of this has taken me out of work and been a huge stress on my family. My PCP hasn't been terribly helpful but they did say if NIH wanted to fax them information on what you all are seeing as far as reactions and how they can be treated that would be helpful to guide them. I would prefer to work directly with NIH if possible though since my PCP doesn't seem too interested in helping me and my local neuro can't see me until the end of July.

Thank you in advance for any help or insight that you can give me.

[b6]

--

[b6]

From: [b6]
Sent: 9/6/2021 12:15:49 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
CC: Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540 [b6]
Subject: Request for consult from [b6]

Hi Dr. Safari,

I was referred to you by another physician who has been in touch with you about [b6] she was diagnosed with after receiving the covid vaccine. I am [b6] and after receiving my 2nd covid vaccine [b6] have had a number of strange neurologic symptoms- paresthesias, limb heaviness, and have now been found to have [b6] [b6] I saw a neuropathy physician [b6] who thinks this is [b6] My Rheum and Neuro lab workups [b6]

b6

I have been told by multiple neurologists that my [b6]

I am quite concerned about the esophageal dysmotility, especially as it is in the proximal esophagus, and was hoping to consult with you if possible.

I hope you are well and I look forward to hearing from you.

Best,

[b6]

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 [b6]
Sent: 3/6/2021 12:43:43 AM
To: [b6] Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6] Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540 [b6]
CC: Chertow, Daniel (NIH/CC/CCMD) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=90edfb54493c44be982e57addb488927 [b6]
Subject: FW: 1 Year Covid Long Hauler

Dear [b6]

Dr. Chertow forwarded me your email. I am sorry to hear of your illness. We will be glad to talk to you and review your records to see what we can do to investigate your symptoms further. I have copied members of our team who will be in touch with you.

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: Friday, March 5, 2021 at 5:01:48 AM
To: "Chertow, Daniel (NIH/CC/CCMD) [E]" [b6]
Subject: Re: 1 Year Covid Long Hauler

Dr. Chertow,

Thank you very much for taking the time to respond. I am grateful for the very important work that you are doing.

I have faith that you and your team are integral parts in helping the medical community understand how this virus is impacting patients. I say this especially after I had to return to the ER last night with massive shaking and had a doctor tell me he wasn't even fully convinced that people experience Covid long haul symptoms. 😞 His reasoning was because there were not any studies done on it.

This leaves us patients feeling so helpless in an already desperate situation. He was not the first of his colleagues to dismiss me and leave me to deal with this scary illness and its manifestations by myself. As I understand, this is how too many people are being regarded.

I would certainly appreciate being connected with other investigators so as to assist in further studies.

God bless you in your dedication. People like you are helping people like me.

May you be successful in all that you do,

[b6]

On Mar 4, 2021, at 8:00 AM, Chertow, Daniel (NIH/CC/CCMD) [E] [b6] wrote:

Dear [b6]

Thank you for your interest in our study and I am very sorry to learn that you continue to experience residual effects related to COVID-19.

Unfortunately, you would not qualify for our study as we require an early visit (within 2-3 months post initial infection) followed by subsequent visit(s).

If you are interested, I will pass your name on to other investigators here at NIH who are also evaluating long-term effects of COVID-19 to determine if you might be eligible for their studies.

Sincerely,

CAPT Daniel S. Chertow, MD, MPH, FCCM, FIDSA
United States Public Health Service
Tenure-Track Investigator
Head, Emerging Pathogens Section
Critical Care Medicine Department, NIH Clinical Center &
Laboratory of Immunoregulation, NIAID

From: [b6]

Date: Tuesday, March 2, 2021 at 10:27 PM

To: Chertow, Daniel (NIH/CC/CCMD) [E] [b6]

Subject: 1 Year Covid Long Hauler

Dr. Chertow,

Thank you for all of the work that you are doing. I read an article on NBC News and came across your name in an article in regards to the research that you are doing in regards to Covid long haulers.

My name is [b6] I am a [b6] living in [b6] I was someone who contracted the virus early on exactly one year ago this week. I would like to be a part of your study.

My symptoms began like an intense flu and I knew something was gravely wrong at onset. Followed by pulmonary, cardiac and neurological long haul manifestations. I went to the hospital 4 times and this week am working on a 5th visit. I think I have been having seizures almost half the day for the past two weeks since my second dose of the vaccine. A manifestation that was altogether new to me last summer, and I thought had gone away since fall. I have ongoing massive chronic fatigue, cognitive challenges and brain fog.

I have had no history of any of these symptoms prior to infection.

I understand proximity to your labs may not allow for me to participate. I would like to understand what is going on with my body and help researchers to do the same.

[b6]

b6

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246; b6
Sent: 10/1/2021 10:09:03 PM
To: b6
Subject: Re: Question

I am sorry

Farinaz

From: b6
Sent: Friday, October 1, 2021 4:27:03 PM
To: Safavi, Farinaz (NIH/NINDS) [E] b6
Subject: Re: Question

Thank you for your quick reply!! Especially, because I know how busy you are. Your words do help. I have; b6

b6
b6

b6 I trust you so thank you for your input.

b6

Sent from my iPhone

On Oct 1, 2021, at 1:17 PM, Safavi, Farinaz (NIH/NINDS) [E] b6 wrote:

Hi b6

I believe I mentioned that we do not know the data for; b6

b6

b6 This is completely anecdotal observation and still there is no available data (which hopefully will be available from FDA in the future) about this topic.
Hope it helps

Farinaz

From: b6
Sent: Friday, October 1, 2021 4:07:53 PM
To: Safavi, Farinaz (NIH/NINDS) [E] b6
Subject: Question

Hello. I hope you are doing well. I'm still waiting for; b6
I did; b6

When you and I first met via Zoom way back in February, you had suggested; b6
b6 Do
you still hold that opinion after all your months of intentional study and research?

Blessings to you,

b6

Sent from my iPhone

REL0000230182

From: [b6]
Sent: 5/11/2021 2:33:14 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: [b6] study

Ok, great, I will see you tomorrow!

Thanks!

[b6]

On Mon, May 10, 2021, 4:58 PM Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

I heard about them and I kind of know what they do. I am not aware about any relationship between them and that company. We can talk about it tomorrow.

I will place [b6]

Best

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: [b6]
Sent: Monday, May 10, 2021 7:14 AM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: [b6] study

Hello,

I just became aware of a study that has been done by [b6] they have made some headway on post vaccine long haulers. I just wanted to see if you have heard of their study? They said they were in contacts with Dr. Collins, who I guess is in the NIH? I'm unsure, but was just curious of your thoughts!

Thank you,

b6

From: [b6]
Sent: 5/7/2021 5:08:13 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Covid-19 Adverse Events

Flag: Flag for follow up

Hello Dr. Safavi,

Good day to you and thank you for your time and efforts, they are appreciated. I have questions I believe you can help with. I am acquainted with several people receiving treatment at the NIH for adverse events following the administration of Covid-19 vaccines. I am not yet one of that cohort but I am part of the larger group suffering from severe, persistent adverse neurological problems. I am a [b6] [b6] I received my first dose of Pfizer [b6] felt tingling in my vax arm fingertips shortly after; headaches, scalp tightness, frontal lobe pressure, fatigue, bilateral tingling in hands, etc the next day. And, since then, it's been a rolling ebb and flow of increasing new symptoms (paresthesias, dysesthesias, incredible headaches, impaired thermoregulation, nausea, muscle spasms/cramps, intestinal motility, fatigue, cardiac, vascular, etc) with fluctuating intensities that often make it impossible for me to function since. Prior to this, [b6] was my only health issue and it was well managed. [b6] neurological symptoms are still migrating and changing but pretty much involve my entire body to a greater or lesser extent, depending on body part, day, and time. I'm sure it's not the first time you've heard any of this. And I know I am not the worst of it. As more vaccines are administered there will be greater numbers suffering and I would like to not only find answers and relief for myself but contribute to bringing that help forward for those who will follow. The sheer volume of administration for these new vaccines makes it imperative we figure out what's going on and offer protocols for our local doctors as well. They are completely clueless right now, it seems the world over, and the scatter-shot or 'let's wait' approach at the local level leaves many of us in a loop of flying blind rather than the collective collaboration that can prove so useful. So, my questions are:

1) Are you currently accepting patients for study at the NIH? Or are there similar NIH sponsored studies for adverse events available elsewhere? I did find one NIH sponsored adverse event study but they require people who have not yet been vaccinated.

2) What resources are available that I can give doctors trying to treat patients with these new morbidities?

- Who can they contact?
- What information sites can they access?

3) What protocols or testing are you currently suggesting doctors follow for patients presenting with these symptoms after vaccination? Neurologists, cardiologists, allergists/immunologists, general practitioners.

Again, thank you for the expertise and work on this ongoing issue.

Kind Regards,

b6

From: [b6]
Sent: 5/15/2021 12:14:58 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: [b6] vaccine injury

Hi Dr Safavi,

I forgot to mention my Dysautonomia in my earlier email. My last hospitalization was because of urinary incontinence. Ive also struggled w orthostatic hypotension, low BP, BP fluctuations, tachycardia, brain fog etc. not to mention sores on my tongue for the last several weeks. My immune system is definitely a mess. I'm really praying that I can get some help. I got this vaccine because [b6]
[b6] This is
horrific and I'm really praying and hoping you can help me!

Thanks again,

[b6]

Sent from my iPhone

From: [b6]
Sent: 5/20/2021 4:48:27 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Fwd: Moderna Vaccine Reaction [b6]

Hello,

I emailed you back on 4/24/2021 about my situation. I am trying to reach out again. I've made contact with Dr. Nath who recommended I see [b6] in Neurology. I am already being followed by [b6] in Neurology, and I have reached out with the treatment recommendations that are. Nath said, but have yet to hear anything back other than [b6]
[b6]

Is there any advice that you or Dr. Nath can provide? A consultation with my doctors that you are willing to do?

Thank you in advance,

[b6]

Begin forwarded message:

From: [b6]
Date: May 14, 2021 at 2:14:34 AM EDT
To: [b6]
Subject: Moderna Vaccine Reaction [b6]

Hello,

My name is [b6] I belong to the CO-19 VASE Family on Facebook. It is from this group page that I got your email contact information. I hope that you don't mind me reaching out to you.

I am a [b6] I'm [b6] highly active, and healthy (no underlying conditions exce

From: [b6]
Sent: 4/20/2021 4:09:55 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Adverse reaction to Moderna.
Flag: Flag for follow up

Hello Dr. Safavi,
My name is [b6] and I am a healthy [b6] with no prior health problems and have had no problems with any vaccine in the past and take a flu shot every year [b6] I had the Moderna [b6] and 12 minutes later I was hot all over my body and felt like I was going to pass out. The medics took my vitals and my Hr was [b6] with a blood pressure of [b6] I have never had blood pressure problems in the past. I started shaking uncontrollably like I had a shot of epi in my system. I was taken to the ER by ambulance and observed for 6 hours. That night I developed a red rash so I started [b6] Over the next 2 days I saw my PCP and my BP was [b6] and resting pulse was [b6] He started me on [b6] I had chronic diarrhea for the next 3 weeks and lost 17 lbs. I felt like I had fight or flight 24/7. I had 5 911 calls and was taken to the ER. I had [b6]
[b6] I've had multiple labs. I have no diagnosis but [b6] I would love for you to review my case and take me on as a patient. Thanks so much.

[b6]

Sent from my iPhone

From: [b6]
Sent: 4/19/2021 2:45:47 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
CC: Billioux, Bridgette (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=be2f8250e99b4622888a4727137339c2 [b6]
Subject: Re: Paresthesia after Covid 19 vaccine 1st dose

Flag: Flag for follow up

Thank you so much!

I look forward to working with your team.

[b6]

Get [Outlook for Android](#)

From: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Sent: Monday, April 19, 2021 9:38:39 AM
To: [b6]
Cc: Billioux, Bridgette (NIH/NINDS) [E] [b6]
Subject: RE: Paresthesia after Covid 19 vaccine 1st dose

Dear [b6]

I am sorry to hear about your illness. I cc a colleague of mine Dr. Billioux in this email who has been involved in this project and may be able to schedule a televisit with you.

Best Regards,

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

From: [b6]
Sent: Saturday, April 17, 2021 3:15 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Paresthesia after Covid 19 vaccine 1st dose

Hello

I found your information through [b6] Facebook group. I took the Pfizer vaccine [b6] and in 5 mins I felt a sharp pinprick pain in my left elbow which was the side where I received the injection.

After about 25 minutes on my drive, my browbone and cheekbone started to prick, tingle and itch. By cheeks felt tightened with heat.

Since then I have had tingling, pricking, sharp stabbing and throbbing along both arms and legs, numbness and tingling on my face with pressure feelings in my ears.

REL0000230243

I also experience hot flashes and banding across my chest and trunk, with chest pain and heaviness in the center of my chest.

I have seen a neurologist who

b6

b6

b6

I also have fatigue lost days.

I'd like to be able to work with you to figure out what is happening to me and if there are any treatments available.

My contact information is

b6

Thank you

b6

Get Outlook for Android

Get Outlook for Android

From: [b6]
Sent: 4/23/2021 12:11:12 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Myself

Hi Farinaz, sorry to bother you so much. I am on my way to [b6] I just had another terrible siege of a severe headache in the right frontal area and severe burning numbness and vibrations throughout my body that lasted several hours. I took [b6] and I feel a little better but I think I need to go in the hospital. I am definitely much worse than I have been.

I have a question to ask you. My [b6] daughter is scheduled to get the Covid vaccine (pfizer) [b6]

b6

Thank you so much,
[b6]

Sent from my iPhone

From: [b6]
Sent: 4/22/2021 5:32:34 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Fwd: [b6]

Hi Farinaz,

This summarizes what has happened to me in the last week. The allergist is [b6] and neurologist is [b6]. The neurologist really does not know what is wrong and doesn't recommend I do anything other than [b6]. He wants to see me back in one month. I hope I am still alive in one month. I think the allergist is more on board with these reactions and will be in favor of treating me.

Thank you for your help.

[b6]

Begin forwarded message:

From: [b6]
Subject: [b6]
Date: April 22, 2021 at 10:24:05 AM PDT
To: [b6]

Hi [b6]

I sent you records yesterday as well as a history summary.

I have been feeling worse since Saturday. 2 nites ago I was awakened by severe terrifying paresthesias from head to toe. My entire body was vibrating and I felt like I was being electrocuted. This lasted for a couple of hours. Not feeling too great since. I have constant fine tremor and fasciculations as well as burning and numbness from head to toe, mostly in my face. My fingers twitch and it is difficult for me to type.

I had [b6] yesterday with [b6]. Will take several weeks to get results. He told me to [b6]. He really does not know what is wrong with me. He thinks I may have [b6]. [b6] I had no symptoms until 30 minutes after receiving the vaccine. I can't imagine that [b6] would suddenly start like this.

I have [b6] and just had a consult with hepatologist [b6] who thinks it may be [b6].

[b6]
He said I could [b6]

[b6] ordered [b6] and I have [b6]. I spoke with hematologist [b6]. He thinks it is [b6]. I am completely panicked. Could the vaccine have triggered this too? I somehow think this vaccine reaction is going to kill me. Is there anyone you know who might have some insight into this [b6] doesn't really know anything

about the vaccine reactions and doesn't really believe I am having a reaction. He thinks it is

b6

I will see you in your office next week and hopefully we can discuss b6 The hepatologist said either would be fine. I very much need to be treated as I am so miserable. I hope you and the others can tie everything together that is happening to me and find a treatment for me. I want to be well again. I hope that can happen.

Thank you so much,

b6

On Apr 21, 2021, at 9:07 PM, b6 wrote:

<! My Health Summary-1.PDF><Medical records .pdf><my cs link><Medical history summary.pdf><Medical records 2.pdf>

I have

b6

b6

Extensive workup at the time was

b6

b6

From: [b6]
Sent: 3/29/2021 4:35:03 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
CC: Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540 [b6] Fletcher, Anita (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=43cbc70e2e87447ea55c8b55335a4df0 [b6]
Subject: Re: COVID 19 vaccine reaction [b6]

Great, thank you so much and I look forward to speaking with you further.

Sincerely,

[b6]

On Mon, Mar 29, 2021 at 12:04 PM Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

I am sorry to hear about your symptoms. We would be happy to speak with you and see how we can help. I cc my colleague Dr. Fletcher to this email and she can coordinate a televisit for you.

Best

Farinaz

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: [b6]
Sent: Monday, March 29, 2021 9:08 AM
To: Safavi, Farinaz (NIH/NINDS) [E]; Wiebold, Amanda (NIH/NINDS) [E]
Subject: COVID 19 vaccine reaction [b6]

Dear Dr. Safavi and Amanda,

Hello my name is [b6] and I am a [b6] from [b6] I received your email addresses from the facebook group I just became a part of yesterday regarding reactions to various COVID 19 vaccinations. I thought you might want to hear my story, I am very interested and motivated to find some answers and help research explore these reactions a little more in depth.

I have no past medical history, I have always been a super healthy person. I played sports in college, I work out pretty consistently, not a big drinker or anything like that, and a VERY healthy eater. I have been taking [b6]
[b6]

I received my first Pfizer vaccination [b6] I didn't experience any sort of reaction from the first dose the next day. Shortly after (maybe 2-3 days after the first dose) I experienced a bit of an itch on my right foot, but went away. Then felt it again the next day. It traveled out of my foot and I started feeling these tingling sensations on my right leg. Thought maybe I had sciatica [b6]
[b6] The tingling would come and go. It moved to my left leg and then my arms. I also felt the tingling in my elbows, fingers, neck, boob area, abdomen. My lower back was a bit sore and felt tight. I didn't totally put the vaccine and these symptoms together. I was also experiencing chest pains, like pressure on my chest that would come on and I feel that my heart rate would increase. I would just breathe through these pains and they would disappear in about a minute. I figured maybe it had to do with stress.

I received the second dose of Pfizer [b6] and experienced the "typical" symptoms I've heard: body aches, fatigue, low grade fever. The symptoms disappeared within 24 hours, and I did not feel any tingling. The following day at night, I started experiencing severe tingling. My stress/anxiety went up immediately; crying a lot and not understanding what was happening to me. The following day I felt the tingling all over my body: legs, torso, forehead, back of head, vagina, tongue, back, etc. I got super scared. It's like my nerves were firing off with nowhere to go. I went to the ER two days later, and they basically told me to go home, saying I should see a neurologist and that I wasn't dying. Days afterwards, I felt this horrible pin pricking sensation down my spine and topical numbness in my right leg that went away. I also began experiencing some muscle twitching. It started in my right leg but I can feel it in various parts of my body (thighs, buttock, calves, arms, hand, and right underneath armpit on my back). I went to a neurologist and she told me it was [b6]
[b6] I had a bad flare up a week and a half after that (no idea what it was from).

My current situation: I have a burning sensation mostly in my thighs, forearms (near elbows area), and upper shoulders. I have pin pricking sensations around my body. And I have muscle twitching in my arms, legs, and hand. I also have been experiencing diarrhea for the past month and a half. I am supposed to be getting [b6]
[b6] I'm really nervous about it, also wondering if it's worth getting?

To be completely honest, I am quite frightened of this whole situation and just looking for some clarity. I would love even just to chat with Dr. Safavi regarding this and learn more about her study. I am supposed to be

b6

Please let me know if Dr. Safavi might be interested in someone like me. I am very flexible in terms of my schedule and can provide her with anything she may need.

My email address is: [b6] my phone number is [b6] Please feel free to reach out to me in whatever fashion suits you. I look forward to your response!

Sincerely, [b6]

From: [b6]
Sent: 4/24/2021 3:40:56 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Abnormal Neuro Vaccine Reaction- Inquiry about Study being conducted

Hello,

My name is [b6] I belong to the CO-19 VASE Family on Facebook. It is from this group page that I got your email contact information. I hope that you don't mind me reaching out to you.

I am a [b6] I'm [b6] highly active, and healthy (no underlying conditions except [b6] Here is the timeline of what happened after I was inoculated with the Moderna Covid-19 vaccine:

[b6] 1st Moderna Covid Vaccine: presented with [b6] 4.5 hrs afterwards for 15-30 minute episodes (never had this occur before the vaccine). Followed up with my primary care provider, and now am being seen by a rheumatologist. Provided counsel that being administered 2nd dose of Moderna COVID-19 Vaccine benefits outweighed the risks.

[b6] 2nd Moderna Covid Vaccine: Started getting itchy bumps on bilateral front of neck about a week later. Then had what seemed like a pimple appear above my right eyebrow on [b6] my right eye was swollen. By [b6] I was diagnosed with [b6] I was sent to the ER to rule out [b6] Had bilateral lower leg muscle weakness, and upper neck/shoulder muscle weakness pain/fatigue. [b6] muscle/joint pain, muscle weakness, paresthesia in various areas of my body at various intervals, nausea, dizziness, constant headache, blurred vision, muscle twitching. I was seen by [b6] seen by [b6]

[b6]

[b6] was unable to provide me with any explanation as to why my body is reacting to the vaccine with these "complicated" symptoms. The best explanation I was given is that [b6]

[b6]

I have been thoroughly evaluated by some of the top [b6] and referred to numerous specialists throughout [b6] plus Rheumatology for extensive bloodwork. These different specialties are unable to find a clear diagnosis to explain any of these symptoms that are happening in my body.

I went from being a highly active, healthy [b6] to a woman who is easily fatigued, has [b6] and different painful, rashes appearing on her body, dry mouth, red eyes, muscle weakness, muscle twitching, numbness in various body parts in different times of the day, vertigo, blurred vision, joint pain, brain fog. Doctors are unable to give me a diagnosis.

I have copies of all my medical records. I did inform my PCP that I was reaching out to you about my interest in the study you are conducting on others who have found me that seem to be experiencing similar symptoms.

Thank you,

[b6]

From: [b6]
Sent: 3/31/2021 5:15:48 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246] [b6]
Subject: [b6]

Thank you Farinaz for sending this comprehensive article. I read it carefully. It is interesting that [b6]

[b6]

I have [b6]

[b6] It is very difficult to get an appt with her or speak to her. I will try to find an expert [b6] who can help me. Now I am very worried that I have a life threatening illness.

I look forward to speaking with you on Monday.
Thank you for all you caring,

[b6]

Sent from my iPhone

On Mar 31, 2021, at 5:33 AM, Safavi, Farinaz (NIH/NINDS) [E] [b6]
wrote:

Hi [b6]

I suggest you to read this paper patiently and carefully and we can discuss it when we meet.

[b6]

Farinaz

From: [b6]
Sent: 3/31/2021 3:13:34 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Fwd: [External] Myself

FYI, I emailed [b6] this evening to find out what the results were of my case being presented at the CDC one week ago. Here is the answer. I look forward to our brief visit on Monday. If you want to contact [b6] her email is below and her phone is [b6]
Thank you for everything.

Sent from my iPhone

Begin forwarded message:

From: [b6]
Date: March 30, 2021 at 7:11:18 PM PDT
To: [b6]
Subject: Re: [External] Myself

Thank you for letting me know. I was anxious to hear and would like to get help. I had no symptoms of [b6] prior to the vaccine. In fact, I felt fine prior to the vaccine. The [b6] I sure hope it will resolve. I would not want to live like this indefinitely. At the moment, my entire head is numb and the band is tight around my chest. I am very uncomfortable.
I am speaking with Farinaz Safavi at the NIH neuro division and she may contact you to give you her ideas. She seems to think [b6]
[b6]

Sent from my iPhone

On Mar 30, 2021, at 6:52 PM, [b6]
wrote:

Hi [b6]

Thanks for the note. Yes, it was a 2 hour presentation - very interesting. I have not received their report yet, but can give you a general overview. The consensus is that it is [b6]

[b6]
[b6] will continue to follow you. I'll let you know as soon as I receive the report. Hope tomorrow is a better day.

[b6]

On 3/30/21, 6:31 PM, [b6] wrote:

Hi [b6]

Has my case been presented to the CDC yet? Were there any recommendations? I am having a bad day today with paresthesias and would like to know what they recommend.

Thanks,

[b6]

Sent from my iPhone

WARNING This email is from an external source. Do not click on links or open attachments unless you know the content is safe. Protect your username and password.

IMPORTANT WARNING: This message is intended for the use of the person or entity to which it is addressed and may contain information that is privileged and confidential, the disclosure of which is governed by applicable law. If the reader of this message is not the intended recipient, or the employee or agent responsible for delivering it to the intended recipient, you are hereby notified that any dissemination, distribution or copying of this information is strictly prohibited. Thank you for your cooperation.

From: [b6]
Sent: 4/6/2021 1:00:28 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: Neurologists

Thank you.

Sent from my iPhone

On Apr 5, 2021, at 5:34 PM, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

[b6]

I am really sorry that you have been going through such a terrifying experience. This pandemic and everything attribute to it is very new. We all basically are learning day by day about COVID related issues. There has not been anything similar to it in modern medicine so that it takes time until we can navigate the right path. I believe you are in the right track and hope you can get the best care. As soon as you see your new physicians, I will be more than happy to communicate with them in details and share our understanding about the situation. Hopefully we will find the best course of action to help you.

Warm Regards,

Farinaz

PS; [b6]
[b6]

From: [b6]
Sent: Monday, April 5, 2021 7:51 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Re: Neurologists

Thank you so much. I have requested an appt with [b6]
[b6] He is also a neuromuscular expert. Hopefully with your help, I can move forward with treatment for my illness.

I also made an appointment with [b6] an allergist/immunologist [b6] I have spoken with him several times about my illness in the past. He was really unaware of these reactions at the time but maybe has more information since we last spoke. He also knows [b6] and [b6] [b6] well and has done some work at the NIH.

I am very sorry and distressed that you have the impression that I have interfered with my medical care. I do not understand where that came from. In my opinion, that is so far from the truth. I have desperately sought medical care and have been unable to find it. I have had so many medical opinions and unfortunately have been left with no diagnosis or recommendations for treatment by two neurologists, one rheumatologist, two allergists, one internist and many other experts that I have consulted with. My last neurologist felt [b6]

[b6] She did order [b6]
[b6] In addition, I could not get

a follow-up appointment or call. Now it makes sense to me when she told me she called a colleague at the NIH and was told that they had no idea what was wrong with me. On top of being so very ill, it has been extremely difficult not to be able to get medical care. I wish that situation on no one. That is why I reached out to experts in other parts of the country. If not for you and the others, I would really be left empty-handed at this point.

b6

b6

I hope this clarifies what I have been going through trying to get medical care for what felt like a life-threatening illness. I am not a difficult patient. In fact, I rarely seek medical care except for routine health maintenance. Even through this illness, I suffered agonizing symptoms without calling my physicians. This has been a unique and very difficult experience.

Not surprisingly, I am very traumatized. Thank you again for all you have done to help me. To have my symptoms validated and to help diagnose and treat me has given me hope.

With great appreciation,

b6

PS:

b6

Sent from my iPhone

On Apr 5, 2021, at 2:49 PM, Safavi, Farinaz (NIH/NINDS) [E]

b6

wrote:

Hi

b6

Here are two neuromuscular physician names at

b6

b6

If I find any other names, I will let you know.

I would be happy to help and speak with any of your physicians and discuss your issues and our understanding about the situation.

Best Regards,

From: [b6]
Sent: 4/12/2021 8:30:51 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246] [b6]

Hi Farinaz,

I am so sorry to bother you. I was contacted today by Kristina Fiore who is:
Director, Enterprise & Investigative Reporting at
MEDPAGE TODAY

She read a comment I wrote about my reaction to the vaccine and wanted to interview me. I mentioned that you are researching these reactions and many in my group (now up to 60 people) and she wondered if you would be willing to speak with her. I told her you are doing research and would not want to divulge anything you may publish and she said she is very aware of this issue would not interfere. If you are willing to speak with her, I will let her know. She is hoping to write something to bring these reactions to the public so that we can be recognized and get appropriate treatment.

Thank you.

[b6]

Sent from my iPhone

From: [b6]
Sent: 4/8/2021 5:13:09 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
CC: [b6]
Subject: Hi there... question for you Dr. Safavi

Hi Dr. Safavi,

[b6] referred me to you and I hope you might have a minute or two to respond to my e-mail. I am having the exact same issues she is with paresthesia and vertigo.. ears ringing.. and just weird feelings. I have never had any problems at all in my past. [b6] almost a totally clean health history with no underlying issues I knew of before I took the vaccine. Now I feel like the nerves in my body are being controlled by somebody else. Really the main question maybe I have is do I take the second vaccine? The first one I took last week is causing me all the problems.

[b6]

[b6]

[b6]

From: [b6]
Sent: Thursday, April 08, 2021 12:30 PM
To: David Bailey
Subject: Re: [b6]

Yes. Her email is

[b6]

Sent from my iPhone

On Apr 8, 2021, at 9:27 AM, [b6] wrote:

I haven't read through everything yet on FB.... Did you contact her via e-mail? I saw her on Twitter.

[b6]

From: [b6]
Sent: Thursday, April 08, 2021 12:10 PM
To: [b6]
Subject: [b6]

b6 try to see Dr. Safavi virtually. Some people in our group have seen another doctor in the group who was not very helpful. I would wait for Dr. Safavi. I think she is super busy because of so many people like us.

Sent from my iPhone

On Apr 8, 2021, at 5:46 AM, b6 wrote:

Yes absolutely b6 if you can invite me to your Facebook group. I will see if I can find you.

From: b6
Sent: Wednesday, April 07, 2021 9:57 PM
To: b6
Subject: b6

Hi b6 I am sorry you're experiencing this. There are many others who have had paresthesias from the vaccines. You are not alone.

I am b6 and became very ill 30 minutes after receiving the first Pfizer vaccine. I was fine prior to getting the vaccine. I am somewhat improved over the past b6 but I still have significant paresthesias especially in my face, scalp, mouth, tongue, chest wall and occasionally limbs. At times, I can barely function. I have seen many doctors who had no clue and could not help me. I reported my reaction many times to VAERS, Pfizer, CDC, FDA, NIH. I have written many letters to the heads of these agencies and head a private group on Facebook. We are 51 people, mostly women and several men, who have all had similar reactions. We have found a doctor at the NIH who is aware of these reactions and is studying them and trying to help us. I would be happy to invite you to join our group if you like. You would need to friend me on Facebook and then I can invite you to the private group. I think you will find it interesting and helpful. It has been a long and difficult journey and we have not yet found answers or real help. Most of our group are improving with time. It is truly amazing that the governmental agencies and drug companies have completely shut their eyes to us and these serious reactions. They are fully aware of them but are refusing to publicize them. For this reason, the medical community knows nothing about these reactions and labels them all as "anxiety".

Let me know if you want to join us. You will find the NIH neurologist's email there. Please give us your story and label it "My Story". Hopefully we will all find help soon.
Sincerely,

b6

Sent from my iPhone

On Apr 7, 2021, at 5:44 PM, b6 wrote:

I have had horrible paresthesia [b6] after my first COVID vaccine shot from Pfizer. Fortunately I don't have weakness. Is there something we can do to let people know what's going on? I have NEVER HAD ANY kind of symptom like this in my life.. I am [b6] Never felt this way. I am worried this is long-term. Do you know anything?

b6

b6

b6

From: [b6]
Sent: 3/20/2021 8:03:39 PM
To: [b6] Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246; [b6]
Subject: Re: Facebook page for people suffering from paresthesias from covid vaccines

Hi
Thx for letting us know.
And if they enroll in the research study , we can do further studies on this and the possible linkage to other co immune conditions.

Best

[b6]

Get Outlook for iOS

From: [b6]
Sent: Saturday, March 20, 2021 12:49:12 PM
To: [b6] Farinaz Safavi; [b6]
[b6]
Subject: Facebook page for people suffering from paresthesias from covid vaccines

Hi Doctors,
We started a closed Facebook page for people suffering from neurological reactions to the vaccines. I thought you might be interested in joining and seeing the similarities in many of our reactions. These are all legitimate people carefully screened by me. [b6]

[b6] Not sure of the significance of this.

Thanks for all you help. I know that you are hearing from a lot of these patients and thank you for your interest in helping us. Feel free to make comments as you see appropriate.

I now have been contacted by at least 30 people with similar reactions.

The link to the Facebook page is

[https://www.facebook.com/groups/\[b6\]](https://www.facebook.com/groups/[b6])

Sincerely,

[b6]

Sent from my iPhone

From: [b6]
Sent: 6/1/2021 9:05:20 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: [b6]

I completed required testing on your protocol May 6, 2021.

[b6]

[b6]

I continue to be puzzled by a statement in your April 24th email, "I believe you benefit from getting medical care from the community physicians to help improve your ongoing disease." (attached screen print). What ongoing disease were you referring to? [b6]

Was there a purpose for my completion of your protocol? I'm still seeking clarity of NIH's role in any of my treatment.

Thank you,

[b6]

Safavi, Farinaz (NIH/NINDS) [E]

Re: Post J&J Shot

To: [b6] Cc: Wiebel, Amanda (NIH/NINDS) [E], Nahar, Kymoni (NIH/NINDS) [E]

April 26, 2021 at 8:03 AM

Details



I am sorry to hear about worsening of your underlying disease and completely understand your aggravated medical conditions prevent you to get needed testing in our research protocol in timely manner. We really appreciate your participation, but if you can not get required testing on our protocol due to your medical conditions, unfortunately we may not be able to proceed with research protocol.

I believe you benefit more from getting medical care from the community physicians to help improving your ongoing disease.

We would be more than happy to facilitate testing at NIH in next couple of weeks if you are able to participate.

I wish you rapid recovery.
Best Regards,

Farinaz Safavi MD, PhD

See more from Barbara Weiss

On Apr 30, 2021, at 8:03 PM, [b6] wrote:

Thanks. Yes, I'd require [b6] I'm not sure where NIH and I fit. [b6]
[b6] but I still have a winged scapula and while it is better, I cannot say how it'll be next week. So, if I cannot get [b6] should I assume NIH will not assess for [b6] and I'm done with the protocol? Everything seems to rest on my ability to complete [b6] next week. I need to plan to proceed with my post-vaccine care.

Am not sure how to interpret [b6]

[b6]

[b6]

REL0000230452

On Apr 30, 2021, at 7:20 PM, Safavi, Farinaz (NIH/NINDS) [E]

b6 wrote:

b6

b6 It is possible that vaccine induces different types of immune mediated neuropathies. Without objective evidence no one can confirm any diagnosis or offer you any treatment.

b6

From: **b6**

Sent: Thursday, April 29, 2021 11:48:52 PM

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

Subject: **b6**

Farinaz,

I received an email from a medical provider who treated me during the onset of recent shoulder symptoms. He's known me for years, and like me, was puzzled by the unknown etiology and intensity of my reaction. His email message said he'd just seen a patient yesterday who had been diagnosed with **b6** and he sent me a link describing the syndrome. His patient's diagnosis was made by a well-known neurosurgeon in this area who said it was a covid vaccine reaction and was "classic."

My provider obviously cannot render a diagnosis. I can only infer that he may have seen similarities between my symptoms and the other patient. I had no injuries or obvious reasons for the insidious then sudden onset of recent, debilitating shoulder pain. My right shoulder tipped markedly forward, and my scapula winged. It was incredibly painful, and worse at night. Laying down was brutal, particularly in a supine position given my ultrasensitive, tipped scapula. It's still uncomfortable and symptomatic, but less severe.

With no other known cause or explanation, I thought my shoulder pain (that extended to my upper arm, down my arm, hand, in my chest) was associated with my spine. I had no reason to think it could be a relatively rare reaction that might be attributed to a vaccine. I did believe, however, inflammation contributed to my intense reaction. And while I thought! **b6**

b6

Is the possibility of this syndrome something that NIH wishes to address? I cannot say that this is an ongoing condition or underlying disease as I've never previously had this collection of clinical symptoms involving my shoulder. You instructed me to go to community physicians. I checked and can be seen by the neurosurgeon who diagnosed the patient with **b6**

b6 from a covid vaccine and another neurologist — to evaluate me for **b6**
b6 Please let me know your thoughts. I realize you wish to wrap up **b6** quickly at NIH for me to stay on the protocol and I'm trying to do so.

Thanks,

b6

From: [b6]
Sent: 6/24/2021 8:33:19 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: Reconnecting

Hi Farinaz,
Thank you for your speedy response.
You must be inundated with questions.
Hope the research continues to go well.
Once again thank you for your support and advice.
All the best,

[b6]

Sent from my iPhone

On 20 Jun 2021, at 12:17, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]
Thank you for the update. As I mentioned in our last communication, we do not have enough evidence to predict your reaction to 2nd dose of vaccine. I believe it is in your discretion to decide to take it or not. As I previously mentioned, we believe these neurological adverse events are immune mediated process and in a subgroup of patients immunotherapeutics may help.
Hope it helps

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

From: [b6]
Sent: Friday, June 18, 2021 7:47 AM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Reconnecting

Dear Dr Farinaz,
I had a telehealth consultation with you way back on 16 March.
Unfortunately I was unable to take part in your study as I am based in UK.
It is now [b6] and I still have flare ups with severe pain in legs and feet plus nausea. I have not taken the 2nd shot of the vaccine and obviously I'm really concerned about catching COVID particularly as the Delta variant is highly contagious and is the prevalent one in UK.
I was wondering whether you have any reports from your research or any preliminary findings that you could share.
Or indeed any information regarding 2nd dose for people who have had these symptoms after the first dose.
Many thanks.

Hope your research is going well.

Kind regards,

b6

Sent from my iPhone

From: [b6]
Sent: 5/25/2021 4:11:41 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: [b6] Consent
Attachments: [b6]

Attached are my consent forms.

[b6]

Sent from Outlook

REQUEST FOR MEDICAL INFORMATION FROM SOURCE OUTSIDE THE NATIONAL INSTITUTES OF HEALTH

INSTRUCTIONS: Complete this form in its entirety and forward directly to the requesting facility.

CC PATIENT IDENTIFICATION

(Patient Name) **b6** (Patient Number) **b6** (Date of Birth) **b6**

SOURCE OF INFORMATION REQUESTED

(Name of Health Care Organization or Physician) **b6** (Phone Number) **b6** (Fax Number) **b6**
(Street Address) **b6** (City) **b6** (State) **b6** (Zip Code) **b6**

INFORMATION REQUESTED

The purpose or need for disclosure: Review of clinical care and consideration for research study

NIH Requestor/Point of Contact: Amanda Wiebold **b6**

Identify the specific items and related dates pertaining to the information to be released.

1. Medical Reports:
Laboratory results, clinic notes, and brain MRI or head CT reports from **b6** date(s).

Send to: National Institutes of Health Clinical Center
National Institute of Neurological Disorders and Stroke
Building 10, Room 7C103
10 CENTER DRIVE MSC 1430
BETHESDA, MD 20892-1430
ATTENTION: Amanda Wiebold/ Dr. Bryan Smith
OR
Fax to: (301) 480-5594
Attn: Amanda Wiebold or
Dr. Bryan Smith

2. MRI scans on CD from **b6** date(s).

Send to: National Institutes of Health Clinical Center
National Institute of Neurological Disorders and Stroke
Building 10, Room 7C103
10 CENTER DRIVE MSC 1430
BETHESDA, MD 20892-1430
ATTENTION: Amanda Wiebold/ Dr. Bryan Smith

3. Tissue/Pathology Slides from **b6** date(s).

Send to: National Institutes of Health Clinical Center
Laboratory of Pathology
Building 10, Room 2B50
10 CENTER DRIVE MSC 1500 BETHESDA,
MD 20892-1500

AUTHORIZATION

I hereby authorize the release of the above requested medical information.

(Sig) **b6** (Printed Name of Patient) **b6** (Date Signed) **b6**
(Street Address) **b6** (City) **b6** (State) **b6** (Zip Code) **b6**

Patient Identification

Request for Medical Information From Source Outside The
National Institutes of Health
NIH-1208 (8-17)
P.A. 09-25-0099

REQUEST FOR MEDICAL INFORMATION FROM SOURCE OUTSIDE THE NATIONAL INSTITUTES OF HEALTH

INSTRUCTIONS: Complete this form in its entirety and forward directly to the requesting facility.

CC PATIENT IDENTIFICATION

(Patient Name) **b6** (Patient Number) **b6**

SOURCE OF INFORMATION REQUESTED

(Name of Health Care Organization or Physician) **b6** (Phone Number) **b6** (Fax Number) **b6**
(Street Address) **b6** **b6** (State) **b6** (Zip Code) **b6**

INFORMATION REQUESTED

The purpose or need for disclosure: Review of clinical care and consideration for research study

NIH Requestor/Point of Contact: Amanda Wiebold **b6**

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Laboratory results, clinic notes, and brain MRI or head CT reports from **b6** date(s).

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National Institute of Neurological Disorders and Stroke
Building 10, Room 7C103
10 CENTER DRIVE MSC 1430
BETHESDA, MD 20892-1430
ATTENTION: Amanda Wiebold/ Dr. Bryan Smith

OR
Fax to: (301) 480-5594
Attn: Amanda Wiebold or
Dr. Bryan Smith

2. MRI scans on CD from **b6** date(s).

Send to: National Institutes of Health Clinical Center
National Institute of Neurological Disorders and Stroke
Building 10, Room 7C103
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BETHESDA, MD 20892-1430
ATTENTION: Amanda Wiebold/ Dr. Bryan Smith

3. Tissue/Pathology Slides from **b6** date(s).

Send to: National Institutes of Health Clinical Center
Laboratory of Pathology
Building 10, Room 2B50
10 CENTER DRIVE MSC 1500 BETHESDA,
MD 20892-1500

AUTHORIZATION

I hereby authorize the release of the above-requested medical information.

(Signature) **b6** (Printed Name of Patient) **b6** (Date Signed) **b6**
(Street Address) **b6** (City) **b6** (State) **b6** (Zip Code) **b6**

Patient Identification

Request for Medical Information From Source Outside The
National Institutes of Health
NIH-1208 (8-17)
P.A. 09-25-0099

REQUEST FOR MEDICAL INFORMATION FROM SOURCE OUTSIDE THE NATIONAL INSTITUTES OF HEALTH

INSTRUCTIONS: Complete this form in its entirety and forward directly to the requesting facility.

CC. PATIENT IDENTIFICATION

(Patient Name) **b6** (Patient Number) **b6** (Date of Birth) **b6**

SOURCE OF INFORMATION REQUESTED

b6 (Phone Number) **b6** (Fax Number) **b6** (City) **b6** (State) **b6** (zip code)

INFORMATION REQUESTED

The purpose or need for disclosure: Review of clinical care and consideration for research study

NIH Requestor/Point of Contact: Amanda Wiebold **b6**

Identify the specific items and related dates pertaining to the information to be released.

1. Medical Reports: **b6** date(s)

Send to: National Institutes of Health Clinical Center
National Institute of Neurological Disorders and Stroke
Building 10, Room 7C103
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BETHESDA, MD 20892-1430
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OR
Fax to: (301) 480-5594
Attn: Amanda Wiebold or
Dr. Bryan Smith

2. MRI scans on CD from **b6** date(s)

Send to: National Institutes of Health Clinical Center
National Institute of Neurological Disorders and Stroke
Building 10, Room 7C103
10 CENTER DRIVE MSC 1430
BETHESDA, MD 20892-1430
ATTENTION: Amanda Wiebold/ Dr. Bryan Smith

3. Tissue/Pathology Slides from **b6** date(s)

Send to: National Institutes of Health Clinical Center
Laboratory of Pathology
Building 10, Room 2B50
10 CENTER DRIVE MSC 1500 BETHESDA,
MD 20892-1500

AUTHORIZATION

I hereby authorize the release of the above-requested medical information.

b6 **b6** **b6**
(Printed Name of Patient) (Date Signed)
b6 **b6**
(Street Address) (City) (State) (zip Code)

Patient Identification

Request for Medical Information From Source Outside The
National Institutes of Health
NIH-1208 (8-17)
P.A. 09-25-0099

REL0000230494.0001

Adult Research Participant: I have read the explanation about this study and have been given the opportunity to discuss it and to ask questions. I consent to participate in this study.

b6

b6

b6

Print Name of Research Participant

Date

Legally Authorized Representative (LAR) for an Adult Unable to Consent: I have read the explanation about this study and have been given the opportunity to discuss it and to ask questions. I am legally authorized to make research decisions on behalf of the adult participant unable to consent and have the authority to provide consent to this study. As applicable, the information in the above consent was described to the adult participant unable to consent who agrees to participate in the study.

Signature of LAR

Print Name of LAR

Date

Parent/Guardian of a Minor Participant: I have read the explanation about this study and have been given the opportunity to discuss it and to ask questions. I give permission for my child to take part in this study.

Signature of Parent/Guardian

Print Name of Parent/Guardian

Date

Signature of Parent/Guardian (as applicable)

Print Name of Parent/Guardian

Date

Assent: (Use this section only when this process is approved by an IRB for older minors. Do not use if an IRB requires a separate assent form for this population.)

I have had this study explained to me in a way that I understand, I have been given the opportunity to discuss it, and I have had the chance to ask questions. I agree to take part in this study.

Assent of Minor: (as applicable)

Signature of Minor

Print Name of Minor

Date

Investigator:

Signature of Investigator

Print Name of Investigator

Date

Witness to the oral short-form consent process only: This section is only required if you are doing the oral short-consent process and this English consent form has been approved by the IRB for use as the basis of translation.

PATIENT IDENTIFICATION

Consent to Participate in a Clinical Research Study

NIH-2977 (4-17)

File in Section 4: Protocol Consent (2)

Version Date: 3/17/2020

Page 8 of 9



IRB NUMBER: 15N0125

IRB APPROVAL DATE: 04/09/2020

From: [b6]
Sent: 9/23/2021 8:36:15 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: Reconnecting
Flag: Flag for follow up

Dear Dr Farinaz,

I am just reconnecting, as it is now 3 months since I last emailed you. I hope your research at NIH is continuing to go well. I would like to ask if there is any more information or preliminary theories based on the research of these neurological reactions to the vaccine. The mechanism of the reactions? Any explanations or blood markers showing who is predisposed to having these severe reactions that could inform future doses?

I am now [b6] since my first dose of Pfizer and still symptomatic.

Pain in feet and legs, muscle twitches in calves, bulging veins in feet, ankles, hands and arms, facial numbness, tinnitus behind left ear and bad nausea. So difficult to live with particularly as I was very healthy with no medical conditions and no medications before.

I, also, have the constant dilemma re 2nd dose (never mind the booster). Has any further information emerged regarding the safety of having further doses for people who have had this reaction or if they are predisposed to having more severe COVID? Would you recommend having the monoclonal antibody treatment for me should I get COVID? Once again I thank you for your continued help and understanding.

Hope all is going well.

Kind regards,

[b6]

Sent from my iPad

On 20 Jun 2021, at 12:17, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

Thank you for the update. As I mentioned in our last communication, we do not have enough evidence to predict your reaction to 2nd dose of vaccine. I believe it is in your discretion to decide to take it or not. As I previously mentioned, we believe these neurological adverse events are immune mediated process and in a subgroup of patients immunotherapeutics may help. Hope it helps

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

From: [b6]
Sent: Friday, June 18, 2021 7:47 AM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Reconnecting

REL0000230518

Dear Dr Farinaz,

I had a telehealth consultation with you way back on 16 March.

Unfortunately I was unable to take part in your study as I am based in Uk.

It is now [b6] and I still have flare ups with severe pain in legs and feet plus nausea. I have not taken the 2nd shot of the vaccine and obviously I'm really concerned about catching COVID particularly as the Delta variant is highly contagious and is the prevalent one in UK.

I was wondering whether you have any reports from your research or any preliminary findings that you could share.

Or indeed any information regarding 2nd dose for people who have had these symptoms after the first dose.

Many thanks.

Hope your research is going well.

Kind regards,

[b6]

Sent from my iPhone

From: [b6]
Sent: 10/12/2021 2:01:39 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: influenza vaccine

Sounds good, thank you for your input!

[b6]

On Mon, Oct 11, 2021 at 10:50 PM Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

Unfortunately we do not have any data regarding the effect of flu vaccine on patients who developed adverse events of COVID vaccine. Since flu vaccine is completely different type of vaccine, the consensus among our team is to take flu vaccine but we always defer to you to make the final decision.

Sorry I can not be more help.

Best

Farinaz

From: [b6]
Sent: Monday, October 11, 2021 10:45:17 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: influenza vaccine

Dear Dr.Safavi,

I hoping that you could share with me your thoughts about the safety of the influenza vaccine for me this year. I usually have no issues with getting it, but I'm worried about it this year. It seems that my immune system is on fire and I worry what my immune system will do in response to the flu vaccine; I would hate for my symptoms to worsen from it or transition into something like GBS. I did ask my local physicians about it but they deferred to your judgement. [b6]

[b6]

Best Regards,

[b6]

b6

From: [b6]
Sent: 12/13/2021 1:48:22 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: [EXTERNAL] Survey results
Attachments: WHO scale post-COVID November.docx

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,

Attached are the updated survey results. I'm sorry for the delay in getting this to you and I will make sure to keep updating it weekly. [b6]

[b6]

Thanks!

[b6]

Date	b6
Over the past 7 days, how much difficulty have you had with the following:	
Standing for long periods such as 30 minutes?	
Taking care of your household responsibilities?	
Learning a new task, e.g. learning how to get to a new place?	
Joining in community activities (e.g. festivities, religious, other)?	
Being emotionally affected by your health problems?	
Concentrating on doing something for ten minutes?	
Walking a long distance such as a kilometre (or equivalent)?	
Washing your whole body?	
Getting dressed?	
Dealing with people you do not know?	
Maintaining a friendship?	
Your day-to-day work/school?	
Total Score	

Score:

- 0 No Difficulty
- 1 Mild Difficulty
- 2 Moderate Difficulty
- 3 Severe Difficulty
- 4 Extreme Difficulty or Cannot do

From: [b6]
Sent: 12/27/2021 5:20:50 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: [EXTERNAL] updated WHO survey
Attachments: WHO scale post-COVID December.docx

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,

I hope you are having a good holiday! Attached are my updated scale scores.

[b6]

b6

Best Regards,

[b6]

Date	<div style="font-size: 100px; text-align: center;">b6</div>
Over the past 7 days, how much difficulty have you had with the following:	
Standing for long periods such as 30 minutes?	
Taking care of your household responsibilities?	
Learning a new task, e.g. learning how to get to a new place?	
Joining in community activities (e.g. festivities, religious, other)?	
Being emotionally affected by your health problems?	
Concentrating on doing something for ten minutes?	
Walking a long distance such as a kilometre (or equivalent)?	
Washing your whole body?	
Getting dressed?	
Dealing with people you do not know?	
Maintaining a friendship?	
Your day-to-day work/school?	
Total Score	

Score:

- 0 No Difficulty
- 1 Mild Difficulty
- 2 Moderate Difficulty
- 3 Severe Difficulty
- 4 Extreme Difficulty or Cannot do

From: [b6]
Sent: 2/19/2022 4:56:39 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
CC: [b6]
Subject: [EXTERNAL] Vaccine injury follow up

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.

Good Evening, Dr. Safavi,

I'm just following up on the email I previously sent below. My daughter and I deeply need to know what research findings you have on situations similar to ours and any genetic connection. I did hear back from NINDS and I was told the broader vaccine injury study won't be started for another two to three more months.

It's important to understand what has happened to so many of us as a result of the COVID-19 vaccinations. My daughter and I were both previously healthy [b6] We know what caused our current problems, we just need to understand why and if we will fully heal.

I look forward to your reply and trust it will give us some hope for our futures,

[b6]

PS I will send some links in a separate email that I have found pertinent to our personal situation. Please check your junk box in case they don't show up!

From: [b6]
Sent: Wednesday, January 26, 2022 3:31 PM
To: 'Safavi, Farinaz (NIH/NINDS) [E]' [b6]
Cc: [b6]
Subject: FW: Mother/daughter adverse mRNA vaccine effects

Hello Dr. Safavi,

I'm including our email chain below to help in the context of this note. Again, I appreciate your contact for the NINDS study, and my daughter ([b6]) and I have been on the list for the online study since September 2021. I did also just reach out to that department to see where things stand with the study as we have heard nothing to this point.

Since our last correspondence, my daughter has been diagnosed with [b6]
[b6] I continue with nerve issues, as well, and has been almost [b6]
[b6] for both of us.

That said, we need to understand why this has happened to us so that we know what to avoid in the future, how to get appropriate medical care, and to possibly help others in our same situation. Could you please let us know what data you have as to a genetic connection for these reactions and any other data you have compiled from your studies over the last year? And, I'm guessing you may have vaccine injury protocols by now, too. Whatever you could provide us would be greatly appreciated as we are still struggling with these life altering health conditions.

Also, we would welcome the NIH studying our family in specific. We are unique in that we have [b6]
[b6] that your institution could study and that would benefit our entire country in regards to the continued vaccine roll out. [b6] I also have a younger daughter [b6]

[b6] I feel our national health centers and medical professionals understanding our experience would save many others from this life altering situation we find ourselves in and would reduce the increased strain on the medical system as a result of these types of side effects.

Thank you so much for your consideration and I look forward to your expertise. And do take good care there.

Sincerely,

[b6]

From: [b6]
Sent: Thursday, September 16, 2021 9:12 AM
To: 'Safavi, Farinaz (NIH/NINDS) [E]'; [b6]
Subject: RE: Mother/daughter adverse mRNA vaccine effects

Dear Dr. Safavi,

Thank you so much. I will reach out to your contact now to see what studies my daughter and I can participate in. We need to know what has happened to our bodies, why, and our long term prognosis. I'm so very hopeful the NINDS studies will provide answers and help for us and everyone else suffering.

I appreciate your kind wishes and my best to you, as well.

[b6]

From: Safavi, Farinaz (NIH/NINDS) [E]; [b6]
Sent: Wednesday, September 15, 2021 7:41 PM
To: [b6]
Subject: Re: Mother/daughter adverse mRNA vaccine effects

Dear [b6]

I am really sorry to hear about your illness. Unfortunately we do not have any active protocol for post vaccine complications.

All recruitment for NINDS studies related to COVID 19 are now being handled through nindspostcovid19@ninds.nih.gov. Please go directly to our email address to inquire about eligibility. For individuals interested in studies of recovery after COVID 19 vaccination, a waiting list is currently being generated to collect information from potential participants.

Wish you both rapid recovery.

Best Regards,

Farinaz

From: [b6]
Sent: Wednesday, September 15, 2021, 4:45 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: [b6] adverse mRNA vaccine effects

Dear Dr. Safavi,

I was given your name from [b6] She mentioned you are doing studies on people with adverse reactions to the COVID-19 vaccines. I want to thank you so much for delving in to this area. My daughter and I have been having problems since [b6] and we are desperately trying to heal and understand what has happened to us. She had both doses of Moderna and I had one dose of Pfizer. My [b6] mother had Moderna, also, but no problems. She'll be getting a booster/third shot [b6]

If you are available and still looking into these issues, I would love to speak with you. My daughter [b6] and I [b6] want to do what we can to help others, understand our own problems, and be a part of the solution as we as a world try to end this pandemic. We did what we thought was right back in the spring and now we need help ourselves. The fact that you are researching gives me hope.

Sincerely,

b6

Farinaz

From: [b6]
Sent: 3/10/2022 2:10:38 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
CC: [b6]
Subject: [EXTERNAL] Pleading with you to please respond

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.

Hello Dr. Safavi,

I've written to you a couple of times this past few weeks and have had no response. I write again tonight to beg for your help. My daughter and I continue to have nervous system/autoimmune issues from our vaccines back in [b6]

[b6] As I have asked in the past, we need to know what has caused this in us and if you have any genetic or other data you could please share with us.

Any information would be greatly appreciated as we certainly need to know what to avoid in the future and even what our future holds for us. The pandemic seems is mostly over for the world now, but for those of us injured by doing what we thought was right, unfortunately, the pandemic continues.

Respectfully,

[b6]

From: [b6]
Sent: 3/3/2022 8:57:26 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: [EXTERNAL] Re: [b6] Treatment Plan

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.

One more thing I wanted to ask - I would like to [b6]

b6

Thank you!

On Thu, Mar 3, 2022 at 2:04 PM [b6] wrote:
Hello Dr. Safavi,

I hope you are having a good week. I wanted to provide you with a few updates. The first is regarding [b6] unfortunately, I don't think the treatment has done much to improve my state. I have been having many negative side effects (headaches, much worse tinnitus, fatigue) and do not see many improvements. As I have told you, my symptoms get worse after ovulation and during my period. I am now 5 days post ovulation in my cycle and the feeling of sickness, low grade fever, malaise, fatigue, chills and other flu-like symptoms are once again intensifying. I am keeping up with the WHO worksheet you sent me but at this point I am not seeing improvements (in fact, tinnitus has gotten much worse and is a bigger issue for me now... please let me know if you come across research about what can help that).

I have read about a few cases where antihistamines have helped individuals with Long Covid and Long Covid like syndrome post vaccine. [b6]

b6

I saw [b6] on Monday per your recommendation. She has reviewed all my lab work before and after the vaccine, including all tests done by the NIH. Her opinion is that [b6]

b6

I am also seeing the following doctors in March:

March 17: rheumatologist

March 18: functional medicine [b6]

March 24: allergist/immunologist [b6]

April 1: appointment with you!

I would love to hear your thoughts on [b6]

b6

Please also let me know if I should ask the above doctors for any additional testing or questions you would bring up. Would you also have an update on [REDACTED]

b6

[REDACTED]
b6

Thank you as always. I am thankful to be working with a top doctor to solve this unfortunate mystery and hope any progress I make can also make a difference for others.

All the best,

[REDACTED]
b6

From: [b6]
Sent: 4/1/2022 9:45:03 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: [EXTERNAL] FW: Pleading with you to please respond

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.

Dear Dr. Safavi,

I now understand through your silence that you are not willing to help any of us who have been injured by the COVID-19 vaccines. It is very disheartening and I'm not including my [b6] daughter on this chain as it would be too much for her. She was told by a rheumatologist on [b6]

[b6]

We trusted the government, the drug companies, our doctors, and the country's health experts as we did the right thing by getting vaccinated. Some of us have been severely hurt and we're just trying to get help and understanding as to our situation. The silence and denial in the media around all of this is causing more injury to us, as well.

All of that said, I'm not giving up on finding answers and I will never give up hope that [b6] will heal someday and be able to have the family she and her husband planned to start after their vaccinations. I am going to keep trusting that someday you will reach out to all of us, too, and help us understand and acknowledge what so many of us are going through as a result of trying to end the pandemic.

Until then, I wish you the best as life moves on post pandemic.

Sincerely,

[b6]

From: [b6]
Sent: Wednesday, March 9, 2022 7:11 PM
To: 'Safavi, Farinaz (NIH/NINDS) [E]' [b6]
Cc: [b6]
Subject: Pleading with you to please respond

Hello Dr. Safavi,

I've written to you a couple of times this past few weeks and have had no response. I write again tonight to beg for your help. My daughter and I continue to have nervous system/autoimmune issues from our vaccines back in [b6] [b6] As I have asked in the past, we need to know what has caused this in us and if you have any genetic or other data you could please share with us.

Any information would be greatly appreciated as we certainly need to know what to avoid in the future and even what our future holds for us. The pandemic seems is mostly over for the world now, but for those of us injured by doing what we thought was right, unfortunately, the pandemic continues.

Respectfully,

REL0000230610

b6

From: [b6]
Sent: 2/19/2022 5:26:19 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: [EXTERNAL] Pertinent vaccine injury links

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.

Hello Again, Dr. Safavi,

After my many months of research, here are a few links I felt applied to my and my daughter's health problems:

<https://pubmed.ncbi.nlm.nih.gov/34957554/>

<https://www.nature.com/articles/s41467-017-00622-4>

<https://onlinelibrary.wiley.com/doi/10.1002/mus.27251>

<https://www.ncbi.nlm.nih.gov/labs/pmc/articles/PMC7046028/>

Guessing you are aware, but thought I'd share.

Thank you,

[b6]

From: [b6]
Sent: 8/21/2022 7:36:30 PM
To: Safavi, Farinaz (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
CC: [b6]
Subject: [EXTERNAL] Neuropsychiatric symptoms following COVID 19 vaccine

Dear Dr. Safavi,

Hello. We are reaching out because we recently read an article in Science that described work you and the NIH had been doing to study post-vaccine adverse effects. We are very interested in this topic because we have [b6] daughter who experienced an adverse reaction after her COVID vaccine. Our journey through diagnosis and treatment has been difficult, as we're sure you can imagine. In our search for answers, we have come across your research and find that there are some potentially relevant correlations. So we are sharing this information in the event that it may be useful to your continued work and/or in the event that you might be able to steer us toward doctors who are treating patients with similar issues, or studies for which she may qualify.

After her first dose, our daughter developed pain in her jaw to the point where she didn't want to open her mouth, but it faded over the course of about a week, so we didn't think too much about it, or connect it to the vaccine. Five days after her second dose, however, she had a sudden and dramatic onset of symptoms including a migraine, severe pain in her knees, criss-cross walking that devolved to an inability to walk, and tremors in her hands, head, and legs. Over the course of the next several months, these original symptoms have mostly subsided, however, she developed additional symptoms including severe panic attacks, OCD intrusive thoughts, isolated incidents of rage, abnormal vision (she can't see people in color), lengthy episodes of non-responsive, vacant staring, and recurring speech regression that waxes and wanes. She also had a period of a couple of months where she couldn't remember how to read or write, and at its worst, she could not remember or recognize people she knows very well, including friends, her teacher, and even my husband and I for a short period.

We originally received a diagnosis of [b6] but that did not seem to accurately reflect the full nature of her symptoms, nor did it explain the sudden onset. We sought additional consultation with a range of specialists which has led to a diagnosis of [b6]
b6

Research we have found on [b6] suggests that it occurs when a causative agent is able to pass through the blood brain barrier, causing inflammation to occur in the brain. After reading your research and that of a few others, we suspect that in my daughter's case, it was the spike protein generated from the vaccine that was able to cross the blood brain barrier and is causing her problems. However, we've had a really hard time finding anyone that can help her.

We have had her in both [b6] [b6] However, no one is quite sure what else to do to treat her. We have had a hard time finding anyone interested in exploring a possible connection to the vaccine, so we are expanding our outreach across the scientific community in the hopes that [b6] story may help advance our collective understanding, and ultimate outcome.

I want to make clear that we are not anti-vax people. [b6]
[b6] and we were so thankful for it. It took us so long to come to

the conclusion that this wasn't just a temporal association because we believed in the science (and we still do), and we didn't want to jump to the conclusion that this was from the vaccine right away. We know that what is happening to **b6** has got to be extremely rare, so our hope here is also that our efforts may be of benefit to others in the future.

For your reference, we've included links below to the relevant studies (including yours) that we have used to piece together our current hypothesis.

Thank you for allowing us to share our daughter's story with you, and thank you in advance for any insight or support you might be able to provide.

Sincerely,

b6

b6

LINKS TO RELEVANT STUDIES AND NEWS ARTICLES:

<https://www.science.org/content/article/rare-cases-coronavirus-vaccines-may-cause-long-covid-symptoms>

<https://www.mdpi.com/1999-4915/13/10/2021>

<https://link.springer.com/article/10.1007/s12035-021-02696-0>

<https://www.cambridge.org/core/journals/acta-neuropsychiatrica/article/inflammatory-neuropsychiatric-disorders-and-covid19-neuroinflammation/DE79FA11E7111CDFC6478C9DD3925926>

[https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642\(21\)00135-8/fulltext](https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642(21)00135-8/fulltext)

<https://newsroom.uw.edu/news/research-strongly-suggests-covid-19-virus-enters-brain>

<https://www.mdpi.com/2076-393X/10/1/1>

<https://www.nejm.org/doi/full/10.1056/NEJMcibr2113694>

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.

From: Nahar, Kymani (NIH/NINDS) [C] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=4F432F899337490EA7CBDE0A4B52EFFB; b6]
Sent: 3/25/2022 3:58:15 PM
To: b6; Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246; b6]
Subject: Re: [EXTERNAL] Re: Please Respond: NIH Visit 4/1/22

Hi b6

Dr. Safavi has been away to help family so she may have to get back to you next week regarding your questions. Thanks so much!

Best,

Kymani N. Howard (C)
Patient Care Coordinator III
Clinical Monitoring Research Program Directorate (CMRPD)
Frederick National Laboratory for Cancer Research
Leidos Biomedical Research, Inc.
Support to: National Institutes of Neurological Disorders and Stroke (NINDS)
9000 Rockville Pike
NIH, Building 10, Room 7C103
Bethesda, Maryland 20892
Office: b6
Mobile: b6
Fax: 301.402.1137
b6

From: b6
Date: Friday, March 25, 2022 at 8:46 AM
To: b6; "Safavi, Farinaz (NIH/NINDS) [E]" b6
Subject: [EXTERNAL] Re: Please Respond: NIH Visit 4/1/22

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 Kymani and Dr. Safavi,

I am confirming the appointment. Dr. Safavi b6
b6

In addition, I was wondering if it would be possible for me to receive the letter of medical exemption from additional COVID-19 immunizations due to this reaction? Is there anything you need from me to generate it?

Thank you as always,
b6

On Thu, Mar 24, 2022 at 2:02 PM Nahar, Kymani (NIH/NINDS) [C] b6 wrote:

Good Morning: b6

This is a friendly reminder about your appointments scheduled **Friday 4/1/22 starting at 8:00am**. I have attached your NIH Visit Schedule above if you need a refresher. Please let me know if you'll need a cab this time!

Please respond to this email to confirm your appointment. Thanks, and we look forward to seeing you next week!

Best,

Kymani N. Howard (C)

Patient Care Coordinator III

Clinical Monitoring Research Program Directorate (CMRPD)

Frederick National Laboratory for Cancer Research

Leidos Biomedical Research, Inc.

Support to: National Institutes of Neurological Disorders and Stroke (NINDS)

9000 Rockville Pike

NIH, Building 10, Room 7C103

Bethesda, Maryland 20892

Office: b6

Mobile: b6

Fax: 301.402.1137

b6

From: [b6]
Sent: 3/29/2022 6:59:06 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
CC: Nahar, Kymani (NIH/NINDS) [C] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4f432f899337490ea7cbde0a4b52effb [b6] Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: [EXTERNAL] Re: Please Respond: NIH Visit 4/1/22

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.

Thank you, Kymani.

If there is nothing else you can do for my recovery - what is the purpose of my visit? [b6]

[b6]

Is anyone else at the NIH looking into these systemic side effects of the vaccine? I would think a team of specialists across the areas affected would be applicable in our cases. In the past month, I saw a neurologist, a rheumatologist and an allergist and each one was surprised that the NIH is recommending we be treated by our community of doctors. Each one said they don't know what is causing our symptoms as they have no prior data to rely upon. We need researchers to take on our cases. When we received the vaccines, the CDC assured us that any adverse reactions are taken seriously. Yet no doctor has been able to help, I received no contact from the government regarding my VAERS submission and the CDC hasn't looked into my situation.

I am very thankful for you, Dr. Nath and Dr. Safavi, for looking at my case and ensuring nothing serious is going on neurologically but I am still suffering on a daily basis. Please let me know if the NIH takes on additional work in this space - that is our only hope in this very unlucky situation.

Thank you,

[b6]

On Mon, Mar 28, 2022 at 3:05 AM Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

[b6]

[b6]

As we discussed at the time of consent your participation in research is voluntary and if you are not interested in anymore please kindly let us know.

I also cc Dr.Nath to kindly add any further comment if needed.

Best

Farinaz

From: [b6]

Sent: Friday, March 25, 2022 5:16:05 PM

To: Nahar, Kymani (NIH/NINDS) [C] [b6] Safavi, Farinaz (NIH/NINDS) [E] [b6]

Subject: [EXTERNAL] Re: Please Respond: NIH Visit 4/1/22

REL0000230620

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 Kymani and Dr. Safavi,

I am confirming the appointment. Dr. Safavi -

b6

b6

In addition, I was wondering if it would be possible for me to receive the letter of medical exemption from additional COVID-19 immunizations due to this reaction? Is there anything you need from me to generate it?

Thank you as always,

b6

On Thu, Mar 24, 2022 at 2:02 PM Nahar, Kymani (NIH/NINDS) [C] wrote:

b6

Good Morning b6

This is a friendly reminder about your appointments scheduled **Friday 4/1/22 starting at 8:00am.** I have attached your NIH Visit Schedule above if you need a refresher. Please let me know if you'll need a cab this time!

Please respond to this email to confirm your appointment. Thanks, and we look forward to seeing you next week!

Best,

Kymani N. Howard (C)

Patient Care Coordinator III

Clinical Monitoring Research Program Directorate (CMRPD)

Frederick National Laboratory for Cancer Research

Leidos Biomedical Research, Inc.

Support to: National Institutes of Neurological Disorders and Stroke (NINDS)

9000 Rockville Pike

NIH, Building 10, Room 7C103

REL0000230620

Bethesda, Maryland 20892

Office: b6

Mobile: b6

Fax: 301.402.1137

b6

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246: [b6]
Sent: 5/5/2021 12:21:44 AM
To: [b6]
CC: [b6] Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540: [b6]
Subject: Re: Post vaccine [b6]

Dear [b6]

Thank you for your email. Amanda informed me that she spoke with [b6]. As soon as we have some contact information we will proceed to coordinate [b6].
Thanks again for helping the process and participating in this research.
Best

Farinaz

From: [b6]
Sent: Tuesday, May 4, 2021 4:41:51 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Cc: [b6] Wiebold, Amanda (NIH/NINDS) [E] [b6]
Subject: Re: Post vaccine [b6]

Good afternoon,

Thanks again for reaching out. I spoke to [b6] and he said he was able to connect with Amanda today and sent her the correct consent form.
[b6] has the contact information for his inpatient neurologist at [b6] hopefully she can send that over when she sees this email

Regards,

[b6]

On Mon, May 3, 2021 at 8:30 PM Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

Sorry for delay response. I had to check a few things with the team here. Our research nurse trying to get sample only consent from [b6] (this is different from medical release form). Last time I spoke to her she said she called him but could not speak with him.

When we have a consent we can receive the samples but in order to do so someone needs to coordinate with the hospital. Can you connect me with a neurologist or someone at his hospital to be able to help sending the samples after consent?

Hope he is doing better.

Please let me know and thank you for participating in our study.

Best

Farinaz

From: [b6]
Sent: Monday, April 26, 2021 7:43:52 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Cc: [b6] Wiebold, Amanda (NIH/NINDS) [E] [b6]
Subject: Re: Post vaccine [b6]

REL0000230635

Good morning Farinaz ,

Hope you're well.

The hospital does have [b6] but neither myself or [b6] are there locally. We were hoping that with the consents on file that the coordinators could arrange shipping with the lab directly?

Regards,

[b6]

On Friday, April 23, 2021, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

Hope all is well and [b6] has been improving.

I would like to follow up with you regarding [b6]

[b6] Is it possible that you send us [b6]

We can provide you with shipment instruction if [b6] is available.

Please kindly let me know.

Best

Farinaz

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: [b6]

Sent: Sunday, April 11, 2021 10:53 AM

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

Cc: [b6]

Subject: Re: Post vaccine [b6]

Good morning

REL0000230635

b6 is improving. He received [b6] He went from needing 2 persist assist with a walker to ambulate, to now being able to walk with a walker mostly on his own. He's improving with hand fine motor skills. So far [b6]

We received the consent forms and should be able to get it to [b6] today to sign.

Thank you

[b6]

On Saturday, April 10, 2021, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hello all,

Hope all is well.

Can you please uodate me with [b6] condition?

Have you received the forms, seems Amanda sent it to you.

Best

Farinaz

From: [b6]

Sent: Monday, April 5, 2021 7:09:13 PM

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

Cc: Wiebold, Amanda (NIH/NINDS) [E] [b6]

[b6]
Subject: Re: Post vaccine [b6]

Good evening Farinaz,

Thank you for this. I have also CC'd [b6] who will be at his hospital tomorrow.

We will certainly be in touch,

Regards

[b6]

On Monday, April 5, 2021, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

It was really nice speaking with you and thank you for sharing the information about [b6] illness.

I cc our research nurse Amanda in this email to coordinate and send you medical release form and consent for sending us samples.

It would be great you communicate with the hospital to keep [b6]

Please let us know if you have any questions or concerns and we would be more than happy to help.

Best Regards

Farinaz

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246: [b6]
Sent: 5/29/2021 3:39:22 AM
To: [b6]
Subject: Re: [b6] Consent

Hi [b6]
It can be [b6] that's why she referred you to Rhum. [b6] can be due dysautonomia as well which is part of the syndrome you have been experiencing. No worries! get the work up and treatment will help you.
Best

Farinaz

From: [b6]
Sent: Saturday, May 29, 2021 1:44:31 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Re: [b6] Consent

Hi Dr Safavi,

My vascular issue is starting to concern me.. I'm becoming very sensitive. For example [b6]
[b6]
[b6] I'm also having issues with my veins looking swollen/ purple with just light house work. I'm waiting to get into rheumatology, [b6] thought that it was [b6] do you have any idea what this might be or what I should be looking to get tested for?

Thank you

[b6]

Sent from my iPhone

On May 25, 2021, at 12:03 PM, Safavi, Farinaz (NIH/NINDS) [E] [b6]
wrote:

My fault. You already sent both
Thanks

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

From: [b6]
Sent: Tuesday, May 25, 2021 2:59 PM

REL0000230652

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

Subject: Re: [b6] Consent

I'm not sure which form you are referring to, those were the only 2 forms Amanda sent me.

Sent from my iPhone

On May 25, 2021, at 7:50 AM, Safavi, Farinaz (NIH/NINDS) [E]

[b6]
wrote:

Thanks Staci,

Can you please sign and send us your medical release form as well?

Amanda will send you a kit and instruction to draw blood and send it to us.

Thanks again.

Please keep me updated about treatment plan with [b6]

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: [b6]

Sent: Tuesday, May 25, 2021 12:12 AM

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

Subject: [b6] Consent

Attached are my consent forms.

[b6]

Sent from Outlook

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246: b6
Sent: 5/1/2021 12:30:56 PM
To: b6
Subject: Re: b6

yes to your both questions

Farinaz

From: b6
Sent: Saturday, May 1, 2021 3:14:04 AM
To: Safavi, Farinaz (NIH/NINDS) [E] b6
Subject: Re: b6

Hi Farinaz,

Thank you for providing me with this rea helpful information.

Did your patient have the Pfizer for 1st and 2nd dose? We're the doses delivered 3 weeks apart?

Many thanks.

All the best,

b6

Sent from my iPhone

On 30 Apr 2021, at 23:34, Safavi, Farinaz (NIH/NINDS) [E] b6 wrote:

Hi b6

I am really sorry that you still experience symotoms.

b6

I highly suggest you discuss it with your physician.

Regarding 2nd dose of vaccibe,I saw one patient similar to you just with sensory symptoms and she received 2nd dose when her symptoms stayed the same.I am sharing this info since it may help you to make a decision for 2nd dose.

Hope you feel better soon.

Best

Farinaz

From: b6
Sent: Friday, April 30, 2021 10:11:36 AM
To: Safavi, Farinaz (NIH/NINDS) [E] b6
Subject: b6

Hi Dr Farinaz,

I fully understand that I am unable to contribute to your research. I sincerely hope that it goes well and I greatly appreciate all the advice and help you have given me.

REL0000230663

Since I am unable to be involved, I would really appreciate if you could provide me with a list of blood tests that the research team will be doing as I would like to have some of the ones that can be analysed in UK done.

You mentioned earlier that I should see a neurologist. At the end of February, I was examined by a neurologist from the National Hospital for Neurology in London and had a video consultation with another at my local hospital, both of whom said [b6]

[b6] I was a healthy active [b6]

[b6] If you know of a neurologist here in the UK and one that would be helpful, please let me know as I don't know if they will only come up with the same diagnosis.

Thank you for asking how are my symptoms.

My symptoms progressed from mild to more severe and still persist now, [b6] since my 1st dose of Pfizer.

Briefly, my symptoms progressed from intermittent formication in legs 3 hours after vaccine, [b6]

[b6] then 2 weeks later, burning in legs, arms, shoulders, chest, neck and face. Numbness on left side of face (from day 5) Nausea from day 11 and recurring every few days but milder than initially. This has now stopped for a few weeks. Now, my main symptoms are intense pain in legs at times and fasciculation in calves with significantly Milder pain in arms. Numbness in feet at toes and tips of fingers varying from day to day and is affected by cold. Tinnitus which only started a few weeks ago. Walking helps the pain in the limbs. Also keeping the legs warm as going from a warm area to colder the pain increases. Massaging the painful area helps the pain. I am hoping this will get better and is not permanent and believe it may just take time as you said. I haven't had [b6]

[b6]

Have you any further insight what is going on post vaccine for people like me?

At the moment I am [b6] post 1st vaccine and am so uncertain about having the 2nd dose as I don't know if it will worsen my symptoms and cause damage. Yet on the other hand not having the vaccine leaves me at danger of the virus. At the moment the only options in UK are Pfizer or AZ and would welcome any information or opinion. In the future we will have Novavax and Jensen.

Dr Farinaz I thank you for taking an interest and listening to my vaccine story and helping me. I can send you a copy of the consultant neurologist report if that maybe helpful.

All the best wishes,

[b6]

Sent from my iPad

Begin forwarded message:

From: "Safavi, Farinaz (NIH/NINDS) [E]" [b6]

Date: 27 April 2021 at 14:25:32 BST

To: [b6]

Subject: RE: [b6]

Hi [b6]

How are you doing?How is your symptoms?

I discussed with our team and it seems that receiving sample from oversease is not that suitable at this time.

I am sure what we do here in a long run will help all patients.

Thanks again for your enthusiasm and willingness to participate in our research

Best

Farinaz

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

From: [REDACTED] b6
Sent: Tuesday, April 27, 2021 1:42 AM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: [REDACTED] b6

Hello Dr Farinaz,

I contacted Amanda regarding [REDACTED] b6 to send to you but she said I should get in touch with you.

I was wondering when I and my GP [REDACTED] b6 would get the instructions regarding [REDACTED] b6 to send to you for your research.

Thanking you in advance.

Kind regards,

[REDACTED] b6

Sent from my iPhone

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246] b6
Sent: 4/12/2021 5:25:21 PM
To: b6
CC: Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540] b6
Subject: Re: Referred by b6 neurological issues post vaccine

Sure,
but generally we get your approval through this form in order to able contact your physician and receive your medical records.
It is all about your permission.
Thank you

Farinaz

From: b6
Sent: Monday, April 12, 2021 1:21:53 PM
To: Safavi, Farinaz (NIH/NINDS) [E] b6
Cc: Wiebold, Amanda (NIH/NINDS) [E] b6
Subject: Re: Referred by b6 neurological issues post vaccine

Hi Dr. Safavi,

I had sent an email just to confirm that I didn't need to run this by my doctor first as the medical release form asked for his information.

Thanks,

b6

On Mon, Apr 12, 2021 at 9:23 AM Safavi, Farinaz (NIH/NINDS) [E] b6 wrote:

Hi b6

Can you please send us medical release form and schedule a time for consent then we can send you a kit for blood draw?

I really appreciate to help us complete our paperwork in your file

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: [b6]
Sent: Friday, March 26, 2021 3:35 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
Cc: Wiebold, Amanda (NIH/NINDS) [E]
Subject: Re: Referred by [b6] neurological issues post vaccine

It was so nice talking to you as well! You really made me feel a lot better about the idea that this won't be a permanent issue. I can't thank you enough.

[b6]

[b6]

I live in [b6]

Hopefully this helps a bit and happy to send blood and anything else you may need! I am so grateful that you're doing this work!

On Fri, Mar 26, 2021 at 12:27 PM Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

It was nice talking to you today. I cc Amanda (our research nurse) to send you medical release form and sample only consent.

I have two quick questions

Do you think have you had COVID infection in last year at all?

Do you have any family history of autoimmune/inflammatory diseases?

BTW where do you live in US?

Thank you. Hope you feel better soon

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: [REDACTED] b6

Sent: Wednesday, March 24, 2021 6:29 PM

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

Subject: Re: Referred by [REDACTED] b6 neurological issues post vaccine

Thank you so much Dr. Safavi. 2pm ET works great for me on Friday. Just let me know what I need to do.
Thank you!!

Sent from my iPhone

> On Mar 24, 2021, at 3:03 PM, Safavi, Farinaz (NIH/NINDS) [E] [REDACTED] b6 wrote:
>

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246: [b6]
Sent: 3/26/2021 7:40:21 PM
To: [b6]
CC: Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540: [b6]
Subject: RE: Referred by [b6] neurological issues post vaccine

Thank you for the information. Feel free to contact me if you have any questions/concerns.
Farinaz

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

From: [b6]
Sent: Friday, March 26, 2021 3:35 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
Cc: Wiebold, Amanda (NIH/NINDS) [E]
Subject: Re: Referred by [b6] neurological issues post vaccine

It was so nice talking to you as well! You really made me feel a lot better about the idea that this won't be a permanent issue. I can't thank you enough.

[b6]

[b6]

I live in [b6]

Hopefully this helps a bit and happy to send blood and anything else you may need! I am so grateful that you're doing this work!

On Fri, Mar 26, 2021 at 12:27 PM Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

It was nice talking to you today. I cc Amanda (our research nurse) to send you medical release form and sample only consent.

I have two quick questions

Do you think have you had COVID infection in last year at all?

Do you have any family history of autoimmune/inflammatory diseases?

REL0000230725

BTW where do you live in US?

Thank you. Hope you feel better soon

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: [REDACTED] b6
Sent: Wednesday, March 24, 2021 6:29 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Re: Referred by [REDACTED] b6 neurological issues post vaccine

Thank you so much Dr. Safavi. 2pm ET works great for me on Friday. Just let me know what I need to do. Thank you!!

Sent from my iPhone

> On Mar 24, 2021, at 3:03 PM, Safavi, Farinaz (NIH/NINDS) [E] [REDACTED] b6 wrote:
>

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246; [b6]
Sent: 4/12/2021 6:26:59 PM
To: [b6]
CC:
Subject: RE: Post vaccine [b6]

Dear [b6]

I am so glad that he is on the path of recovery.

I had a meeting with our research nurse, Amanda, and she has not received any paperwork from. I cc her email again and appreciate if you kindly coordinate with her.

Thank you

Farinaz

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

From: [b6]
Sent: Sunday, April 11, 2021 10:53 AM
To: Safavi, Farinaz (NIH/NINDS) [E]
Cc: [b6]
Subject: Re: Post vaccine [b6]

Good morning

Dad is improving. He received [b6] He went from needing 2 persist assist with a walker to ambulate, to now being able to walk with a walker mostly on his own. He's improving with hand fine motor skills. So far [b6]

We received the consent forms and should be able to get it to [b6] today to sign.

Thank you

[b6]

On Saturday, April 10, 2021, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hello all,
Hope all is well.
Can you please uodate me with your dad condition?
Have you received the forms, seems Amanda sent it to you.
Best

Farinaz

From: [b6]
Sent: Monday, April 5, 2021 7:09:13 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]

Cc: Wiebold, Amanda (NIH/NINDS) [E]

b6

Subject: Re: Post vaccine b6

Good evening Farinaz,

Thank you for this. I have also CCd my sister who will be at his hospital tomorrow.

We will certainly be in touch,

Regards

b6

On Monday, April 5, 2021, Safavi, Farinaz (NIH/NINDS) [E] b6 wrote:

Dear b6

It was really nice speaking with you and thank you for sharing the information about your father's illness.

I cc our research nurse Amanda in this email to coordinate and send you medical release form and consent for sending us samples.

It would be great you communicate with the hospital to keep b6

Please let us know if you have any questions or concerns and we would be more than happy to help.

Best Regards

Farinaz

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246: b6
Sent: 3/21/2021 6:58:10 PM
To: b6
Subject: Re: Tremor evaluation

Dear b6

Thank you very much for your email. I completely understand your frustration and I am sorry you feel that way. I discussed your case with Dr. Nath again and we do believe your symptoms. We will review your records/imagings and discuss it with other colleagues on what might be the best course of further investigation and management for you.

Please do not hesitate to contact me if you have any questions or concerns and I will be in touch.

Best Regards,

Farinaz

From: b6
Sent: Sunday, March 21, 2021, 11:21 AM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Re: Tremor evaluation

Dear Dr. Safavi,

I'm glad I got to meet both you and Dr. Nath. You both have been helpful and we appreciate you guys seeing cases like me- that is why I came to not only get some guidance but also get some kind of research started to help others who are like me. This has been a nightmare for a lot of us, and challenging for healthcare providers.

b6 I know that everyone has a right to state their opinion but I did not like the route Dr. Hallet took with my case. Yes, I am frustrated but I am not one to give up, hence why I came to NIH. I came from an initial neurologist who said that I was the only one having this reaction and it's not been reported. She felt it unnecessary to report my side effect in vaers and b6

b6

b6 I know he feels that I'm not doing enough but it was quite the contrary that I had to be told to limit my activity even more twice. My muscles literally get non-functional from easy overuse and can become rigid/tight fast. I have learned my limits the hard way so that is why I know how far I can push myself. Imagine that I had gotten to the point that I had difficulty breathing, had slight dysphagia, could not stand for long, my skeletal structure could not support my muscles, neck is so tight it cannot support the weight of head- I cannot go to the ER or urgent care for this because I can still breathe, and I'm not choking. Yes, I know my physical exam does not match my symptoms which is why I was seeking help. Dr. Hallet knows this and decided to b6

b6 I felt like he had already formed an opinion and tried to make his history taking and physical exam match his theory, selective hearing and selective exam. b6

b6 I was perfectly aware of what he was doing, not only was he not listening- what was he trying to prove when putting something in my hand to hold, when my complaint was I have difficult time picking objects up. Those are two different actions- initiating plus sustain vs just sustaining. That did not even demonstrate my grip at all nor did he pay attention that it's harder for me to do against gravity or that after holding onto a potato long enough to shred all of it caused me unable to close my hand in a fist. I also heard

outside the conversation he was having about me being quiet and how anxiety and chronic fatigue syndrome are linked. I am not an anxious person and the frustration I'm having cannot be fixed with a pill. Human Resources not calling you back or helping you cannot be fixed with a pill, medical providers who think you're having a psychiatric condition or you are faking symptoms cannot be fixed with a pill but rather listening and nonjudgmental attitude when things don't fit textbook. I am aware I am not textbook and this is all new, but that should not stop one from investigating and writing it off. I was looking for someone to help me think outside the box. In healthcare, physiological reactions that are not explained are sometimes attributed to psychiatric issues, but we need to remember there are things that are still new and we are still discovering. **b6**

b6

With that being said, I really do want to help you in any way I can with your research and to help those who come behind me. I have been reading stories about these neurological side effects from vaccine and am in touch with people all over the world having reactions. That is how I found **b6** **b6** while I was trying to figure this out. Moderna, Pfizer, Astra Zeneca, Sputnik- they are all different types of vaccines but yet all have in common the spike protein. I have started to compile which vaccine they took with their symptoms in easy and quick to read medical format. **b6**

I appreciate that you all will be discussing my case in the neuroimmunology group- you and Dr. Nath have been helpful. I am going to **b6** **b6** If you think doing the tremor evaluation will be beneficial to your research please let me know.

Sincerely,

b6

On Fri, Mar 19, 2021, 3:50 PM Safavi, Farinaz (NIH/NINDS) [E] **b6** wrote:

Hi Tejal,

It was nice seeing you today. I gave your information to Dr. Hallett team and they will contact you for further studies. We also will discuss your case in neuroimmunology group and will let you know about the next step. Please let me know if you have any questions or concerns.

Farinaz

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246-[b6]
Sent: 3/24/2021 10:03:30 PM
To: [b6]
Subject: Re: Referred by [b6] neurological issues post vaccine

Dear [b6]

I am really sorry to hear about your illness. I would be happy to have a televisit with you and discuss your issues.

Does Friday 2pm ET work for you?

please let me know

Farinaz

From: [b6]
Sent: Wednesday, March 24, 2021 3:37:34 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Referred by [b6] neurological issues post vaccine

Hi Dr. Safavi!

My name is [b6] referred me to you in regards to neurological issues I am having since receiving the first dose of the Pfizer vaccine.

I am in desperate need of some help and relief.

Since receiving the vaccine, I have been having extreme paraesthesia and head pressure. The paraesthesia is concentrated mostly to my left head, face, and behind my left eyeball. The skin beneath my eye alternates between burning, tingling, and stretching like a piece of silly puddy. It feels like there are ants attacking half my face. It is unrelenting and accompanies me from the time I wake up to the second I go to bed. It now spreading into my left hand and causing my pains in my forearm.

My neurologist tried to diagnose it as [b6]
[b6]

I would do anything to get some relief and the right treatment... And some hope that this is not a permanent condition. You can reach me at this email or call me anytime at [b6]

Thank you so much in advance!

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246; [b6]
Sent: 3/24/2021 9:29:12 PM
To: [b6] Fletcher, Anita (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=43cbc70e2e87447ea55c8b55335a4df0; [b6]
Subject: Re: Moderna first dose reaction

Dear [b6]

Thank you very much for detailed information. We would be happy to help. I cc my colleague Dr. Anita Fletcher who is one of our team members in this project to schedule a televisit with you.

Please do not hesitate to contact us if you have any questions or concerns.

Best Regards,

Farinaz

From: [b6]
Sent: Wednesday, March 24, 2021 7:51:55 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Re: Moderna first dose reaction

Hello Dr Safavi,

I had the first dose Moderna on [b6] 4 minutes after injection I had what felt like a giant wave hit me from the top of my head to my feet. Dizziness, thirst and not feeling well followed. I was treated in clinic with [b6] Symptoms continued to happen that day such as migraine, partial limb full numbness, all limbs, general unwell feeling, metal taste in mouth. Continued next couple days. [b6] almost passed out multiple times, thirst started, nerve sensations on face started, hives outside and inside started, ER trip that night treated for [b6] Prescribed [b6] ER trip for same reasons treated [b6] I also started drinking a liter of water an hour during daytime somewhere [b6] A few days in I would switch to all electrolyte water alternating with alkaline spring water. This continued to [b6] at this level of water an hour. It was unquenchable thirst. [b6] symptoms continued, had doctors visit for more meds. I became aware that everything felt like it was burning. Every tissue in my body was burning hot and I also felt full body tremors, each cell vibrating and felt like a full bees nest. I was afraid of dying in my sleep starting [b6] had hard time breathing then moved into heart. ER visit that night for chest pain, high bp, high pulse, abdominal pressure. [b6] had migrating hives internal and external that came on like giant waves and you could see them moving. Hard time breathing, abdominal pressure, hives, went to ER again. [b6] more of the same. My body felt like it had the pedal to the metal and everything burning for 8 days straight now. Bp high, [b6] [b6] burning everywhere, hives come and go, no end in sight, I felt like I was going to die and made arrangements for that event. I tried [b6] which put out the fire all over my body, stopped the unquenchable thirst, felt like it saved my life and then I was vomiting for 2 days, not taking much in but not burning to death and systems started to calm. I was then bed bound, tremors, weak, but feeling so much better. I was like this [b6] was able to get out of bed for a few minutes. [b6] mostly resting, eating healthy, taking meds. [b6] was able to get outside and walk down the block for the first time.

[b6] I have tremors, deep shaking, reactive skin, injection arm numbness and nerve tingling, chest pressure occasionally,

Headache, weakness, my heart has returned to normal range bp and pulse has lowered too although not my normal.

I have so much more detail typed up day by day.

Do you offer consultation?

On Tue, Mar 23, 2021 at 4:32 PM Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

I am sorry to hear about your illness.

Can you please provide me with more detailed information with timeline of your issues since you have received the vaccine?

Thank you

Farinaz

From: [b6]

Sent: Sunday, March 21, 2021 10:02:44 PM

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

[b6]

Subject: Moderna first dose reaction

To whom it may concern,

I'm reaching out regarding the first dose moderna vaccine reaction I've experienced. My injection was [b6] and I've had multiple health issues as a result including near anaphylactic shock, heart pain, bp pressure and pulse changes, hives, tremors, inquenchable thirst and more.

I understand you may be studying these reactions and/or helping with caring for the reactions.

Any feedback welcome.

Sincerely,

[b6]

[b6]

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246 [b6]
Sent: 8/4/2021 7:54:53 PM
To: [b6]
Subject: RE: [b6] Consent
Attachments: WHO scale post-COVID.docx

Hi [b6]

Please find the scale as attached. If you can give us an estimate score when your symptoms at peak and one for now that would be great.

I also would like to see all your records including [b6]

[b6]

Thank you!

Farinaz

From: [b6]
Sent: Friday, May 28, 2021 5:14 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Re: [b6] Consent

Hi Dr Safavi,

My vascular issue is starting to concern me.. I'm becoming very sensitive. For example [b6]

[b6]

I'm also having issues with my veins looking swollen/ purple with just light house work. I'm waiting to get into rheumatology [b6] thought that it was [b6] do you have any idea what this might be or what I should be looking to get tested for?

Thank you

[b6]

Sent from my iPhone

On May 25, 2021, at 12:03 PM, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

My fault. You already sent both
Thanks

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

From: [b6]
Sent: Tuesday, May 25, 2021 2:59 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Re: [b6] Consent

I'm not sure which form you are referring to, those were the only 2 forms Amanda sent me.

Sent from my iPhone

On May 25, 2021, at 7:50 AM, Safavi, Farinaz (NIH/NINDS) [E] [b6]
wrote:

Thanks [b6]
Can you please sign and send us your medical release form as well?
Amanda will send you a kit and instruction to draw blood and send it to us.
Thanks again.
Please keep me updated about treatment plan with [b6]

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

From: [b6]
Sent: Tuesday, May 25, 2021 12:12 AM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: [b6] Consent

Attached are my consent forms.

[b6]

Sent from Outlook

Date							
Over the past 7 days, how much difficulty have you had with the following:							
Standing for long periods such as 30 minutes?							
Taking care of your household responsibilities?							
Learning a new task, e.g. learning how to get to a new place?							
Joining in community activities (e.g. festivities, religious, other)?							
Being emotionally affected by your health problems?							
Concentrating on doing something for ten minutes?							
Walking a long distance such as a kilometre (or equivalent)?							
Washing your whole body?							
Getting dressed?							
Dealing with people you do not know?							
Maintaining a friendship?							
Your day-to-day work/school?							
Total Score							

Score:

- 0 No Difficulty
- 1 Mild Difficulty
- 2 Moderate Difficulty
- 3 Severe Difficulty
- 4 Extreme Difficulty or Cannot do

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246: [b6]
Sent: 8/18/2021 3:08:09 PM
To: [b6]
Subject: RE: @@@@ INJURED BY J&J @@@@

Thank you for contacting our team inquiring about research studies after COVID vaccination. All recruitment for NINDS studies related to COVID 19 are now being handled through nindspostcovid19@ninds.nih.gov . Please go directly to our email address to inquire about eligibility. For individuals interested in studies of recovery after COVID 19 vaccination, a waiting list is currently being generated pending study approval.

Thank you for your interest in our study.

Best Regards,

Farinaz Safavi MD, PhD

NINDS, NIH

From: [b6]
Sent: Monday, August 16, 2021 5:17 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: @@@@ INJURED BY J&J @@@@

Hello Dr,

I was given your name by an injured post vaccine group. My name is [b6] from [b6] will be as brief as I can.

[b6] I had the J&J vaccine. I felt a little off immediately but thought it was anxiety. 5 to 7 days later other flu symptoms started, I was so weak.

[b6] stayed in bed most of the day with chills, severe leg pain, kidney area aches and over all felt horrible. But at 7pm, I willed myself to get up and get out for a bit. I felt horrible as my husband and I drove to get ice cream.

At an intersection, I woke up from passing out, he took me to a near by Fire Station who then called an ambulance. They initially could not find my pulse or pressure, it was weak. When they finally did find it, it was [b6] my pulse was [b6]. I was able to speak but confused.

[b6] While in ER, I could hardly feel my legs then arms.. I kept saying I'm going to pass out and I feel like I have icy hot on me with a weighted blanket.. They did no tests as to why my legs were numb. They just said I was sick and my body didn't like it. My face was on fire with red flushing my husband was constantly putting cool washcloths and ice on me.

My heart and pressure remained high for some time. It raced everytime I had the syncope feeling and rush of adrenaline from head to toe. They started me on [b6]

REL0000230838

The news broke about J&J being halted for clots the next morning while in the hospital. The day of dismissal I had severe stomach cramps and diarrhea, the Dr put [b6] on my patient dismissal forms. That's bothered me more than my symptoms.

Since that day here are a list of symptoms that seem to morph as time goes on and wax and wain..

1. Severe weakness
2. Headaches daily
3. Double vision for months
4. Heart SVT's, PAC's, PVC's, Bradycardia
5. Electric shocks throughout my body
6. Aches, pains, throbbing in mainly legs and arms, feet and hands
7. Severe restless leg syndrome
8. Consistent new lower leg painful neuropathy, itching, burning, tingles
9. Toes turn purple
10. Chest pains
11. Severe stomach pain, bloating and horrible gas
12. Left side facial numbness
13. Vibrations or whole body tremors
14. Mild hand tremors
15. Unbalanced when walking. I have fallen
16. Severe Diarrhea
17. Insomnia for first month
18. Two different rashes on legs and mainly face (Lupus Malar looking)
19. Flushing of face and neck
20. Phantom sharp pains
21. Brain Fog so bad I'm scared
22. I keep myself awake at night for fear of dying with this passing out feeling. I tell myself to breathe.

[b6] If this can help you please let me know.

Please help [b6]

Sent from Yahoo Mail on Android

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246; [b6]
Sent: 11/6/2021 7:35:08 PM
To: [b6]
Subject: RE: Question

Hi [b6]

Sorry for delay respond. I wanted to discuss your symptoms with our team first.

Can you please update me with timing of events including COVID exposure [b6] symptoms, ...?

Had you been [b6]

Did you check [b6]

Thank you

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

From: [b6]
Sent: Tuesday, November 2, 2021 3:49 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Re: Question

Hello, Farinaz!! I hope you are well.

I wanted to check-in with you and give you a update. [b6]

[b6]
[b6] The symptoms did slowly reduce over the course of several weeks. I appealed my insurance for [b6] A doctor I follow on Twitter suggested plasmapheresis to someone else having a neurological reaction. My own doctor is unsure because know one seems to know how to treat this type of reaction. Have you seen or theorize any benefit to this treatment of plasmapheresis? I am inching toward [b6] and slowly losing hope that I will heal.

Thank you so much,

[b6]

On Oct 2, 2021, at 3:11 PM, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

No problem [b6]

I highly recommend you discuss this with her physycians.

Regarding your symptoms [b6] may consider [b6]
[b6]

I also would like to ask you is it possible you send us [b6]

please let me know if you have any question.
Thank you

Farinaz

From: [REDACTED] b6
Sent: Friday, October 1, 2021 4:27:03 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [REDACTED] b6
Subject: Re: Question

Thank you for your quick reply!! Especially, because I know how busy you are. Your words do help. I have [REDACTED] b6

[REDACTED] b6
[REDACTED] b6 I trust you so thank you for your input.
[REDACTED] b6

Sent from my iPhone

On Oct 1, 2021, at 1:17 PM, Safavi, Farinaz (NIH/NINDS) [E] [REDACTED] b6 wrote:

Hi [REDACTED] b6

I believe I mentioned that we do not know the data for [REDACTED] b6

[REDACTED] b6

[REDACTED] b6 This is completely anecdotal observation and still there is no available data (which hopefully will be available from FDA in the future) about this topic.
Hope it helps

Farinaz

From: [REDACTED] b6
Sent: Friday, October 1, 2021 4:07:53 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [REDACTED] b6
Subject: Question

Hello. I hope you are doing well. I'm still waiting for [REDACTED] b6

[REDACTED] b6
I did get [REDACTED] b6

When you and I first met via Zoom way back in February, you had suggested [REDACTED] b6

[REDACTED] b6
[REDACTED] b6 Do you still hold that opinion after all your months of intentional study and research?

Blessings to you,
[REDACTED] b6

Sent from my iPhone

REL0000230877

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246; **b6**
Sent: 12/20/2021 12:15:52 AM
To: **b6**
Subject: RE: [EXTERNAL] Survey results

Hi **b6**

Thanks for survey and sorry for delay respond.

b6

Please let me know if you have any questions

Best Regards

Farinaz

From: **b6**
Sent: Sunday, December 12, 2021 8:48:22 PM
To: Safavi, Farinaz (NIH/NINDS) [E] **b6**
Subject: [EXTERNAL] Survey results

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,

Attached are the updated survey results. I'm sorry for the delay in getting this to you and I will make sure to keep updating it weekly. **b6**

b6

Thanks!

b6

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246: b6
Sent: 2/12/2022 4:51:21 PM
To: b6
Subject: RE: [EXTERNAL] b6 update - 2/12/2022
Attachments: WHO scale post-COVID.docx

Thank you b6 for update.

b6

Please find the scale as an attached file.

Please first score it based on your symptoms before b6 then start from next Monday weekly.

Thank you

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

From: b6
Sent: Saturday, February 12, 2022 10:05 AM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: [EXTERNAL] b6 update - 2/12/2022

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.

Good morning Dr. Safavi,

As promised, here is an update on my condition. Yesterday, my headache came back but was bearable so I did not take

b6 In addition to the headache, my dizziness was significantly worse.

This morning, I still have a mild headache (3 on the 10 scale) and the bad dizziness persists. The tinnitus has also gotten noticeably worse. I am also quite fatigued and something seems to have upset my stomach as I'm having a bit of diarrhea. I am resting and hoping that these are side effects of the medication that will go away with time, as you mentioned. I very much hope to see some relief of my post-vaccine symptoms in the coming weeks.

Thank you for checking in on me throughout the treatment and answering my questions. Let me know if I should do anything this weekend or next week.

I hope you have a nice weekend,

b6

Date							
Over the past 7 days, how much difficulty have you had with the following:							
Standing for long periods such as 30 minutes?							
Taking care of your household responsibilities?							
Learning a new task, e.g. learning how to get to a new place?							
Joining in community activities (e.g. festivities, religious, other)?							
Being emotionally affected by your health problems?							
Concentrating on doing something for ten minutes?							
Walking a long distance such as a kilometre (or equivalent)?							
Washing your whole body?							
Getting dressed?							
Dealing with people you do not know?							
Maintaining a friendship?							
Your day-to-day work/school?							
Total Score							

Score:

0 No Difficulty

1 Mild Difficulty

2 Moderate Difficulty

3 Severe Difficulty

4 Extreme Difficulty or Cannot do

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246; b6
Sent: 5/13/2021 2:20:37 PM
To: b6
CC: Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540; b6
Subject: Re: Post vaccine b6

Hi b6
I would like to follow up with you regarding b6. I have not received any information about your father neurologist who may help sending us b6.
Please kindly advise.
Thank you

Farinaz

From: b6
Sent: Tuesday, May 4, 2021 4:41:51 PM
To: Safavi, Farinaz (NIH/NINDS) [E] b6
Cc: b6; Wiebold, Amanda (NIH/NINDS) [E] b6
Subject: Re: Post vaccine b6

Good afternoon,

Thanks again for reaching out. I spoke to my dad and he said he was able to connect with Amanda today and sent her the correct consent form.
b6 has the contact information for his inpatient neurologist at b6. hopefully she can send that over when she sees this email

Regards,

b6

On Mon, May 3, 2021 at 8:30 PM Safavi, Farinaz (NIH/NINDS) [E] b6 wrote:

Hi b6

Sorry for delay response. I had to check a few things with the team here. Our research nurse trying to get sample only consent from your dad (this is different from medical release form). Last time I spoke to her she said she called him but could not speak with him.

When we have a consent we can receive the samples but in order to do so someone needs to coordinate with the hospital. Can you connect me with a neurologist or someone at his hospital to be able to help sending the samples after consent?

Hope he is doing better.

Please let me know and thank you for participating in our study.

Best

Farinaz

From: b6
Sent: Monday, April 26, 2021 7:43:52 AM
To: Safavi, Farinaz (NIH/NINDS) [E] b6
Cc: b6; Wiebold, Amanda (NIH/NINDS) [E] b6
Subject: Re: Post vaccine b6

Good morning Farinaz ,

Hope you're well.

The hospital does have [b6] but neither myself or my sister are there locally. We were hoping that with the consents on file that the coordinators could arrange shipping with the lab directly?

Regards,

[b6]

On Friday, April 23, 2021, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

Hope all is well and your Dad has been improving.

I would like to follow up with you regarding [b6]

[b6] Is it possible that you send us [b6]

We can provide you with shipment instruction if [b6] is available.

Please kindly let me know.

Best

Farinaz

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: [b6]

Sent: Sunday, April 11, 2021 10:53 AM

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

Cc: [b6]

Subject: Re: Post vaccine [b6]

Good morning

Dad is improving. He received [b6] He went from needing 2 persist assist with a walker to ambulate, to now being able to walk with a walker mostly on his own. He's improving with hand fine motor skills. So far [b6]

We received the consent forms and should be able to get it to my dad today to sign.

Thank you

[b6]

On Saturday, April 10, 2021, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hello all,

Hope all is well.

Can you please uodate me with your dad condition?

Have you received the forms,seems Amanda sent it to you.

Best

Farinaz

From: [b6]

Sent: Monday, April 5, 2021 7:09:13 PM

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

Cc: Wiebold, Amanda (NIH/NINDS) [E] [b6]

[b6]

Subject: Re: Post vaccine [b6]

Good evening Farinaz,

Thank you for this. I have also CCd my sister who will be at his hospital tomorrow.

We will certainly be in touch,

Regards

b6

On Monday, April 5, 2021, Safavi, Farinaz (NIH/NINDS) [E] b6 wrote:

Dear b6

It was really nice speaking with you and thank you for sharing the information about your father illness.

I cc our research nurse Amanda in this email to coordinate and send you medical release form and consent for sending us samples.

It would be great you communicate with the hospital to keep b6

Please let us know if you have any questions or concerns and we would be more than happy to help.

Best Regards

Farinaz

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246: [b6]
Sent: 9/16/2021 1:26:31 AM
To: [b6]
Subject: Re: [b6] adverse mRNA vaccine effects

From: [b6]
Sent: Wednesday, September 15, 2021 4:45:10 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: [b6] adverse mRNA vaccine effects

Dear Dr. Safavi,

I was given your name from [b6]. She mentioned you are doing studies on people with adverse reactions to the COVID-19 vaccines. I want to thank you so much for delving in to this area. My daughter and I have been having problems since [b6] and we are desperately trying to heal and understand what has happened to us. She had both doses of Moderna and I had one dose of Pfizer. [b6] mother had Moderna, also, but no problems. She'll be getting a booster/third shot [b6].

If you are available and still looking into these issues, I would love to speak with you. My daughter [b6] and I [b6] want to do what we can to help others, understand our own problems, and be a part of the solution as we as a world try to end this pandemic. We did what we thought was right back in [b6] and now we need help ourselves. The fact that you are researching gives me hope.

Sincerely,

[b6]

From: [b6]
Sent: 10/6/2022 9:17:50 PM
To: Safavi, Farinaz (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: [EXTERNAL] Re: exemption letter

Okay, thank you!

From: Safavi, Farinaz (NIH/NIAID) [E] [b6]
Sent: Thursday, October 6, 2022 3:49:08 PM
To: [b6]
Subject: RE: exemption letter

[b6]
Hope you feel better soon

From: [b6]
Sent: Thursday, October 6, 2022 3:05 PM
To: Safavi, Farinaz (NIH/NIAID) [E] [b6]
Subject: [EXTERNAL] Re: exemption letter

Dear Dr. Safavi,
Hope everyone is doing well,

I have a question:

b6

please advise
Thank you.

b6

From: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Sent: Thursday, January 6, 2022 6:08 PM
To: [b6] Wiebold, Amanda (NIH/NINDS) [E] [b6]
Subject: exemption letter

Hi [b6]

We can give you a letter. Can you please confirm the date you received your vaccine and it was Pfizer first dose correct?
Thank you

Farinaz Safavi MD, PhD

REL0000230946

Division of Neuroimmunology and Neurovirology
NINDS, NIH, Bethesda, MD

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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.

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6] b6
Sent: 9/8/2021 6:00:04 PM
To: b6 Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246] b6
Subject: Re: Question

Yes, we can give you a letter.

Farinaz,

Can you draft one for me to sign?

Thanks.

Avi

From: b6
Date: Wednesday, September 8, 2021 at 1:49 PM
To: Safavi, Farinaz (NIH/NINDS) [E] b6 Nath, Avindra (NIH/NINDS) [E] b6
Subject: Question

Drs. Nath and Safavi,

As you are aware, much of the world is requiring or soon will require proof of vaccination for many things.

As we have discussed, it is not a good idea for me to get any of the available vaccines and therefore, I remain "not fully vaccinated".

Many places will allow for medical exemption, would it be possible to get a letter from either of you stating that I am unable to become fully vaccinated?

Thank you,

b6

From: Hallett, Mark (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=98CB5E4227D14425AB89953B32F7ECB0: [b6]
Sent: 5/13/2021 1:50:24 PM
To: [b6] Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246: [b6]
Subject: RE: Help Covid Vaccine

Dear [b6]

Please send me the medical records. I will review them and then we can likely arrange for you to come to NIH.

Best wishes,

Mark Hallett

=====
Mark Hallett, M.D., D.M.(hon)
Chief, Human Motor Control Section, NINDS
Distinguished NIH Investigator
NIH, Building 10, Room 7D37
10 Center Dr MSC 1428
Bethesda, MD 20892-1428
Tel: [b6]
Fax: 301-480-2286
email: [b6]
<https://research.ninds.nih.gov/researchers/faculty/mark-hallett-md>
=====

From: [b6]
Sent: Wednesday, May 12, 2021 11:24 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Cc: Hallett, Mark (NIH/NINDS) [E] [b6]
Subject: Re: Help Covid Vaccine

Ok.. I am ready to do or go anywhere. Just let me know.

Thank you,

[b6]

Sent from my iPhone

On May 12, 2021, at 8:49 PM, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

I spoke with Dr. Hallett, our movement disorder expert, and showed him your original video. He kindly agreed to evaluate your condition. I cc him in this email. Hopefully his expertise helps you to recover from this illness.

Best Regards,

Farinaz

From: [b6]
Sent: Wednesday, May 12, 2021 1:08:34 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Re: Help Covid Vaccine

Hi,

I am reaching out again because I am still having convulsions and cannot find any help within my state. I think you and Julie discussed my case and she advised to send a follow up email.

I have all my medical records and can send them in a PDF. I need help. It's been [b6] and no change.

[b6] or by email

Thanks,

[b6]

Sent from my iPhone

On Mar 30, 2021, at 1:58 PM, Safavi, Farinaz (NIH/NINDS) [E] [b6]
wrote:

Dear [b6]

I am sorry to hear about your symptoms. Where are you located?

If you live close to Maryland, our movement disorder team would be happy to see you in outpatient setting.

Please let me know.

Farinaz

From: [b6]
Sent: Tuesday, March 30, 2021 2:45:07 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Fwd: Help Covid Vaccine

Sent from my iPhone

Begin forwarded message:

From: [b6]
Date: March 30, 2021 at 1:43:50 PM CDT
To: [b6]
Subject: Help Covid Vaccine

Amanda,

[b6] gave me your email and asked I reach out to you. I have been having severe reactions since [b6] from the Pfizer vaccine. Headaches, muscle weakness, muscle tremors, full body convulsions, a rash that lasted for 15 days, blurred vision, memory loss

and brain fog. I am a [b6] and took the vaccine on
[b6] I have been to numerous doctors. [b6]
[b6] I am begging for help. Please reach out to me on my
cell [b6]
Thanks,
[b6]

Sent from my iPhone

From: [b6]
Sent: 12/11/2021 5:31:18 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6] Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: [b6]
Attachments: [b6]

b6

Life is finally coming back...I can see my life returning to normal function. No more relapses, no more tremors. My pots is now under control, my neuropathy is less, the dreaded internal vibrations are way down.

Another friend of mine ended her life, same scenario as my first friend [b6] Vax just electrified her and she couldn't do it any longer. Couldn't get [b6] Couldn't get medical help. Was [b6] [b6] even with her connections she couldn't get help.

My updated [b6] data...

b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6] b6
Sent: 12/16/2021 3:20:37 AM
To: b6 Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246] b6
Subject: Re: b6

Dear b6

Thanks for the update and glad to know that you are doing better.

I have received a few emails from other patients who have developed neurological complaints associated with the vaccines. They claim that you have suggested that they contact me for enrolling on a clinical trial. Sorry, we do not have any clinical trial for such vaccine related complications. It is best for such patients to receive care from their local physicians.

Best wishes.

Avi

From: b6
Date: Saturday, December 11, 2021 at 12:31 AM
To: Nath, Avindra (NIH/NINDS) [E] b6 Safavi, Farinaz (NIH/NINDS) [E]
b6
Subject: b6

b6

Life is finally coming back...I can see my life returning to normal function. No more relapses, no more tremors. My pots is now under control, my neuropathy is less, the dreaded internal vibrations are way down.

Another friend of mine ended her life, same scenario as my first friend b6 Vax just electrified her and she couldn't do it any longer. Couldn't get b6 Couldn't get medical help. Was b6 b6 even with her connections she couldn't get help.

My updated b6 data...

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 b6]
Sent: 9/8/2021 8:56:53 PM
To: b6 Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 b6]
Subject: Re: Question
Attachments: Bri Letter.pdf

See attached. This is for your personal use only. Not to be put on social media, internet or shared with other patients etc etc
Avi

From: b6
Date: Wednesday, September 8, 2021 at 1:49 PM
To: Safavi, Farinaz (NIH/NINDS) [E] b6 Nath, Avindra (NIH/NINDS) [E]
b6
Subject: Question

Drs. Nath and Safavi,

As you are aware, much of the world is requiring or soon will require proof of vaccination for many things.

As we have discussed, it is not a good Idea for me to get any of the available vaccines and therefore, I remain "not fully vaccinated".

Many places will allow for medical exemption, would it be possible to get a letter from either of you stating that I am unable to become fully vaccinated?

Thank you,

b6

b6

From: [b6]
Sent: 3/30/2021 7:07:10 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: Help Covid Vaccine

I live in [b6] We have a private group of about 20 of us on Facebook that all have similar symptoms. Two of them stated they have televisits set up with the NIH for a study and gave me your address and Amanda's address and told us to reach out. I am open to travel. I have all of my medical records since [b6]

Sent from my iPhone

On Mar 30, 2021, at 1:58 PM, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Dear [b6]
I am sorry to hear about your symptoms. Where are you located?
If you live close to Maryland, our movement disorder team would be happy to see you in outpatient setting.
Please let me know.

Farinaz

From: [b6]
Sent: Tuesday, March 30, 2021 2:45:07 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Fwd: Help Covid Vaccine

Sent from my iPhone

Begin forwarded message:

From: [b6]
Date: March 30, 2021 at 1:43:50 PM CDT
To: [b6]
Subject: Help Covid Vaccine

Amanda,
[b6] gave me your email and asked I reach out to you. I have been having severe reactions since [b6] from the Pfizer vaccine. Headaches, muscle weakness, muscle tremors, full body convulsions, a rash that lasted for 15 days, blurred vision, memory loss and brain fog. I am a [b6] and took the vaccine on [b6] I have been to numerous doctors. [b6]
[b6] I am begging for help. Please reach out to me on my cell [b6]

Thanks,

b6

Sent from my iPhone

From: [b6]
Sent: 5/24/2021 6:41:20 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: Vaccine side affects

Thank you for your quick response. I have another appointment with my neurologist [b6] today. I may ask him if he will contact you for guidance.

Sent from my iPhone

On May 24, 2021, at 10:49 AM, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

I am sorry to hear about your illness. Our enrollment is on pause since we can not offer very large scale medical care at NIH. I would be more than happy to speak with your PCP or neurologist to share our understanding about your adverse reaction and guide them through some treatments.

Thank you

Farinaz

From: [b6]
Sent: Monday, May 24, 2021 1:44:56 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Re: Vaccine side affects

Dr. Safavi,

I keep hearing about more people getting to patients of your in our group and don't understand that I have not. When I joined the group there were just 4 of us and it has grown to hundreds. People who seem to have contacted you after me say they are being seen by NIH. Would you please consider me.

Thank you,

[b6]

My name is [b6] I am a [b6] female and I live in [b6] I got my first dose of Moderna on [b6] Within 20 minutes my face was tingling and numb. My neck felt like I was in a car accident. A dull headache set in within the hour. I was told by the Medical Director at the vaccine site that's was an unusual reaction and it should go away in 24-48 hours.

Today, I still have those symptoms. My face is still completely numb. I have pressure on my sinuses which make it hard to breathe. I have aches in my finger joints and sporadic

body pain. I have electrical like shooting pain at times. I have neuropathy in my hands and feet. Also pain in my feet at times makes it unbearable to walk. Some dull lower back pain. I have had brain fog at times and can't think clearly. I am not sure if this from the continual dull pain in the head or neck.

I had two weeks of migraine headaches with blurred vision and light sensitivity. I treated it with Acupuncture and peppermint oil and had success. Now I just get a dull pain that starts at the forehead and spreads to my neck.

I have not had any relief from the continual facial numbing. It feels like the dull numb after having novacane or if you are out side in freezing cold weather too long. I have tried acupuncture, massage and infrared treatments. I have seen an Allergist and Neurologist for this.

My General Practitioner is at odds of what to do to treat me. She knows I have never experienced these symptoms until my vaccination.

b6

I filed a report with VAERS **b6** CDC text weekly for an update. I have never received any response from CDC regarding the VAERS report or the weekly updates I send to them. I also called Moderna within days of the vaccination. They really didn't offer much. They said they can't give medical advice. But she did stress several times that people with severe reactions shouldn't get the second dose and what I experienced was a severe reaction. Two and half months later Moderna has sent a follow up email. I replied and have not heard back from them.

I take **b6** Most of these I was taking before the vaccine for **b6** per my General Practitioner, after the vaccination. I also take **b6**

My previous health issues before the vaccination and currently are **b6**

b6

b6

b6

Moderna Vaccine **b6**

Sent from my iPhone

On Apr 17, 2021, at 5:24 AM, Safavi, Farinaz (NIH/NINDS) [E]

b6 wrote:

Dear: [b6]

Sorry to hear about your illness. Unfortunately we pause enrolling any further patients since our protocol has a limited capacity. I highly suggest you follow up with a neurologist and make sure to get a proper work up.

If we resume enrolling patients, I will inform you.

Best

Farinaz

From: [b6]

Sent: Friday, April 16, 2021 3:49:56 PM

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

Cc: [b6]

Subject: Vaccine

Thank you,

[b6]

Sent from my iPhone

From: [b6]
Sent: 4/17/2021 5:02:10 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: Vaccine side affects
Flag: Flag for follow up

Thank you for your response. I do have a upcoming appointment with a neurologist. I have made notes from others who have seen you on what to mention and ask for. Is there anything you recommend I ask for regards to testing?

Thanks again.

Sent from my iPhone

On Apr 17, 2021, at 5:24 AM, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

Sorry to hear about your illness. Unfortunately we pause enrolling any further patients since our protocol has a limited capacity. I highly suggest you follow up with a neurologist and make sure to get a proper work up.

If we resume enrolling patients, I will inform you.

Best

Farinaz

From: [b6]
Sent: Friday, April 16, 2021 3:49:56 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6] Wiebold, Amanda (NIH/NINDS) [E]
[b6]
Cc: [b6]
Subject: Vaccine side affects

Dr. Safavi,

I have been in the Facebook group with [b6] for a couple of months now. I thought I was getting better. The headaches have subsided and the numbness was less. Today the numbness came back to my arms and chest, along with my entire face. I have had no change in diet, sleep or exercise. I was wondering if I could get an appointment with you.

Here is my story:

My name is [b6] I am a [b6] female and I live in [b6] I got my first dose of Moderna on [b6] Within a half hour my face was tingling and numb. My neck felt like I was in a car accident. A dull headache set in within

the hour. I was told by the Medical Director at the vaccine site that's his was an unusual reaction and it should go away in 24-48 hours.

Today, I still have those symptoms. The tingling in my face stopped, but my face is still completely numb. I have aches in my finger joints and sporadic body pain. I have electrical like shooting pain at times. Some dull lower back pain. I have had brain fog at times and can't think clearly. I am not sure if this from the continual dull pain in the head or neck.

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I have not had any relief from the facial numbing. It feels like the dull numb after having novacane or if you are out side in freezing cold weather too long. I have tried acupuncture, massage and infrared treatments

My General Practitioner is at odds of what to do to treat me. She knows I have never experienced these symptoms until my vaccination.

I filed a report with VAERS [b6] CDC text weekly for an update. I have never received any response from CDC regarding the VAERS report or the weekly updates I send to them. I also called Moderna with days of the vaccination. They really didn't offer much. They said they can't give medical advice. But she did stress several times that people with severe reactions shouldn't get the second dose and what I experienced was a severe reaction.

I take [b6] Most of these I was taking before the vaccine for [b6] per my General Practitioner, after the vaccination.

My previous health issues before the vaccination and currently are [b6]
[b6]

[b6]

[b6]

Thank you,

[b6]

Sent from my iPhone

From: [b6]
Sent: 7/12/2021 5:00:51 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6] Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: [b6]
Flag: Flag for follow up

Hi
As I was reviewing my pictures of rash, I noted the **rash before May 24 was always a Erythema Multiforme** (central blister with erythema around that initially started L.LE with Sacroiliitis symptoms etc and fatigue and migratory stabbing paresthesias/ in [b6]

However the rash after May 22 2021 is "itchy rash" which always occurs as a crop of 2-3 papules. No blisters. Seems that is different etiology of CNS Upper Motor Neuron than the microfibril neuropathy that started as "stabbing paresthesia migratory patches" after the vaccine.

I say this because my rash has been suddenly spreading with itching to my hand, wrist and thigh as small papules since July 9. I went to Animal Park on May 22 feeding animals in the open like deers, camels, goats, zebras, bulls, etc. I suddenly got worsening of burning like on 5/24 on my neck and back and then May 25 Upper Motor Neuron symptoms with the similar papular rash that I have now on my hand and is spreading. **That rash biopsy on L.upper midline back near neck had shown Lymphocytic vasculitis Dermis.** I wonder if I got a tick?? that was suppressed with [b6]

[b6]

It is weird that the type of rash changed! Confusing the picture totally.

[b6]

Rash Before May 22 Animal Park were all Central Blister or Bullae. Not itchy but Ant biting jst until blister/Bullae fully formed.

[b6]

b6

Rash on May 25 2021 and after that (Itchy rash which is different. Same rash spreading May 9 onwards.
It had resolved in June 14 after

b6

b6

On Fri, Jul 9, 2021 at 9:21 AM [b6] wrote:

Hi

Regarding [b6]

b6

I can give permission to get access to [b6] If you send me the form, or I can send a letter authorizing to get them.

To be honest, I am more worried about UMN symptoms (sharp L. Headaches, L. Eye tighter, spastic weakness LUE and LLE with L. neck & Inner ear and Left LS spine pain that came back along with stinging paresthesias after [b6] It improved by half day 70%. My Central and peripheral nervous system are affected.

Sent from my iPhone

b6

On Jul 8, 2021, at 9:40 PM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

I just looked at the results a little more carefully. [b6]

b6

Avi

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

Date: Thursday, July 8, 2021 at 10:22 PM

To: [b6]

Subject: [b6]

[b6]

Avi

From: [b6]

Date: Tuesday, July 6, 2021 at 12:30 PM

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

Subject: [b6]

Hi

I am sending [b6]

I have not received any response for appointment from [b6] last month.

From: [b6]
Sent: 7/6/2021 4:30:03 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [b6]
Attachments: [b6]

Hi

I am sending [b6]

I have not received any response for appointment from [b6] last month.

b6

b6

b6

From: [b6]
Sent: 10/5/2022 1:23:25 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: [EXTERNAL] Re: Odd symptoms post Moderna Bivalent Vaccine

Understood, and thanks again for your time.

[b6]

On Wed, Oct 5, 2022 at 8:43 AM Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

I am glad that you are getting better. Thanks for sharing your experience. Vaccine side effects is not my area of expertise and I do not have any ongoing studies for monitoring them. That is the purview of the manufacturers, CDC and the FDA

Best wishes.

Avi

From: [b6]
Date: Wednesday, October 5, 2022 at 8:25 AM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Re: [EXTERNAL] Re: Odd symptoms post Moderna Bivalent Vaccine

Good morning, Dr. Nath,

I genuinely appreciate your taking the time to reply, and your suggestion is good. In fact, my symptoms continue to resolve, fortunately, and I'm hoping I won't need to pursue that option. The last [b6] since the injections have been pretty stressful, but seem to be *finally* resolving.

I was actually contacting you not really for personal medical advice as such, but more to see if you were aware of similar odd reactions being reported relative to the new Moderna Bivalent Vaccine.

In thinking about this further, it almost seems as if my basic thermoregulation was impacted, resulting in the recurrent fever, as well as the relative cold intolerance, sometimes while feeling warm at the same time. And while my appetite was relatively normal throughout, it was different than usual, in that at the same time I didn't 'feel' like eating. Similarly, there was a significant amount of fatigue, a tendency to fall asleep more readily, sleep longer, etc.

REL0000231501

[b6] these symptoms seem to suggest something odd going on in the Hypothalamus. Does this correspond to anything you've seen clinically, or via research, in connection to the new (or older) Covid Vaccines?

This whole episode also complicates the decision regarding future Covid vaccine injections. With a reaction like I've experienced this time, would it be worse the next time around? I know there's no way for anyone to give a definitive answer now, but hopefully research will shed some light on this.

[b6]

On Tue, Oct 4, 2022 at 11:40 PM Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

I am sorry to hear of your illness. My suggestion would be to see an infectious disease specialist at one of the major medical centers such as [b6] Sorry, I do not know them.

Best.

Avi

From: [b6]

Date: Tuesday, October 4, 2022 at 2:26 PM

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

Subject: [EXTERNAL] Re: Odd symptoms post Moderna Bivalent Vaccine

Hello Dr. Nath,

This is [b6] a [b6] I had emailed you on Oct. 1, providing details on an unusual reaction to the new Moderna Bivalent Covid Vaccine (persistent fever for a week or so). That email is copied below. In case it went to spam, I thought I'd just try again.

REL0000231501

I am still experiencing some odd symptoms at times (cold sensitivity, decreased wakefulness, etc.) even after resolution of the fever. I would be interested in further exploring and understanding what might be underlying these symptoms, which is the reason I contacted you.

Or if you happen to have colleagues with interest and experience in these areas located in the medical centers in [b6] I would be interested in getting in touch with one of them.

I tried calling the numbers listed for you on the NIH website, but only got a Verizon message that those numbers are not in operation.

Thank you.

[b6]

On Sat, Oct 1, 2022 at 1:13 PM [b6] wrote:

Hello Dr. Natha,

My name is [b6] living in [b6] I am a [b6] and I'm researching an odd reaction to receiving the Moderna Bivalent Covid Vaccine, along with the Fluzone shot, on [b6] The first 2 days were slightly better than with the previous shots (original 2, and 2 boosters, the most recent [b6]). But starting on the 3rd day, and continuing for 7 days, I ran a fever every day that was above 101, and as high as 103 on one occasion.

[b6] so I am always concerned when running any type of fever [b6]
[b6] I had no systemic symptoms other than fatigue, chills when the fever was rising, and an exacerbation of the urinary symptoms I have [b6]

The fever finally resolved [b6] after 7 continuous days of fever, but I continue to experience fatigue, decreased cold tolerance, and am more inclined to be sleepy or even fall asleep when at my computer screen or watching TV. I have little energy or motivation to tackle the usual tasks I enjoy in a technical field I have taken on after retiring from

[b6] I resumed, and can still take my usual 2-mile walks starting yesterday, but it is much more of an effort.

I did submit a VAERS report, as well as contacting the CDC for any insight, given the persistence of the fever beyond a few days.

I've read some accounts of 'long Covid' symptoms occurring after Covid vaccines, and your name came up in that connection.

I'm not aware of anyone in the [b6] (where [b6] is present), who might have expertise in this rather rare scenario, so wanted to touch base with you to see if you had any insight, suggestions to help understand what's going on, etc.

Thank you.

[b6]

b6

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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.

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 b6]
Sent: 7/9/2021 2:42:56 PM
To: b6
Subject: b6

b6

b6

b6

Anyway Farinaz will meet with you and try to sort it out.
Avi

From: b6
Date: Friday, July 9, 2021 at 10:21 AM
To: Nath, Avindra (NIH/NINDS) [E] b6
Subject: b6

Hi

b6

I can give permission to get access to b6 If you send me the form, or I can send a letter authorizing to get them.

To be honest, I am more worried about UMN symptoms (sharp L. Headaches, L. Eye tighter, spastic weakness LUE and LLE with L. neck & Inner ear and Left LS spine pain that came back along with stinging paresthesias after dropping Pred to 20mg (3rd day) and had to go back up yesterday in fear of another stroke. It improved by half day 70%. My Central and peripheral nervous system are affected.

Sent from my iPhone

b6

On Jul 8, 2021, at 9:40 PM, Nath, Avindra (NIH/NINDS) [E] b6 wrote:

I just looked at the results a little more carefully.

b6

b6

Avi

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

b6

Date: Thursday, July 8, 2021 at 10:22 PM

To: b6

Subject: b6

b6

Avi

From: b6

Date: Tuesday, July 6, 2021 at 12:30 PM

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

Subject: b6

Hi

I am sending b6

I have not received any response for appointment from b6 last month.

From: [Gavin, Angelique \(NIH/NINDS\) \[C\]](#)
To: (b) (6)
Subject: RE: NIH COVID-19 study
Date: Monday, December 14, 2020 2:27:00 PM

Thank you (b) (6)! I will send this out tomorrow

Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

<https://clinicaltrials.gov - study number 000089>

-

From: (b) (6) <Office365@messaging.microsoft.com>
Sent: Monday, December 14, 2020 2:04 PM
To: Gavin, Angelique (NIH/NINDS) [C] (b) (6)
Cc: (b) (6)
Subject: Re: NIH COVID-19 study

Hi Angelique,

Here's the list of providers I've seen or talked to this year:

(b) (6)

(b) (6)

A large rectangular area of the document is completely redacted with a solid gray fill.

(b) (6)

A large rectangular area of the document is completely redacted with a solid gray fill.

(b) (6)

A large rectangular area of the document is completely redacted with a solid gray fill.

(b) (6)

A large rectangular area of the document is completely redacted with a solid gray fill.

(b) (6)

A large rectangular area of the document is completely redacted with a solid gray fill.

All except (b) (6) were through (b) (6) so the records may be included with my primary doctor, but I listed the others in case.

Would they also want dental records from this year? Here's the information for my dentist:

(b) (6)

A large rectangular area of the document is completely redacted with a solid gray fill.

Thank you,

(b) (6)

From: Gavin, Angelique (NIH/NINDS) [C] (b) (6)

Sent: Friday, December 11, 2020 11:52:36 AM

To: (b) (6)

Subject: RE: NIH COVID-19 study

Thank you (b) (6)! I have attached the medical record request form. Please complete and return to me via secure email. You do not need a witness. If we are sending to more than one medical provider, you can leave the "To" section blank and send me the list of who to send to. I will copy the form and send it out to all.

Sincerely,

Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

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Building 10, Room 3B19, MSC 1251

Bethesda, MD 20814-9692

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

<https://clinicaltrials.gov> - study number 000089

From: (b) (6) <Office365@messaging.microsoft.com>
Sent: Thursday, December 10, 2020 2:02 PM
To: Gavin, Angelique (NIH/NINDS) [C] (b) (6)
Cc: (b) (6)
Subject: Re: NIH COVID-19 study

Hi Angelique,

I have attached a copy of a negative COVID PCR test as well a copy of my records from my pulmonologist. I am having trouble accessing my records from my primary doctor and neurologist as they recently switched systems and after several attempts with the IT department I've decided it may be easier for you to request them. Can you please send me the form?

Thank you,

(b) (6)

PS. My records will be under my full name (b) (6)

From: Gavin, Angelique (NIH/NINDS) [C] (b) (6)
Sent: Monday, December 7, 2020 2:17:47 PM
To: (b) (6)
Subject: NIH COVID-19 study

Hi (b) (6):

Thank you for taking the time to speak with me today. It was such good news to hear that you're feeling better.

To be eligible to proceed to the next phase of the study, our team will need medical

documentation of :

1. a negative COVID PCR test (typically a nasal swab),
2. negative COVID antibody test (typically a blood test), and
3. medical documentation that your medical provider attributes the symptoms you have to COVID 19 infection. This should be a diagnosis in a medical note signed by your provider. Problem lists without medical signatures are not considered adequate medical documentation.

When you obtain these 3 items, you may send them to me either via attaching to this encrypted email, or by faxing them to me at the efax number below. If you decide obtaining the medical records is too cumbersome, then let me know and I will send a medical records release form and we will obtain the results on your behalf.

If you have any additional questions, please let me know. When we receive these forms and validate, then I will set up the next interview with you.

In addition, I have attached our study consent form for you review. Please read it over prior to our second interview and let me know if you have any questions.

Thank you, and have a nice day.

Sincerely,

Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

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10 Center Drive

Building 10, Room 3B19, MSC 1251

Bethesda, MD 20814-9692

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

<https://clinicaltrials.gov> - study number 000089

-

From: (b) (6)
To: [Gavin, Angelique \(NIH/NINDS\) \[C\]](#)
Cc: (b) (6)
Subject: Re: Information Request: Clinical Center Study PI000089-N
Date: Wednesday, November 9, 2022 4:17:49 PM
Attachments: [vcARD.jpg](#)
[VCARD2.jpg](#)

Thank You for your quick response. I have contacted NIH several times and spoken with Dr. Nath.

I am interested in participating in any and all ongoing research at NIH.

(b) (6)

Questions are answered below; marked in **RED**.

From: Gavin, Angelique (NIH/NINDS) [C] (b) (6)
Sent: Wednesday, November 9, 2022 2:24:37 PM
To: (b) (6)
Subject: RE: Information Request: Clinical Center Study PI000089-N

Good Day (b) (6):

Thank you for your interest in the COVID-19 Convalescence study at the National Institutes of Health. I am emailing you because you had previously contacted the NIH about participating in this study. To ensure that your information and communication remains secure, you are receiving this via encrypted email. Please respond using encrypted email.

Our study is looking at the experience of recovery for individuals after a COVID-19 infection or after COVID 19 vaccination. The attached consent form provides more information about our study, which involves a phone interview and online questionnaires.

In order to be considered for the study, please respond to this email with answers to the following questions:

1. What is your full name? (b) (6)
2. What is your preferred phone number? (b) (6)
3. How old are you? (b) (6)
4. Are you fluent in speaking, reading and writing English? **Yes** /No
5. Do you live in the United States? **Yes**/No

a. If yes, please provide the city, state and zip code where you live. (b) (6)

6. Are you an NIH employee, contractor, trainee or otherwise affiliated with the NIH? Yes/**No**

7. Have you had a COVID-19 infection? (b) (6)

a. If yes, how many COVID-19 infections have you had?

b. What is the date of your first COVID-19 infection?

c. Are you having persistent side effects after your first COVID-19 infection? Yes No

d. Do you have test results confirming your COVID 19 infection? Yes No

e. If you responded yes, please provide a copy of your COVID 19 test results with your email response.

For tests performed at a laboratory or by a medical provider, results need to include your name, date of test result, type of test, and result of test. If you do not have a copy of your test result, please let us know and we can assist you in obtaining your records from your medical lab or provider.

For tests performed using a home testing kit, a photograph of the results with time and date are required.

8. Have you received a COVID-19 vaccine? **Yes** No

a. If you responded yes, please provide a copy of your COVID 19 vaccination card with your email response.

b. If yes, do you have persistent side effects after receiving a COVID-19 vaccination?

Yes No

When you respond to this email, please provide answers to each question above, as well as a Copy of your COVID-19 test results and/or the front and back of your COVID-19 vaccination card, if applicable. **Copy of vaccination card front attached. Back has nothing marked. Copy of vaccination confirmation from Health Department attached.**

Your responses and documentation will allow us to determine if you are eligible for our research study. If you do not answer all questions or provide the requested documentation, you will not be considered for the study. If you wish to provide a short summary of your condition, we invite you to.

If you are eligible, then we will email you within 10 business days to schedule a time to obtain verbal consent and perform a study interview. Please let me know if you have any additional questions. I look forward to hearing from you.

Thank you,
Angelique Gavin
COVID 19 Convalescence Study Team

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group
National Institutes of Health
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Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

<https://clinicaltrials.gov - study number 000089-N>

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(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

<https://clinicaltrials.gov - study number 000089-N>

-

From: (b) (6)

Sent: Tuesday, November 8, 2022 4:26 PM

To: Gavin, Angelique (NIH/NINDS) [C] (b) (6)

Subject: Information Request: Clinical Center Study PI000089-N

LastName :

FirstName :

Organization :

Building Mail Stop:

Street Addresss:

City/State/Zip:

Phone:

Fax:

Patient's First Name(if

(b) (6)

different from sender
name):

Patient's Last Name((if
different from sender
name):

Comments :

Is NIH doing any data gathering or clinical research on post-COVID
vaccine adverse responses? I am interesting in participating.

COVID-19 Vaccination Record Card

Please keep this record card, which includes medical information about the vaccines you have received.

Por favor, guarde esta tarjeta de registro, que incluye información médica sobre las vacunas que ha recibido.



(b) (6)

Other		<u> </u> / <u> </u> / <u> </u> mm dd yy	
Other		<u> </u> / <u> </u> / <u> </u> mm dd yy	

(b) (6)



From: (b) (6)
To: [Gavin, Angelique \(NIH/NINDS\) \[C\]](#); [NINDSPostCovid19](#); [Espinoza, Claudia \(NIH/NINDS\) \[C\]](#)
Cc: [Bartrum, Elizabeth \(NIH/NINDS\) \[E\]](#)
Subject: Re: COVID-19 Study at NIH
Date: Monday, August 15, 2022 4:39:15 PM

Thank you, Angelique, and I'll wait to hear from you. I also have some questions about this and other studies regarding vaccine adverse events and look forward to getting clarity when I can ask those questions to your department in person. Till then!

Sincerely,

(b) (6)

From: Gavin, Angelique (NIH/NINDS) [C] (b) (6)
Sent: Monday, August 15, 2022 10:04:25 AM
To: (b) (6) NINDSPostCovid19
<nindspostcovid19@ninds.nih.gov>; Espinoza, Claudia (NIH/NINDS) [C] (b) (6)
Cc: Bartrum, Elizabeth (NIH/NINDS) [E] (b) (6)
Subject: RE: COVID-19 Study at NIH

Thank you Kathy! I am waiting on records from (b) (6). Once received and reviewed, we will get back to you regarding the next steps in the process. Have a great day!

Sincerely,
Angelique

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
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Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692
(b) (6) (office)
(b) (6) (cell)
(301) 480-5368 (efax)

(b) (6)
<https://clinicaltrials.gov - study number 000089-N>

-

From: (b) (6) <Office365@messaging.microsoft.com>

Sent: Friday, August 12, 2022 2:03 PM

To: NINDSPostCovid19 <nindspostcovid19@ninds.nih.gov>; Espinoza, Claudia (NIH/NINDS) [C]

(b) (6)

Cc: Bartrum, Elizabeth (NIH/NINDS) [E] (b) (6)

Subject: Re: COVID-19 Study at NIH

Dear Research Team,

I just wanted to follow up on a few things:

1. Do you need anything else from me at this point?
2. The consent form mentioned this study may lead to participation in other NIH studies, as well. As I have mentioned over the months, my daughter (b) (6) and I are extremely interested in studies looking at the mechanisms behind our vaccine adverse effects. We feel strongly that our cases together may help others and make vaccines safer in the future. Are there any studies being done on that now?

Thank you,

(b) (6)

From: NINDSPostCovid19 <nindspostcovid19@ninds.nih.gov>

Sent: Wednesday, July 27, 2022 11:31:53 AM

To: (b) (6); Espinoza, Claudia (NIH/NINDS) [C]

(b) (6)

Cc: Bartrum, Elizabeth (NIH/NINDS) [E] (b) (6)

Subject: RE: COVID-19 Study at NIH

Thank you (b) (6)! I will forward this to (b) (6) today.

Sincerely,
Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

10 Center Drive

Building 10, Room 3B19, MSC 1251

Bethesda, MD 20814-9692

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

<https://clinicaltrials.gov - study number 000089-N>

-

From: (b) (6) <Office365@messaging.microsoft.com>

Sent: Tuesday, July 26, 2022 11:35 PM

To: Gavin, Angelique (NIH/NINDS) [C] (b) (6) Espinoza, Claudia
(NIH/NINDS) [C] (b) (6)

Subject: Re: COVID-19 Study at NIH

Good Evening Ms. Gavin and Ms. Espinoza,

Attached is the requested HIPPA release form. I had to send it in two separate PDFs. Please let me know if these documents come over ok.

Thank you so much and I look forward to participating in your study.

Sincerely,

(b) (6)

(b) (6)

From: Bartrum, Elizabeth (NIH/NINDS) [E] (b) (6)

Sent: Friday, July 22, 2022 10:37:27 AM

To: (b) (6)

Cc: Gavin, Angelique (NIH/NINDS) [C] (b) (6) Espinoza, Claudia
(NIH/NINDS) [C] (b) (6)

Subject: RE: COVID-19 Study at NIH

Good afternoon (b) (6)

Thank you for your responses. To determine if you are eligible to proceed we need medical records to confirm that the symptom onset was after COVID vaccination.

Please complete the attached medical record release form for a medical provider whom managed your care at the onset of symptoms after vaccination. Return the form to Ms. Gavin and Ms. Espinoza and we will obtain the records on your behalf.

Once we have received the records and reviewed them, if you are eligible to proceed we will schedule the phone interview.

Please let me know if you have any additional questions. I look forward to speaking with you soon.

Sincerely-

Elizabeth A Bartrum, FNP-BC

From: (b) (6) <Office365@messaging.microsoft.com>

Sent: Wednesday, July 20, 2022 1:19 PM

To: Bartrum, Elizabeth (NIH/NINDS) [E] (b) (6)

Subject: Re: COVID-19 Study at NIH

Dear Elizabeth,

Thank you so much for this opportunity to participate in your study. My daughter (b) (6) and I have been suffering with persistent neurological issues since our vaccinations (b) (6) (b) (6). I have been diagnosed with (b) (6) after one dose of Pfizer, and (b) (6). She had both doses of Moderna. Neither of us has had the virus.

I have included a copy of my vaccine card and will answer your questions below. Again, please know how much this means to us and I know your research will mean much to many others, too. I keep hopeful we will get to the bottom of what has happened to those of us hurt so we can avoid these problems in the future. I hope a mother/daughter pair is helpful to you, also. Sincerely, (b) (6)

What is your full name? (b) (6)

What is your preferred phone number? (b) (6)

How old are you? (b) (6)

Are you fluent in speaking, reading and writing English? YES

Do you live in the United States? YES

If yes, please provide the city, state and zip code where you live. (b) (6)

(b) (6)

Are you an NIH employee, contractor, trainee or otherwise affiliated with the NIH? NO

Have you had a COVID-19 infection? (b) (6)

8a. If yes, how many COVID-19 infections have you had? (b) (6)

8b. What is the date of your first COVID-19 infection? (b) (6)

8c. Are you having persistent side effects after your first COVID-19 infection? (b) (6)

8d. Do you have test results confirming your COVID 19 infection? (b) (6)

8e. *If you responded yes, please provide a copy of your COVID 19 test results with your email response.* (b) (6)

For tests performed at a laboratory or by a medical provider, results need to include your name, date of test result, type of test, and result of test. If you do not have a copy of your test result, please let us know and we can assist you in obtaining your records from your medical lab or provider.

For tests performed using a home testing kit, a photograph of the results with time and date are required.

Have you received a COVID-19 vaccine? YES

9a. *If you responded yes, please provide a copy of your COVID 19 vaccination card with your email response.*

9b. If yes, do you have persistent side effects after receiving a COVID-19 vaccination?
YES

From: Bartrum, Elizabeth (NIH/NINDS) [E] (b) (6)
Sent: Wednesday, July 13, 2022 6:27:15 PM
To: (b) (6)
Cc: Bartrum, Elizabeth (NIH/NINDS) [E] (b) (6)
Subject: COVID-19 Study at NIH

Good evening-

Thank you for your patience and your interest in the COVID-19 Convalescence study at the National Institutes of Health. I am emailing you because you had previously contacted the NIH about participating in this study. To ensure that your information and communication remains secure, you are receiving this via encrypted email. Please respond using encrypted email.

Our study is looking at the experience of recovery for individuals after a COVID-19 infection or after COVID-19 vaccination. The attached consent form provides more information about our study, which involves a phone interview and online questionnaires.

In order to be considered for the study, please respond to this email with answers to the following questions:

What is your full name?

What is your preferred phone number?

How old are you?

Are you fluent in speaking, reading and writing English? Yes /No

Do you live in the United States? Yes/No

If yes, please provide the city, state and zip code where you live.

Are you an NIH employee, contractor, trainee or otherwise affiliated with the NIH? Yes/No

Have you had a COVID-19 infection? Yes/No/Unsure

8a. If yes, how many COVID-19 infections have you had?

8b. What is the date of your first COVID-19 infection?

8c. Are you having persistent side effects after your first COVID-19 infection? Yes No

8d. Do you have test results confirming your COVID 19 infection? Yes No

8e. If you responded yes, please provide a copy of your COVID 19 test results with your email response.

For tests performed at a laboratory or by a medical provider, results need to include your name, date of test result, type of test, and result of test. If you do not have a copy of your test result, please let us know and we can assist you in obtaining your records from your medical lab or provider.

For tests performed using a home testing kit, a photograph of the results with time and date are required.

Have you received a COVID-19 vaccine? Yes No

9a. If you responded yes, please provide a copy of your COVID 19 vaccination card with your email response.

9b. If yes, do you have persistent side effects after receiving a COVID-19 vaccination?
Yes No

When you respond to this email, please provide answers to each question above, as well as a copy of your COVID-19 test results and/or the front and back of your COVID-19 vaccination card, if applicable.

Your responses and documentation will allow us to determine if you are eligible for our research study. If you do not answer all questions or provide the requested documentation, you will not be considered for the study. If you wish to provide a short summary of your condition, we invite you to.

If you are eligible, then we will email you within 10 business days to schedule a time to obtain verbal consent and perform a study interview. Please let me know if you have any additional questions. I look forward to hearing from you.

Thank you-
Elizabeth A Bartrum, FNP-BC
COVID 19 Convalescence Study Team

From: [Gavin, Angelique \(NIH/NINDS\) \[C\]](#)
To: (b) (6)
Subject: RE: [EXTERNAL] Re: NIH COVID-19 Vaccine Study
Date: Friday, August 26, 2022 9:20:00 AM

Hi (b) (6):

I just tried to open the HIPAA and SHDS files you attached but they are protected files. Can you resend in another format please?

Thank you,
Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

<https://clinicaltrials.gov - study number 000089-N>

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From: (b) (6) <Office365@messaging.microsoft.com>
Sent: Thursday, August 25, 2022 4:16 AM
To: Gavin, Angelique (NIH/NINDS) [C] (b) (6)
Cc: (b) (6)
Subject: Re: [EXTERNAL] Re: NIH COVID-19 Vaccine Study

Hello,

I attached the picture with the time stamp. I also attached my records for this year at (b) (6) (b) (6) and the HIPAA release form. I filled it out to be sent to (b) (6) medical records department. Please let me know if I need to correct anything.

Thank you, (b) (6)

From: Gavin, Angelique (NIH/NINDS) [C] (b) (6)
Sent: Wednesday, August 24, 2022 12:07:33 PM
To: (b) (6)
Subject: RE: [EXTERNAL] Re: NIH COVID-19 Vaccine Study

Hi (b) (6):

I have good news and bad news. I greatly appreciate your efforts in resending the test result.

Sadly, we need the year of the result on that time stamp. Is this possible for you to resend it? In the meantime, to determine if you are eligible to proceed to the next phase of the study, we need medical records to confirm that symptom onset was after your COVID vaccination.

Please complete the attached medical record release form for a medical provider who managed your care at the onset of symptoms after vaccination. Return the form to me using this secure email and I will obtain records on your behalf.

Once we have received and reviewed your records, if you are eligible to proceed, we will schedule the phone interview. Please let me know if you have any additional questions. I am looking forward to speaking with you soon.

Sincerely,

Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

10 Center Drive

Building 10, Room 3B19, MSC 1251

Bethesda, MD 20814-9692

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(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

<https://clinicaltrials.gov - study number 000089-N>

-

From: (b) (6)
Sent: Tuesday, August 23, 2022 3:24 PM
To: Gavin, Angelique (NIH/NINDS) [C] (b) (6)
Subject: [EXTERNAL] Re: NIH COVID-19 Vaccine Study

Hello,

Sorry for the delayed response. Here is the picture with the time stamp.

On Mon, Aug 15, 2022 at 8:59 AM Gavin, Angelique (NIH/NINDS) [C]
(b) (6) wrote:

Hello (b) (6):

Thank you for providing your test result with the time stamp. Typically we ask for the phone's date/time stamp, not one the participant puts on the picture. If you can re-send the test result with the phone's stamp, it would be appreciated. So sorry to make you go through so much effort.

Sincerely,

Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

[10 Center Drive](#)

[Building 10](#), Room 3B19, MSC 1251

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(b) (6)

<https://clinicaltrials.gov> - study number 000089-N

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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.

From: [Gavin, Angelique \(NIH/NINDS\) \[C\]](#)
To: (b) (6)
Subject: RE: NIH COVID-19 study
Date: Monday, May 10, 2021 2:11:00 PM

Perfect! Thank you (b) (6) !

Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

10 Center Drive

Building 10, Room 3B19, MSC 1251

Bethesda, MD 20814-9692

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

<https://clinicaltrials.gov - study number 000089>

-

From: (b) (6) <Office365@messaging.microsoft.com>
Sent: Monday, May 10, 2021 2:10 PM
To: Gavin, Angelique (NIH/NINDS) [C] (b) (6)
Cc: (b) (6)
Subject: Re: NIH COVID-19 study

Thursday at 11 works great!

From: Gavin, Angelique (NIH/NINDS) [C] (b) (6)
Sent: Monday, May 10, 2021 2:08:36 PM
To: (b) (6)
Subject: RE: NIH COVID-19 study

Thank you (b) (6) ! I can do any of the following:

Thursday, May 13, anytime between 11 and 2

Friday, May 14, 3:30 or 4

Monday, May 17, anytime between 9-2

Wednesday, May 19, anytime between 11 and 3

Friday, May 21, anytime after noon.

Thank you!

Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

10 Center Drive

Building 10, Room 3B19, MSC 1251

Bethesda, MD 20814-9692

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

<https://clinicaltrials.gov> - study number 000089

-

From: (b) (6) <Office365@messaging.microsoft.com>

Sent: Monday, May 10, 2021 2:02 PM

To: Gavin, Angelique (NIH/NINDS) [C] (b) (6)

Cc: (b) (6)

Subject: Re: NIH COVID-19 study

Good afternoon,

My meetings are usually on and off throughout the day. It may be easier if you give me a few dates/times and I'll work off my schedule. Look forward to speaking!

Thank you,

(b) (6)

From: Gavin, Angelique (NIH/NINDS) [C] (b) (6)
Sent: Monday, May 10, 2021 11:09:03 AM
To: (b) (6)
Subject: RE: NIH COVID-19 study

Thank you (b) (6)! This is sufficient for our needs. I'd like to arrange our next interview which will take approximately 45 minutes to one hour of your time. Please send me a good day and time to reach you and I'll get back to you with something that will work for us both. I look forward to speaking with you soon!

Sincerely,

Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

10 Center Drive

Building 10, Room 3B19, MSC 1251

Bethesda, MD 20814-9692

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

<https://clinicaltrials.gov - study number 000089>

-

From: (b) (6) <Office365@messaging.microsoft.com>
Sent: Friday, May 7, 2021 6:10 PM
To: Gavin, Angelique (NIH/NINDS) [C] (b) (6)
Cc: (b) (6)
Subject: Re: NIH COVID-19 study

Hello Angelique,

It was a pleasure to speak with you. Thank you for sending the documentation. Attached is the positive PCR test from December 2020. Please let me know if you need any other information.

I look forward to speaking with you soon.

Have a terrific weekend!

From: Gavin, Angelique (NIH/NINDS) [C] (b) (6)
Sent: Friday, May 7, 2021 12:42:37 PM
To: (b) (6)
Subject: NIH COVID-19 study

Hi (b) (6):

Thank you for volunteering for our COVID-19 study here at the NIH. It was good speaking with you today! I have attached our study consent form for your review. Please read it over prior to our next interview. Please use this secure email to attach your positive COVID-19 test result. Once reviewed, I will arrange our next interview which I anticipate will take approximately 45 minutes to one hour of your time. Feel free to contact me with any questions you may have.

Sincerely,

Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

10 Center Drive

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Bethesda, MD 20814-9692

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(b) (6)

<https://clinicaltrials.gov> - study number 000089

-

From: [NINDSPostCovid19](#)
To: (b) (6)
Subject: RE: NIH COVID-19 Vaccine Study
Date: Monday, August 15, 2022 1:53:00 PM

Thank you (b) (6)! We will review what you have provided and I will get back to you soon regarding your eligibility. Have a great day!

Sincerely,
Angelique

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692
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(b) (6) (cell)
(301) 480-5368 (efax)
(b) (6)

<https://clinicaltrials.gov> - study number 000089-N

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From: (b) (6)
Sent: Monday, August 15, 2022 1:50 PM
To: Gavin, Angelique (NIH/NINDS) [C] (b) (6)
Subject: Re: NIH COVID-19 Vaccine Study

Please see vaccine card photos attached.



From: Gavin, Angelique (NIH/NINDS) [C] (b) (6)

Sent: Monday, August 15, 2022 11:11 AM

To: (b) (6)

Subject: [EXTERNAL] RE: NIH COVID-19 Vaccine Study

Thank you (b) (6) for your response. Please send me a copy of your vaccine card, front and back. Once received, we can determine if you are eligible to move forward in the study.

Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

10 Center Drive

Building 10, Room 3B19, MSC 1251

Bethesda, MD 20814-9692

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

<https://clinicaltrials.gov - study number 000089-N>

-

From: (b) (6)

Sent: Friday, August 12, 2022 3:25 PM

To: Gavin, Angelique (NIH/NINDS) [C] (b) (6)

Subject: Re: NIH COVID-19 Vaccine Study

In order to be considered for the study, please respond to this email with answers to the following questions:

1. What is your full name?

2.

(b) (6)

3. What is your preferred phone number?

(b) (6)

4. How old are you?

(b) (6)

5. Are you fluent in speaking, reading and writing English? Yes /No

Yes

5. Do you live in the United States? Yes/No

Yes

a. If yes, please provide the city, state and zip code where you live.

(b) (6)

1. Are you an NIH employee, contractor, trainee or otherwise affiliated with the NIH? Yes/No

No

7. Have you had a COVID-19 infection? Yes/No/Unsure

(b) (6)

a. If yes, how many COVID-19 infections have you had?

(b) (6)

b. What is the date of your first COVID-19 infection?

(b) (6)

c. Are you having persistent side effects after your first COVID-19 infection? Yes No

(b) (6)

d. Do you have test results confirming your COVID 19 infection? Yes No

e. If you responded yes, please provide a copy of your COVID 19 test results with your email response.

For tests performed at a laboratory or by a medical provider, results need to include your name, date of test result, type of test, and result of test. If you do not have a copy

of your test result, please let us know and we can assist you in obtaining your records from your medical lab or provider.
For tests performed using a home testing kit, a photograph of the results with time and date are required.

8. Have you received a COVID-19 vaccine? Yes No

YES

a. *If you responded yes, please provide a copy of your COVID 19 vaccination card with your email response.*

b. If yes, do you have persistent side effects after receiving a COVID-19 vaccination?

Yes No

YES



From: Gavin, Angelique (NIH/NINDS) [C] (b) (6)
Sent: Monday, August 8, 2022 4:17 PM
To: (b) (6)
Subject: [EXTERNAL] NIH COVID-19 Vaccine Study

Good Day (b) (6):

Thank you for your patience and your interest in the COVID-19 Convalescence study at the National Institutes of Health. I am emailing you because you had previously contacted the NIH about participating in this study. To ensure that your information and communication remains secure, you are receiving this via encrypted email. Please respond using encrypted email.

Our study is looking at the experience of recovery for individuals after a COVID-19 infection or after COVID 19 vaccination. The attached consent form provides more information about our study, which

involves a phone interview and online questionnaires.

In order to be considered for the study, please respond to this email with answers to the following questions:

1. What is your full name?
2. What is your preferred phone number?
3. How old are you?
4. Are you fluent in speaking, reading and writing English? Yes /No
5. Do you live in the United States? Yes/No
 - a. If yes, please provide the city, state and zip code where you live.
6. Are you an NIH employee, contractor, trainee or otherwise affiliated with the NIH? Yes/No
7. Have you had a COVID-19 infection? Yes/No/Unsure
 - a. If yes, how many COVID-19 infections have you had?
 - b. What is the date of your first COVID-19 infection?
 - c. Are you having persistent side effects after your first COVID-19 infection? Yes No
 - d. Do you have test results confirming your COVID 19 infection? Yes No
 - e. *If you responded yes, please provide a copy of your COVID 19 test results with your email response.*
For tests performed at a laboratory or by a medical provider, results need to include your name, date of test result, type of test, and result of test. If you do not have a copy of your test result, please let us know and we can assist you in obtaining your records from your medical lab or provider.
For tests performed using a home testing kit, a photograph of the results with time and date are required.
8. Have you received a COVID-19 vaccine? Yes No
 - a. *If you responded yes, please provide a copy of your COVID 19 vaccination card with your email response.*
 - b. If yes, do you have persistent side effects after receiving a COVID-19 vaccination?
Yes No

When you respond to this email, please provide answers to each question above, as well as a Copy of your COVID-19 test results and/or the front and back of your COVID-19 vaccination card, if applicable.

Your responses and documentation will allow us to determine if you are eligible for our research

study. If you do not answer all questions or provide the requested documentation, you will not be considered for the study. If you wish to provide a short summary of your condition, we invite you to.

If you are eligible, then we will email you within 10 business days to schedule a time to obtain verbal consent and perform a study interview. Please let me know if you have any additional questions. I look forward to hearing from you.

Thank you,
Angelique Gavin
COVID 19 Convalescence Study Team

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

<https://clinicaltrials.gov> - study number 000089-N

Gavin, Angelique (NIH/NINDS) [C]

From: Gavin, Angelique (NIH/NINDS) [C]
Sent: Thursday, August 25, 2022 3:54 PM
To: (b) (6)
Subject: RE: NIH COVID-19 Vaccine Study

Thank you (b) (6)! I will get back to you when we have received and reviewed your records. All my best to you in the meantime!

Sincerely,
Angelique

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

<https://clinicaltrials.gov - study number 000089-N>

-

From: (b) (6)
Sent: Thursday, August 25, 2022 3:48 PM
To: Gavin, Angelique (NIH/NINDS) [C] (b) (6)
Subject: Re: NIH COVID-19 Vaccine Study

Hi Angelique,

Please see the attached forms.

(b) (6)



From: Gavin, Angelique (NIH/NINDS) [C] (b) (6)
Sent: Wednesday, August 24, 2022 2:34 PM
To: (b) (6)
Subject: [EXTERNAL] FW: NIH COVID-19 Vaccine Study

Thank you (b) (6) for the information you've provided thus far. To determine if you are eligible to proceed, we need medical records to confirm that the symptom onset was after COVID vaccination.

Please complete the attached medical record release form for a medical provider whom managed your care at the onset of symptoms after vaccination. Please return the form to me using this encrypted email and I will obtain the records on your behalf.

Once we have received and reviewed the records, if you are eligible to proceed, we will schedule a telephone interview. Please let me know if you have any additional questions. I look forward to speaking with you very soon.

Sincerely,
Angelique Gavin

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

(b) (6) (office)
(b) (6) (cell)
(301) 480-5368 (efax)
(b) (6)

<https://clinicaltrials.gov - study number 000089-N>

-

From: NINDSPostCovid19
Sent: Monday, August 15, 2022 2:15 PM
To: (b) (6)
Subject: RE: NIH COVID-19 Vaccine Study

Thank you (b) (6) for the information you've provided thus far. To determine if you are eligible to proceed, we need medical records to confirm that the symptom onset was after COVID vaccination.

Please complete the attached medical record release form for a medical provider whom managed your care at the onset of symptoms after vaccination. Please return the form to me using this encrypted email and I will obtain the records on your behalf.

Once we have received and reviewed the records, if you are eligible to proceed, we will schedule a telephone interview. Please let me know if you have any additional questions. I look forward to speaking with you very soon.

Sincerely,
Angelique Gavin

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
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(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

<https://clinicaltrials.gov - study number 000089-N>

-

From: (b) (6)

Sent: Monday, August 15, 2022 1:50 PM

To: Gavin, Angelique (NIH/NINDS) [C] (b) (6)

Subject: Re: NIH COVID-19 Vaccine Study

Please see vaccine card photos attached.

(b) (6)

From: Gavin, Angelique (NIH/NINDS) [C] (b) (6)

Sent: Monday, August 15, 2022 11:11 AM

To: (b) (6)

Subject: [EXTERNAL] RE: NIH COVID-19 Vaccine Study

Thank you (b) (6) for your response. Please send me a copy of your vaccine card, front and back. Once received, we can determine if you are eligible to move forward in the study.

Angelique

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
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Bethesda, MD 20814-9692

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(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

<https://clinicaltrials.gov - study number 000089-N>

-

From: (b) (6)

Sent: Friday, August 12, 2022 3:25 PM

To: Gavin, Angelique (NIH/NINDS) [C] (b) (6)

Subject: Re: NIH COVID-19 Vaccine Study

In order to be considered for the study, please respond to this email with answers to the following questions:

1. What is your full name?

2.

(b) (6)

3. What is your preferred phone number?

(b) (6)

4. How old are you?

(b)
(6)

5. Are you fluent in speaking, reading and writing English? Yes /No

Yes

5. Do you live in the United States? Yes/No

Yes

a. If yes, please provide the city, state and zip code where you live.

(b) (6)

1. Are you an NIH employee, contractor, trainee or otherwise affiliated with the NIH? Yes/No

No

7. Have you had a COVID-19 infection? Yes/No/Unsure

(b) (6)

a. If yes, how many COVID-19 infections have you had?

(b) (6)

b. What is the date of your first COVID-19 infection?

(b) (6)

c. Are you having persistent side effects after your first COVID-19 infection? Yes No

(b) (6)

d. Do you have test results confirming your COVID 19 infection? Yes No

e. If you responded yes, please provide a copy of your COVID 19 test results with your email response.

For tests performed at a laboratory or by a medical provider, results need to include your name, date of test result, type of test, and result of test. If you do not have a copy of your test result, please let us know and we can assist you in obtaining your records from your medical lab or provider.

For tests performed using a home testing kit, a photograph of the results with time and date are required.

8. Have you received a COVID-19 vaccine? Yes No

YES

a. If you responded yes, please provide a copy of your COVID 19 vaccination card with your email response.

b. If yes, do you have persistent side effects after receiving a COVID-19 vaccination?

Yes No

YES

(b) (6)

From: Gavin, Angelique (NIH/NINDS) [C]

(b) (6)

Sent: Monday, August 8, 2022 4:17 PM

To: [REDACTED] (b) (6)

Subject: [EXTERNAL] NIH COVID-19 Vaccine Study

Good Day [REDACTED] (b) (6):

Thank you for your patience and your interest in the COVID-19 Convalescence study at the National Institutes of Health. I am emailing you because you had previously contacted the NIH about participating in this study. To ensure that your information and communication remains secure, you are receiving this via encrypted email. Please respond using encrypted email.

Our study is looking at the experience of recovery for individuals after a COVID-19 infection or after COVID 19 vaccination. The attached consent form provides more information about our study, which involves a phone interview and online questionnaires.

In order to be considered for the study, please respond to this email with answers to the following questions:

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3. How old are you?
4. Are you fluent in speaking, reading and writing English? Yes /No
5. Do you live in the United States? Yes/No
 - a. If yes, please provide the city, state and zip code where you live.
6. Are you an NIH employee, contractor, trainee or otherwise affiliated with the NIH? Yes/No
7. Have you had a COVID-19 infection? Yes/No/Unsure
 - a. If yes, how many COVID-19 infections have you had?
 - b. What is the date of your first COVID-19 infection?
 - c. Are you having persistent side effects after your first COVID-19 infection? Yes No
 - d. Do you have test results confirming your COVID 19 infection? Yes No
 - e. If you responded yes, please provide a copy of your COVID 19 test results with your email response.
For tests performed at a laboratory or by a medical provider, results need to include your name, date of test result, type of test, and result of test. If you do not have a copy of your test result, please let us know and we can assist you in obtaining your records from your medical lab or provider.
For tests performed using a home testing kit, a photograph of the results with time and date are required.
8. Have you received a COVID-19 vaccine? Yes No
 - a. If you responded yes, please provide a copy of your COVID 19 vaccination card with your email response.
 - b. If yes, do you have persistent side effects after receiving a COVID-19 vaccination?
Yes No

When you respond to this email, please provide answers to each question above, as well as a Copy of your COVID-19 test results and/or the front and back of your COVID-19 vaccination card,

if applicable.

Your responses and documentation will allow us to determine if you are eligible for our research study. If you do not answer all questions or provide the requested documentation, you will not be considered for the study. If you wish to provide a short summary of your condition, we invite you to.

If you are eligible, then we will email you within 10 business days to schedule a time to obtain verbal consent and perform a study interview. Please let me know if you have any additional questions. I look forward to hearing from you.

Thank you,
Angelique Gavin
COVID 19 Convalescence Study Team

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

<https://clinicaltrials.gov> - study number 000089-N

Gavin, Angelique (NIH/NINDS) [C]

From: Bartrum, Elizabeth (NIH/NINDS) [E]
Sent: Tuesday, October 25, 2022 9:37 PM
To: (b) (6)
Cc: Gavin, Angelique (NIH/NINDS) [C]; Ashade, Adedamola (NIH/NINDS) [F]; Walitt, Brian (NIH/NINDS) [E]
Subject: RE: COVID 19 Research Study at NIH

Hello (b) (6)

Thank you very much for this information. I will notify you when I receive the records. Please feel free to reach out if you have questions while we are awaiting the records.

Thank you and have a nice evening-
Elizabeth

From: (b) (6) <Office365@messaging.microsoft.com>
Sent: Tuesday, October 25, 2022 1:37 PM
To: Bartrum, Elizabeth (NIH/NINDS) [E] (b) (6)
Cc: Gavin, Angelique (NIH/NINDS) [C] (b) (6) Ashade, Adedamola (NIH/NINDS) [F]
(b) (6) Walitt, Brian (NIH/NINDS) [E]
(b) (6)
Subject: Re: COVID 19 Research Study at NIH

Hello Elizabeth,

I have sent the medical release forms out and you should be getting the information shortly. You will be getting records from:

(b) (6)

Attached to this email:

1) vaccination notes from (b) (6) plus all the records they gleamed from the system after I notified them of my adverse reaction.

2) (b) (6) notes from ambulance trips (b) (6). I have included this to show my health status at the time of transport.

Please let me know if you do not receive the medical records.

(b) (6)

From: Bartrum, Elizabeth (NIH/NINDS) [E] (b) (6)
Sent: Tuesday, October 18, 2022 10:44:58 AM
To: (b) (6)
Cc: Gavin, Angelique (NIH/NINDS) [C] (b) (6); Ashade, Adedamola (NIH/NINDS) [F]
(b) (6)
Subject: RE: COVID 19 Research Study at NIH

(b) (6)

Thanks so much, and I appreciate you reaching out to our team.

The records you describe will likely be sufficient for what we need. Once we review them, then we can address next steps.

Thanks very much, and I look forward to understanding more about what you have suffered in the past year.

Kind regards-

Elizabeth

From: (b) (6) <Office365@messaging.microsoft.com>
Sent: Tuesday, October 18, 2022 10:31 AM
To: Bartrum, Elizabeth (NIH/NINDS) [E] (b) (6)
Cc: Gavin, Angelique (NIH/NINDS) [C] (b) (6); Ashade, Adedamola (NIH/NINDS) [F]
(b) (6)
Subject: Re: COVID 19 Research Study at NIH

Elizabeth,

Thank you for your kind words. It has been challenging, for sure.

I will get the records release completed and sent in. I did not have a primary doctor prior to this happening to me. I was a healthy man and not on any medications. I may of had (b) (6)

(b) (6) Other than that I can not recall anything that was not out of the ordinary.

I will have my records from (b) (6) sent.

Hope this works,

(b) (6)

From: Bartrum, Elizabeth (NIH/NINDS) [E] (b) (6)

Sent: Monday, October 17, 2022 9:49:04 AM

To: (b) (6)

Cc: Gavin, Angelique (NIH/NINDS) [C] (b) (6) Ashade, Adedamola (NIH/NINDS) [F]

(b) (6)

Subject: COVID 19 Research Study at NIH

Hi (b) (6)

I'm so sorry to hear of this devastating experience. There are no words to convey how difficult your life has been for over a year. I'm very sorry.

Thank you for your interest in our study. The next step will be to obtain medical records from you. The records ideally are from a primary medical provider who can document your health in the year prior to

vaccination, as well as document your health after vaccination. To begin, we will review from your primary provider, and then if we need additional detail we will request additional records.

I've attached a copy of the medical records release form. Please complete this, sign it and return to me and Angelique Gavin. Once it is completed and we receive the records then we can proceed to the interview and questionnaire portions of the study.

If you have additional questions, please let me know.

My best to you-

Elizabeth

Gavin, Angelique (NIH/NINDS) [C]

From: (b) (6)
Sent: Wednesday, November 2, 2022 9:49 AM
To: Bartrum, Elizabeth (NIH/NINDS) [E]
Cc: Gavin, Angelique (NIH/NINDS) [C]; Ashade, Adedamola (NIH/NINDS) [F]; Walitt, Brian (NIH/NINDS) [E]; (b) (6)
Subject: Re: COVID 19 Research Study at NIH

Good morning Elizabeth,
I'm glad to hear the records arrived. It is quite a series of events. Terrifying.
I would like for (b) (6) to sit in on the interview if that is possible.

If today is not too soon, I can do the interview at 3:30 pm.

Otherwise, after work would be best. We are hours ahead of you, so if there is no cut off hour, . Say any day after 5:30 pm, with notice so we can schedule accordingly. If this isn't possible then I will send you dates and times to call.

Thank you for your time,

(b) (6)

From: Bartrum, Elizabeth (NIH/NINDS) [E] (b) (6)
Sent: Wednesday, November 2, 2022 12:32:41 AM
To: (b) (6)
Cc: Gavin, Angelique (NIH/NINDS) [C] (b) (6); Ashade, Adedamola (NIH/NINDS) [F] (b) (6); Walitt, Brian (NIH/NINDS) [E] (b) (6)
Subject: RE: COVID 19 Research Study at NIH

Hi (b) (6)

We received your outside records, and I reviewed them this evening. I'm so sorry for all that you have been through.

You are eligible for the next portion of the study, which involves the interview. Please provide some dates and times when you are available over the next two weeks for 30 minutes to an hour. During the call we will discuss your health before and after vaccination and review the attached consent form.

Sincerely-
Elizabeth

From: (b) (6) <Office365@messaging.microsoft.com>
Sent: Tuesday, October 25, 2022 1:37 PM
To: Bartrum, Elizabeth (NIH/NINDS) [E] (b) (6)
Cc: Gavin, Angelique (NIH/NINDS) [C] (b) (6); Ashade, Adedamola (NIH/NINDS) [F] (b) (6); Walitt, Brian (NIH/NINDS) [E] (b) (6)
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Attached to this email:

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- 2) (b) (6) notes from ambulance trips (b) (6). I have included this to show my health status at the time of transport.

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(b) (6)
Subject: RE: COVID 19 Research Study at NIH

(b) (6)

Thanks so much, and I appreciate you reaching out to our team.

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Thanks very much, and I look forward to understanding more about what you have suffered in the past year.

Kind regards-

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(b) (6)
Subject: Re: COVID 19 Research Study at NIH

Elizabeth,

Thank you for your kind words. It has been challenging, for sure.

I will get the records release completed and sent in. I did not have a primary doctor prior to this happening to me. I was a healthy man and not on any medications. I may of had a (b) (6)

(b) (6) Other than that I can not recall anything that was not out of the ordinary.

I will have my records from both facilities sent.

Hope this works,

(b) (6)

From: Bartrum, Elizabeth (NIH/NINDS) [E] (b) (6)
Sent: Monday, October 17, 2022 9:49:04 AM
To: (b) (6)
Cc: Gavin, Angelique (NIH/NINDS) [C] (b) (6) Ashade, Adedamola (NIH/NINDS) [F]
(b) (6)
Subject: COVID 19 Research Study at NIH

Hi (b) (6)

I'm so sorry to hear of this devastating experience. There are no words to convey how difficult your life has been for over a year. I'm very sorry.

Thank you for your interest in our study. The next step will be to obtain medical records from you. The records ideally are from a primary medical provider who can document your health in the year prior to vaccination, as well as document your health after vaccination. To begin, we will review from your primary provider, and then if we need additional detail we will request additional records.

I've attached a copy of the medical records release form. Please complete this, sign it and return to me and Angelique Gavin. Once it is completed and we receive the records then we can proceed to the interview and questionnaire portions of the study.

If you have additional questions, please let me know.

My best to you-

Elizabeth

Gavin, Angelique (NIH/NINDS) [C]

From: Bartrum, Elizabeth (NIH/NINDS) [E]
Sent: Sunday, September 4, 2022 3:18 PM
To: Gavin, Angelique (NIH/NINDS) [C]; Vetter, Courtney (NIH/NINDS) [F]
Cc: Walitt, Brian (NIH/NINDS) [E]
Subject: RE: COVID 19 Research Study At NIH

Hi Brian-
Can you confirm that we are not accepting non-US citizens for the vaccine trial?

Thanks-
Liz

From: Gavin, Angelique (NIH/NINDS) [C] (b) (6)
Sent: Friday, September 2, 2022 12:48 PM
To: Vetter, Courtney (NIH/NINDS) [F] (b) (6); Bartrum, Elizabeth (NIH/NINDS) [E]
(b) (6)
Subject: FW: COVID 19 Research Study At NIH

Hello:

This participant is not in the USA. Not sure if he can qualify. Also, can't open the attachment.

Thanks,
Angelique

Angelique Gavin, MS (Contractor)
NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692
(b) (6) (office)
(b) (6) (cell)
(301) 480-5368 (efax)
(b) (6)

<https://clinicaltrials.gov - study number 000089-N>

-

From: (b) (6) <Office365@messaging.microsoft.com>
Sent: Friday, September 2, 2022 12:21 PM
To: Vetter, Courtney (NIH/NINDS) [F] (b) (6)
Cc: Bartrum, Elizabeth (NIH/NINDS) [E] (b) (6); Gavin, Angelique (NIH/NINDS) [C]
(b) (6)
Subject: Re: COVID 19 Research Study At NIH

1. What is your full name? (b) (6)

2. What is your preferred phone number? (b) (6)

3. How old are you? (b) (6)

4. Are you fluent in speaking, reading and writing English? **Yes**

5. Do you live in the United States? **No** (b) (6)

a. If yes, please provide the city, state and zip code where you live. (b) (6)

6. Are you an NIH employee, contractor, trainee or otherwise affiliated with the NIH? **No**

7. Have you had a COVID-19 infection? (b) (6)

a. If yes, how many COVID-19 infections have you had? (b) (6)

b. What is the date of your first COVID-19 infection? (b) (6)

c. Are you having persistent side effects after your first COVID-19 infection? (b) (6)

d. Do you have test results confirming your COVID 19 infection? (b) (6)

e. If you responded yes, please provide a copy of your COVID 19 test results with your email response.

For tests performed at a laboratory or by a medical provider, results need to include your name, date of test result, type of test, and result of test. If you do not have a copy of your test result, please let us know and we can assist you in obtaining your records from your medical lab or provider.

For tests performed using a home testing kit, a photograph of the results with time and date are required.

8. Have you received a COVID-19 vaccine? **Yes**

a. If you responded yes, please provide a copy of your COVID 19 vaccination card with your email response.

b. If yes, do you have persistent side effects after receiving a COVID-19 vaccination?

YES

From: Vetter, Courtney (NIH/NINDS) [F] (b) (6)
Sent: Friday, September 2, 2022 8:08:35 AM
To: (b) (6)
Cc: Bartrum, Elizabeth (NIH/NINDS) [E] (b) (6) Gavin, Angelique (NIH/NINDS) [C]
(b) (6)
Subject: COVID 19 Research Study At NIH

Good morning-

Thank you for your patience and your interest in the COVID-19 Convalescence study at the National Institutes of Health. I am emailing you because you had previously contacted the NIH about participating in this study. To ensure that your information and communication remains secure, you are receiving this via encrypted email. Please respond using encrypted email.

Our study is looking at the experience of recovery for individuals after a COVID-19 infection or after COVID 19 vaccination. The attached consent form provides more information about our study, which involves a phone interview and online questionnaires.

In order to be considered for the study, please respond to this email with answers to the following questions:

1. What is your full name?
2. What is your preferred phone number?
3. How old are you?
4. Are you fluent in speaking, reading and writing English? Yes /No
5. Do you live in the United States? Yes/No

a. If yes, please provide the city, state and zip code where you live.

6. Are you an NIH employee, contractor, trainee or otherwise affiliated with the NIH? Yes/No

7. Have you had a COVID-19 infection? Yes/No/Unsure

a. If yes, how many COVID-19 infections have you had?

b. What is the date of your first COVID-19 infection?

c. Are you having persistent side effects after your first COVID-19 infection? Yes No

d. Do you have test results confirming your COVID 19 infection? Yes No

e. If you responded yes, please provide a copy of your COVID 19 test results with your email response.

For tests performed at a laboratory or by a medical provider, results need to include your name, date of test result, type of test, and result of test. If you do not have a copy of your test result, please let us know and we can assist you in obtaining your records from your medical lab or provider.

For tests performed using a home testing kit, a photograph of the results with time and date are required.

8. Have you received a COVID-19 vaccine? Yes No

a. If you responded yes, please provide a copy of your COVID 19 vaccination card with your email response.

b. If yes, do you have persistent side effects after receiving a COVID-19 vaccination?

Yes No

When you respond to this email, please provide answers to each question above, as well as a copy of your COVID-19 test results and/or the front and back of your COVID-19 vaccination card, if applicable.

Your responses and documentation will allow us to determine if you are eligible for our research

study. If you do not answer all questions or provide the requested documentation, you will not be considered for the study. If you wish to provide a short summary of your condition, we invite you to.

If you are eligible, then we will email you within 10 business days to schedule a time to obtain verbal consent and perform a study interview. Please let me know if you have any additional questions. I look forward to hearing from you.

Thank you-

COVID 19 Convalescence Study Team

From: [Wiebold, Amanda \(NIH/NINDS\) \[E\]](#)
To: [Nath, Avindra \(NIH/NINDS\) \[E\]](#); [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Cc: (b) (6)
Subject: Update on (b) (6)
Date: Friday, July 30, 2021 2:30:18 PM

Dr. Nath and Dr. Safavi,

(b) (6), copied here, reached out to me to provide some updates on her care since she enrolled on the samples only arm of 15N0125 and was hoping for information/recommendations.

(b) (6)

(b) (6)

Her concerns/questions:

(b) (6)

I told (b) (6) that I would share her updates with you and ask that if you have any recommendations you could reach out to her for follow up. She is included on this email and her number is (b) (6).

Thank you,

Amanda Wiebold, BSN, RN, CNRN
Research Nurse Specialist
NINDS Section of Infections of the Nervous System
10 Center Drive, Building 10/7C107, MSC 1430
Bethesda, Maryland 20892

Office: (b) (6)

Cell: (b) (6)

Fax: 301-480-5594

Email: (b) (6)