
From: [b6]
Sent: 1/10/2022 7:20:14 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [EXTERNAL] For your potential research

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

Dr Nath,

I forgot to share my recent [b6] labs with you. I don't expect you to comment or consult on my specific case but a lot of us vaccine injured are coming back positive for these. My rheumatologist doesn't know what to do with these labs but thought they would be of interest to you for potential research.

Sincerely,

[b6]

b6

Sent from my iPhone

From: [b6]
Sent: 2/23/2022 2:48:57 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6] Brown, Warren (NIH/NINDS) [C] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=bef0730648434bb69542199fca79f67e [b6]
CC: [b6]
Subject: RE: [EXTERNAL] Vaccine Related Injury Assistance

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Hi Warren:

We patiently await your contact to set up a phone call appointment with Dr. Nath.

I have copied [b6] email address. Her cell phone is: [b6]

Thank you!

[b6]

From: Nath, Avindra (NIH/NINDS) [E] [b6]
Sent: Saturday, February 19, 2022 10:25 AM
To: [b6] Brown, Warren (NIH/NINDS) [C] [b6]
Subject: Re: [EXTERNAL] Vaccine Related Injury Assistance

Dear [b6]

Not sure I have much to add, but I will be glad to talk to you. I have copied Warren who can set up a meeting.

Avi

From: [b6]
Date: Saturday, February 19, 2022 at 6:50 AM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: RE: [EXTERNAL] Vaccine Related Injury Assistance

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Dear Dr. Nath:

NINDS of NIH did respond and provided additional information. We sincerely appreciate you taking the time to contact them on our behalf. We realize you are extremely busy at NIH and assisting [b6] is not on your daily "to do" list, so again much appreciated.

REL0000229261

However, before we fade off into the sunset I want to take a few more minutes of your time. And I promise the very next time I get near Bethesda I will drop by and buy you lunch, bring you a bottle of fine wine, whatever. You have been so gracious.

So here goes...

One of the links NINDS sent was the article from Science magazine which spoke about the small study (with [b6] others) you ran before it was abandoned by NIH. [b6] seemed to indicate a similar study is still being conducted??).

First, I read where the FDA declined to accept the study. I understand. Would you be able to provide the results of that small study? Was there any "potential solutions" to vaccine injury?

Second, you were stated as saying you weren't convinced these health problems were vaccine related. I can not be 100% sure [b6] condition was caused by the vaccine, however we are [b6] (the point is I know [b6] pretty well)—and the only thing between a healthy, biking, hiking, gym attending vibrant women and her condition now were two Moderna vaccines. And we have had every test 12 different doctors have prescribed and no "regularly understood disease" has been found. And she is not alone, as you are aware. Every vaccine ever produced has had a small percentage with adverse reactions. To think these vaccines would not?? And because the medical community at large—as you so well stated—is so unfamiliar with these conditions, there are probably a lot more individuals suffering from vaccine injury and they just don't know it.

Yes, a small percentage. But if you are one of those effected, well....you get it.

[b6] take-after 10 months of chasing down every rabbit hole we can find to offer her assistance and a solution is—the government provided "emergency use authorization" to develop these vaccines, how about they provide some emergency use to help those the vaccines have injured instead of seemingly considering [b6] and others "casualties of war" if you will.

Give Dr. Nath and the NIH authorization.

What has the CDC done with the reports from VAERS for those adversely effected? A rhetorical question...I know you are not the CDC.

Sorry for the rambling. Frustration.

You are a good man, Dr. Nath. I truly believe in my heart you want to help, but your hands are tied.

Sincerely,

[b6]

From: Nath, Avindra (NIH/NINDS) [E] [b6]
Sent: Tuesday, February 15, 2022 4:52 PM
To: [b6]
Subject: Re: [EXTERNAL] Vaccine Related Injury Assistance

Dear [b6]

I am terribly sorry to hear of your illness. Also I am sorry that you have not been able to get adequate help for the symptoms. In the intramural program where I work we do not have the infrastructure or clinics like other academic institutions do to treat patients. I have forwarded your email to other NIH officials who maybe able to provide additional information. I would be glad to review the records, but am not sure how much additional help that would be since you

have seen nearly all the subspecialists. I guess the medical community has not seen these kinds of illnesses and are struggling themselves to determine what to do and how to manage them.

Best wishes.

Avi

From: [REDACTED] b6
Date: Tuesday, February 15, 2022 at 1:47 PM
To: "Nath, Avindra (NIH/NINDS) [E]" [REDACTED] b6
Subject: [EXTERNAL] Vaccine Related Injury Assistance

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Dr. Avindra Nath, Clinical Director/ Senior Investigator
NIH
Building 10-CRC Room 7C103
10 Center Drive
Bethesda, MD 20814

Dear Dr. Nath:

This is our second letter/email to NIH. I wrote to Dr. Collins in November, 2021. She forwarded the letter to the CDC. The CDC suggested [REDACTED] b6 physician contact CISA. Thus far each physician we have seen kicks us down the road to another "ologist" when they can't determine a simple solution or one that fits their background/expertise (if you are a hammer, everything is a nail), so we don't have one clear "go to" physician willing to contact CISA. We have been given your name as a contact. We hope we have better results with you.

[REDACTED] b6 has entered a trial through [REDACTED] b6 to help others find a solution to vaccine related and long haul Covid issues, but the trial offers no immediate remedy to its participants.

We need your help. Please take a few minutes to read this letter. Thank you.

After 23 doctor's visits (neurologists, virologists, infectious disease, ENT, cardiologist, functional, rheumatologist, primary care) and multiple tests [REDACTED] b6 it has been determined [REDACTED] b6 is "vaccine injured" following two Moderna vaccines.

Let me be clear, we are NOT anti-vaxers. We are NOT conspiracy theorists. Our interest is NOT monetary. Our interest is NOT legal. We are successfully retired, well educated professionals needing help with a vaccine related problem.

Pharma scientists, NIH, the CDC and the FDA combined to develop and approve a vaccine transmission system which seems to work well for the masses, but for a small percentage of the vaccinated population it causes intense pain and misery. **We just want a solution, a remedy, some direction, some help with [REDACTED] b6 condition.**

Since May 2021 she has suffered from memory loss, cognitive issues, headaches, nerve pain throughout her body, racing heart palpitations. She has lost weight, has trouble sleeping, can no longer drive. It is debilitating.

The only thing standing between a healthy hiking, biking, gym passionate [REDACTED] b6 and her current condition were two Moderna vaccines.

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We will make available all [b6] test results to you.

We have supplied this information to VAERS several times. Apparently, that is as far as it goes.

Will you help us? We you review our case? We both got vaccinated for the greater good, for the good of us individually as well as societally—but [b6] has been injured, severely injured.

Please don't let us down.

Thank you!

Sincerely,

b6

From: [b6]
Sent: 2/19/2022 4:24:40 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6] Brown, Warren (NIH/NINDS) [C] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=bef0730648434bb69542199fca79f67e [b6]
CC: [b6]
Subject: RE: [EXTERNAL] Vaccine Related Injury Assistance

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Dear Dr. Nath:

Greatly appreciated sir!!

Warren:

I have copied [b6] email and her cell phone is [b6] If you would be so kind as to reach out to her directly to set up a mutually convenient time for a phone call with Dr. Nath it would be most welcome.

Thank you both again!!

[b6]

PS We have a summary of all the tests [b6] has had as well as a compilation of her symptoms, if these would be helpful. Please advise.

From: Nath, Avindra (NIH/NINDS) [E] [b6]
Sent: Saturday, February 19, 2022 10:25 AM
To: [b6] Brown, Warren (NIH/NINDS) [C] [b6]
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Subject: RE: [EXTERNAL] Vaccine Related Injury Assistance

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Dear Dr. Nath:

REL0000229263

NINDS of NIH did respond and provided additional information. We sincerely appreciate you taking the time to contact them on our behalf. We realize you are extremely busy at NIH and assisting [b6] is not on your daily "to do" list, so again much appreciated.

However, before we fade off into the sunset I want to take a few more minutes of your time. And I promise the very next time I get near Bethesda I will drop by and buy you lunch, bring you a bottle of fine wine, whatever. You have been so gracious.

So here goes...

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First, I read where the FDA declined to accept the study. I understand. Would you be able to provide the results of that small study? Was there any "potential solutions" to vaccine injury?

Second, you were stated as saying you weren't convinced these health problems were vaccine related. I can not be 100% sure [b6] condition was caused by the vaccine, however we are [b6] (the point is I know [b6] pretty well)—and the only thing between a healthy, biking, hiking, gym attending vibrant women and her condition now were two Moderna vaccines. And we have had every test 12 different doctors have prescribed and no "regularly understood disease" has been found. And she is not alone, as you are aware. Every vaccine ever produced has had a small percentage with adverse reactions. To think these vaccines would not?? And because the medical community at large—as you so well stated—is so unfamiliar with these conditions, there are probably a lot more individuals suffering from vaccine injury and they just don't know it.

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Sincerely,

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Best wishes.

Avi

From: [REDACTED] b6

Date: Tuesday, February 15, 2022 at 1:47 PM

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

Subject: [EXTERNAL] Vaccine Related Injury Assistance

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Dr. Avindra Nath, Clinical Director/ Senior Investigator
NIH
Building 10-CRC Room 7C103
10 Center Drive
Bethesda, MD 20814

Dear Dr. Nath:

This is our second letter/email to NIH. I wrote to Dr. Collins in November, 2021. She forwarded the letter to the CDC. The CDC suggested [REDACTED] b6 physician contact CISA. Thus far each physician we have seen kicks us down the road to another "ologist" when they can't determine a simple solution or one that fits their background/expertise (if you are a hammer, everything is a nail), so we don't have one clear "go to" physician willing to contact CISA. We have been given your name as a contact. We hope we have better results with you.

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We need your help. Please take a few minutes to read this letter. Thank you.

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Since May 2021 she has suffered from memory loss, cognitive issues, headaches, nerve pain throughout her body, racing heart palpitations. She has lost weight, has trouble sleeping, can no longer drive. It is debilitating.

The only thing standing between a healthy hiking, biking, gym passionate [b6] and her current condition were two Moderna vaccines.

We will make available all [b6] test results to you.

We have supplied this information to VAERS several times. Apparently, that is as far as it goes.

Will you help us? We you review our case? We both got vaccinated for the greater good, for the good of us individually as well as societally—but [b6] has been injured, severely injured.

Please don't let us down.

Thank you!

Sincerely,

b6

From: [b6]
Sent: 3/11/2022 5:19:27 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6] Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
CC: Fouanta, Ladifatou (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=a5ebaa8d0da84114ab631d6a3b913706 [b6]
Subject: [EXTERNAL] Vaccine Side Effects Root Cause and Treatment Plan
Attachments: [b6]

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Hi Dr. Safavi and Dr. Nath,

It has now been almost a year since I received the Pfizer vaccines and 6 months since we started working together. However, I am no closer to understanding the root cause of my debilitating symptoms nor a treatment plan that will address it. I have seen a plethora of specialists none of whom are equipped to handle complex and severe reactions to this new vaccine. The best they can offer are harsh drugs to address my symptoms that come with big risks and side effects.

When we first started working together, I sent you a list of my symptoms; they remain the same, if not more severe, as follows:

- Extreme muscle weakness, fatigue and malaise since vaccine
- Elevated temperature [b6]
- Sore throat and tonsils, chest pain, shortness of breath, feeling of inflammation in lungs
- Severe night sweats
- Dizziness and tinnitus
- Joint, muscle and back pain
- Heart palpitations
- Prolonged menstrual periods, change in cycle, bleeding and spotting outside of period (this has not resolved - my previous cycle was the longest I have ever had in my life)
- Rash of small red dots on arms, legs and torso (also not resolved)
- Weight loss and muscle degeneration (have not restored weight to baseline)
- Loss of appetite
- Twitching all over body
- Veins protruding
- Brain fog
- New allergies and constant reactions to food

None of these symptoms have resolved. Following your suggested protocol testing has been extremely stressful for my body and caused me significant setbacks. I am still experiencing [b6] [b6] and I will have [b6] for the rest of my life (I still don't have the result from them many months later). Has your research uncovered anything that can help?

Dr. Safavi and Dr. Nath - I am respectfully requesting that given the new and complex nature of reactions to these new vaccines, the extreme nature of my health condition and all the research data you have collected from me, that you continue to spearhead my case. [b6] or any other specialist are not focused on vaccine cases like you are. They are not following the latest research. They cannot help.

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In the meantime, I am seeing others with my post-vaccine issues develop severe, incurable, devastating medical conditions. Besides the above symptoms and constant inflammation, I am unable to exercise and have been [b6] I still do not understand how a healthy, athletic [b6] [b6] that was an avid runner, hiker, biker and swimmer can become so disabled after the vaccine. I have no answers and my life is on hold as my condition is deteriorating. This whole situation has been devastating to me and my family. We had very high hopes for [b6] but it has not resolved my symptoms, while making my tinnitus worse and causing severe headaches, dizziness and blood clots.

I am wondering what else we can do to understand the root cause. Is it autoimmune? Is it Mast Cell Activation Syndrome? Is it the spike protein? Why is my condition so similar to Long COVID?

I am attaching an [b6] test [b6] - is it possible to run this for me?

Now, more than ever, there is a huge urgency to address my condition because I am not getting better and everyday that my body suffers from inflammation and symptoms puts it at risk for developing further complications. This is not a way to live and you are my only hope. Please help any way you can.

Thank you,

[b6]

On Thu, Mar 10, 2022 at 12:24 PM Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

I am out of office with limited access to my email.

It is completely fine to follow [b6] recommendations since she is the neurologist who eventually will follow and provide you with care.

Hope it helps.

Farinaz

From: [b6]

Sent: Thursday, March 3, 2022 10:34:25 PM

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

Subject: [EXTERNAL]: [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.

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. I have started taking [REDACTED] b6

[REDACTED] b6

[REDACTED] b6

I saw [REDACTED] 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 [REDACTED] b6

[REDACTED] b6

[REDACTED] Her recommended treatment plan is to

[REDACTED] b6

[REDACTED] b6

I am also seeing the following doctors in March:

March 17: rheumatologist

March 18: functional medicine for gut health, hormonal and nutritional testing

March 24: allergist/immunologist for calming allergies and [REDACTED] b6 advice

April 1: appointment with you!

I would love to hear your thoughts on [REDACTED] b6 in my case and especially if there is hope that giving my body and immune system a break from fighting can help it calm down permanently. I am scared of [REDACTED] b6

[REDACTED] b6 There is no guarantee that they will be a permanent solution. Lastly, I of course want to run this by you to make sure it does not interfere with anything you have planned or recommend.

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 by any chance? I don't suspect [REDACTED] b6 but it would be good to know definitely.

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

b6

b6

b6

From: Fouanta, Ladifatou (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=A5EBAA8D0DA84114AB631D6A3B913706] b6
Sent: 4/6/2022 5:53:07 PM
To: b6 Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6] b6
CC: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246] b6
Subject: RE: [EXTERNAL] Vaccine Side Effects Root Cause and Treatment Plan

Hi b6

Dr. Nath and Dr. Safavi are both away this week. They might not see your email until they return. Just want to give you the heads-up in case you don't hear from them this week.

Best,

Ladi Fouanta, BSN, RN, CNRN
Research Nurse Specialist
NINDS Section of Infections of the Nervous System

From: b6
Sent: Tuesday, April 5, 2022 1:29 PM
To: Nath, Avindra (NIH/NINDS) [E] b6
Cc: Safavi, Farinaz (NIH/NINDS) [E] b6 Fouanta, Ladifatou (NIH/NINDS) [E]
b6
Subject: Re: [EXTERNAL] Vaccine Side Effects Root Cause and Treatment Plan

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Hello Dr. Nath and Dr. Safavi,

It would be great if I could get b6 Thank you.

I also wanted to share a note from b6 the neurologist Dr. Safavi recommended:

b6 10:30 AM (1 hour ago)
b6 As for research for post-vaccine reactions. NIH is doing most of this work. Johns Hopkins is also interested in studying patients with these issues also. Feel free to reach out to them and see if they have other ideas. b6

As you can see, she does not know how to treat me. Every doctor I have seen has said the same thing. She is telling me the NIH is doing work to study why many people have life-altering reactions like mine. I understand that my symptoms are systemic so what other avenues do I have to understand what is causing them and how to get treatment? We are being dismissed by doctors, and I have seen upwards of 20 of them. I complied with the vaccine mandate and I followed the guidance of the CDC. The CDC said that they take adverse reactions seriously. I don't understand where I am supposed to go to get treatment as my life has been drastically impacted by this mandated vaccine and I am a shell of the person I used to be. I am very thankful for your work with me but A YEAR LATER I am still suffering. All I wish is to

REL0000229312

return to the health I had before the vaccine. Who else is researching these reactions at the NIH, FDA and CDC? The doctors are looking to you to provide them with guidance.

I also wanted to see if you have advice on what to do in the meantime so I can survive this period. As you know [b6]
[b6]
[b6] I know you have also treated patients with vaccine reactions with [b6] How successful was the treatments? Would you recommend it for me? Would you recommend [b6]

Lastly, I want to call urgency to the situation. Many of us are now reaching a year after our vaccines and that is too long to suffer like this. I lost my [b6] to these side effects. It has been a very long year of pain, suffering and torture. My job performance suffered for the first time in my life, my body no longer has muscle even though I used to be incredibly athletic, I am deeply depressed and my family is in ruins. Several people in my support group have committed suicide. We cannot keep bouncing from doctor to doctor, only to be told they don't know or it's not their area of expertise. These doctors are looking at the NIH for guidance. Only you can help us.

Thank you,
[b6]

On Fri, Mar 11, 2022 at 4:10 PM Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

I am terribly sorry to hear of your on going illness. We are at a loss to know how to help. The symptoms below are more systemic and not neurological so probably now out of our area of expertise. All the tests that we had done [b6]
[b6] We can send you copies of the results if you have not received them yet.

With best wishes.

Avi

From: [b6]
Date: Friday, March 11, 2022 at 12:20 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6] Nath, Avindra (NIH/NINDS) [E]
[b6]
Cc: Fouanta, Ladifatou (NIH/NINDS) [E] [b6]
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- New allergies and constant reactions to food

None of these symptoms have resolved. Following your suggested protocol testing has been extremely stressful for my body and caused me significant setbacks. I am still experiencing [b6] and I will have [b6] for the rest of my life (I still don't have the result from them many months later). Has your research uncovered anything that can help?

Dr. Safavi and Dr. Nath - I am respectfully requesting that given the new and complex nature of reactions to these new vaccines, the extreme nature of my health condition and all the research data you have collected from me, that you continue to spearhead my case. [b6] or any other specialist are not focused on vaccine cases like you are. They are not following the latest research. They cannot help.

In the meantime, I am seeing others with my post-vaccine issues develop severe, incurable, devastating medical conditions. Besides the above symptoms and constant inflammation, I am unable to exercise and have been forced to [b6] I still do not understand how a healthy, athletic [b6] that was an avid runner, hiker, biker and swimmer can become so disabled after the vaccine. I have no answers and my life is on hold as my condition is deteriorating. This whole situation has been devastating to me and my family. We had very high hopes for [b6] but it has not resolved my symptoms, while making my tinnitus worse and causing severe headaches, dizziness and blood clots.

I am wondering what else we can do to understand the root cause. Is it autoimmune? Is it Mast Cell Activation Syndrome? Is it the spike protein? Why is my condition so similar to Long COVID?

I am attaching an [b6] test [b6] - is it possible to run this for me?

Now, more than ever, there is a huge urgency to address my condition because I am not getting better and everyday that my body suffers from inflammation and symptoms puts it at risk for developing further complications. This is not a way to live and you are my only hope. Please help any way you can.

Thank you,

[b6]

On Thu, Mar 10, 2022 at 12:24 PM Safavi, Farinaz (NIH/NINDS) [E]: [b6] wrote:

Hi [b6]

I am out of office with limited access to my email.

It is completely fine to follow [b6] recommendations since she is the neurologist who eventually will follow and provide you with care.

Hope it helps.

Farinaz

From: [b6]
Sent: Thursday, March 3, 2022 10:34:25 PM
To: Safavi, Farinaz (NIH/NINDS) [E]: [b6]
Subject: [EXTERNAL]: [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.

Hello Dr. Safavi,

REL0000229312

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. I have started taking [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]

Her recommended treatment plan is to [b6]

[b6]

[b6]

I am also seeing the following doctors in March:

March 17: rheumatologist

March 18: functional medicine for gut health, hormonal and nutritional testing

March 24: allergist/immunologist for calming allergies and [b6] advice

April 1: appointment with you!

I would love to hear your thoughts on [b6] in my case and especially if there is hope that giving my body and immune system a break from fighting can help it calm down permanently. I am scared of [b6] [b6] There is no guarantee that they will be a permanent solution. Lastly, I of course want to run this by you to make sure it does not interfere with anything you have planned or recommend.

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 [b6] by any chance? I don't suspect [b6] but it would be good to know definitely.

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,

b6

From: [b6]
Sent: 9/6/2022 6:47:30 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [EXTERNAL] Adverse reaction to Pfizer COVID-19 vaccine
Attachments: [b6]

Hello Dr. Nath,

I hope this email finds you well.

I ran across your contribution to the article <https://www.science.org/content/article/rare-cases-coronavirus-vaccines-may-cause-long-covid-symptoms>

I would love to find a solution to my reaction to the Pfizer booster shot.

I'm [b6] in good health, I received the 1st and second COVID-19 Pfizer vaccines in [b6] [b6] and I had no side effects. I received the Pfizer booster on [b6] On [b6] my knee joints became quite swollen. I was skiing in for a week so I assumed my knee swelling was a mechanical issue. I saw an orthopedist on [b6] He suggested I ice my knees twice a day and come back for a followup. I went for the follow up two weeks later and showed him that my knees were still swollen and new bilateral swelling on my wrists, ankles and fingers. He suggested I see a rheumatologist. Before I went to the rheumatologist, I saw my primary care physician on [b6] She ran a number of tests including [b6] [b6] She prescribed [b6] The day after I completed [b6] everything became swollen again. I saw the rheumatologist at [b6] She ran a couple more tests [b6] She prescribed [b6] [b6] I asked my rheumatologist to run [b6] and [b6] She also ran [b6] I had [b6] According to the rheumatologist [b6] So her suggested next course of action is [b6] [b6] I'm hesitant to start the prescription because of the side effects. I don't want to trade side effects of a vaccine for side effects of a medication to treat the side effects of the vaccine.

Attached are my test results and photos from different swelling stages of hands/wrists/knuckles. I am hoping you can inform me further. Maybe [b6] might work. I'm able to easily travel to NIH [b6]

Thank you in advance,
[b6]

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b6

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From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6] b6
Sent: 10/28/2021 2:53:40 PM
To: b6
Subject: Re: Injured by Johnson & Johnson Vax

For vaccine related events there is no other research study that I am involved in except for data gathering at the moment.
Avi

From: b6
Date: Thursday, October 28, 2021 at 12:57 AM
To: Nath, Avindra (NIH/NINDS) [E] b6
Subject: Re: Injured by Johnson & Johnson Vax

Hello Dr Nath,

I have not received any information as to how to proceed with your research study. Yet, I've heard that a study is starting.. Could I please be part of your study? There are many of us with severe reactions to all Covid vaccines.. We would appreciate any help.

Sent from Yahoo Mail on Android

On Wed, Aug 18, 2021 at 10:02 PM, b6 wrote:

Thank you, much appreciated.

Sent from Yahoo Mail on Android

On Mon, Aug 16, 2021 at 5:59 PM, Nath, Avindra (NIH/NINDS) [E] b6 wrote:

Dear b6

Terribly sorry to hear of your illness. Thanks for reaching out to me. We are a research organization. We have an online study to gather information to better understand these complications. I have copied our research team on this email and they can guide you on how to provide us the details. Your help is most appreciated. With regards to treatment, I would suggest it would be best for you to continue to work with your physicians close to home.

With best wishes.

Avi

Avindra Nath MD

Chief, Section of Infections of the Nervous System

Clinical Director,

National Institute of Neurological Disorders and Stroke

REL0000229485

National Institutes of Health, Bethesda, MD

b6 (Office)

b6

From: b6

Date: Monday, August 16, 2021 at 4:31 PM

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

Subject: Injured by Johnson & Johnson Vax

Hello,

I was given your name by an injured post vaccine group. My name is b6 from b6 I 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 b6 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.

After many tests in ER, they found 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 b6 It raced everytime I had the syncope feeling and rush of adrenaline from head to toe. They started me on b6

REL0000229485

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. b6
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.

Please help b6

Sent from Yahoo Mail on Android

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6] b6
Sent: 2/17/2022 4:55:13 AM
To: b6
Subject: Re: [EXTERNAL] Vaccine Related Injury Assistance

Sorry, I am not aware of any such program at NIH.

Avi

From: b6
Date: Wednesday, February 16, 2022 at 11:29 AM
To: "Nath, Avindra (NIH/NINDS) [E]" b6
Subject: RE: [EXTERNAL] Vaccine Related Injury Assistance

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:

Thank you so very much for your prompt response.

We understand there is a very "select" program being run by NIH for vaccine injured individuals.

Are you familiar with this program?

If not, who at NIH would have this information?

We would like to have b6 engaged in the program.

Looking forward to your reply.

Thank you again!

b6

From: Nath, Avindra (NIH/NINDS) [E] b6
Sent: Tuesday, February 15, 2022 4:52 PM
To: b6
Subject: Re: [EXTERNAL] Vaccine Related Injury Assistance

Dear b6

I am terribly sorry to hear of your illness. Also I am sorry that you have not been able to get adequate help for the symptoms. In the intramural program where I work we do not have the infrastructure or clinics like other academic

REL0000229496

institutions do to treat patients. I have forwarded your email to other NIH officials who maybe able to provide additional information. I would be glad to review the records, but am not sure how much additional help that would be since you have seen nearly all the subspecialists. I guess the medical community has not seen these kinds of illnesses and are struggling themselves to determine what to do and how to manage them.

Best wishes.

Avi

From: [REDACTED] b6

Date: Tuesday, February 15, 2022 at 1:47 PM

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

Subject: [EXTERNAL] Vaccine Related Injury Assistance

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

Dr. Avindra Nath, Clinical Director/ Senior Investigator
NIH
Building 10-CRC Room 7C103
10 Center Drive
Bethesda, MD 20814

Dear Dr. Nath:

This is our second letter/email to NIH. I wrote to Dr. Collins in November, 2021. She forwarded the letter to the CDC. The CDC suggested [REDACTED] b6 physician contact CISA. Thus far each physician we have seen kicks us down the road to another "ologist" when they can't determine a simple solution or one that fits their background/expertise (if you are a hammer, everything is a nail), so we don't have one clear "go to" physician willing to contact CISA. We have been given your name as a contact. We hope we have better results with you.

[REDACTED] b6 has entered a trial through [REDACTED] b6 to help others find a solution to vaccine related and long haul Covid issues, but the trial offers no immediate remedy to its participants.

We need your help. Please take a few minutes to read this letter. Thank you.

After 23 doctor's visits (neurologists, virologists, infectious disease, ENT, cardiologist, functional, rheumatologist, primary care) and multiple tests [REDACTED] b6 it has been determined [REDACTED] b6 is "vaccine injured" following two Moderna vaccines.

Let me be clear, we are NOT anti-vaxers. We are NOT conspiracy theorists. Our interest is NOT monetary. Our interest is NOT legal. We are successfully retired, well educated professionals needing help with a vaccine related problem.

Pharma scientists, NIH, the CDC and the FDA combined to develop and approve a vaccine transmission system which seems to work well for the masses, but for a small percentage of the vaccinated population it causes intense pain and misery. **We just want a solution, a remedy, some direction, some help with [REDACTED] b6 condition.**

Since May 2021 she has suffered from memory loss, cognitive issues, headaches, nerve pain throughout her body, racing heart palpitations. She has lost weight, has trouble sleeping, can no longer drive. It is debilitating.

REL0000229496

The only thing standing between a healthy hiking, biking, gym passionate [b6] and her current condition were two Moderna vaccines.

We will make available all [b6] test results to you.

We have supplied this information to VAERS several times. Apparently, that is as far as it goes.

Will you help us? We you review our case? We both got vaccinated for the greater good, for the good of us individually as well as societally—but [b6] has been injured, severely injured.

Please don't let us down.

Thank you!

Sincerely,

b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 [b6]
Sent: 4/9/2022 1:13:25 AM
To: [b6]
CC: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6] Fouanta, Ladifatou (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=a5ebaa8d0da84114ab631d6a3b913706 [b6]
Subject: Re: [EXTERNAL] Vaccine Side Effects Root Cause and Treatment Plan

Dear [b6]

Sorry to hear of your ongoing symptoms and we appreciate your efforts in trying to find something that may treat them. However, we have no way of assessing the validity of these observations or the treatments. Also many of these things are way outside our area of expertise.

Best
Avi

From: [b6]
Date: Friday, April 8, 2022 at 3:10 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Cc: Safavi, Farinaz (NIH/NINDS) [E] [b6] Fouanta, Ladifatou (NIH/NINDS) [E]
[b6]
Subject: Re: [EXTERNAL] Vaccine Side Effects Root Cause and 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.

Hello Dr. Nath and Dr. Safavi,

I wanted to share an article that recently came out in Germany about post-vaccine syndrome: <https://www.medical-tribune.de/praxis-und-wirtschaft/praxismanagement/artikel/aerzte-melden-nebenwirkung-zu-selten/>

Here is a translation of a relevant section:

The administration of cholesterol and blood pressure lowering drugs, vitamin D plus a special diet have now proven to be the first therapy. "The control circuit via the ACE2 receptor is thus broken, the inflammation and the associated endothelial disease decrease," reports the cardiologist. He wants to encourage his patients: "Post-Vac can be cured, even if you have to be patient."

He considers the broad approach of plasma apheresis, with which autoantibodies and mini-clots are supposed to be washed out of the blood, to be less advisable. This therapy is also occasionally recommended in patient forums. "But this is an extremely complex and also immunocompromising procedure," warns Prof. Schieffer. The data so far only speak for a 50:50 chance of success.

What do you know about the ACE2 receptor, the spike protein and possible complications of vaccines? I was able to get in touch with several patients of this doctor and they are being prescribed [b6]
What are your thoughts on the hypothesis that somehow, in some of us, the spike protein continues to attach to cells, thus signaling to our body to destroy our own cells? That would explain the ongoing inflammation and why I keep feeling hot, malaise, fatigue, etc. Is there a specialist at the NIH that understands the process of the vaccine and could comment on the possibility of this happening and how the drugs above could help? Is there someone you know in academia or research that could comment? Do you know anyone else treating post-vaccine syndrome like this doctor in Germany?

REL0000229520

In addition, many patient report significant recovery after doing HBOT - hyperbaric oxygen therapy. I believe based on my symptoms of constant shortness of breath, complete muscle weakness and shaking and debilitating fatigue that not enough oxygen travels to my muscles as a result of the vaccine. I was extremely active before the vaccine and yet right after, I could not lift my hand due to weakness. It is not a result of the sedentary lifestyle I have been forced into, it was there from the start.

As you can see, I am at my wit's end with still feeling debilitated by this vaccine. All I want is to go back my pre-vaccine state. I am doing everything possible but I am so concerned with the lack of research happening to help situations like mine. Is there anything else at all I can do to further research into situations like mine?

Thank you,

b6

On Tue, Apr 5, 2022 at 1:28 PM [b6] wrote:

Hello Dr. Nath and Dr. Safavi,

It would be great if I could get [b6] Thank you.

I also wanted to share a note from [b6] the neurologist Dr. Safavi recommended:

b6

10:30 AM (1 hour ago)

[b6] As for research for post-vaccine reactions, NIH is doing most of this work. Johns Hopkins is also interested in studying patients with these issues also. Feel free to reach out to them and see if they have other ideas. [b6]

As you can see, she does not know how to treat me. Every doctor I have seen has said the same thing. She is telling me the NIH is doing work to study why many people have life-altering reactions like mine. I understand that my symptoms are systemic so what other avenues do I have to understand what is causing them and how to get treatment? We are being dismissed by doctors, and I have seen upwards of 20 of them. I complied with the vaccine mandate and I followed the guidance of the CDC. The CDC said that they take adverse reactions seriously. I don't understand where I am supposed to go to get treatment as my life has been drastically impacted by this mandated vaccine and I am a shell of the person I used to be. I am very thankful for your work with me but A YEAR LATER I am still suffering. All I wish is to return to the health I had before the vaccine. Who else is researching these reactions at the NIH, FDA and CDC? The doctors are looking to you to provide them with guidance.

I also wanted to see if you have advice on what to do in the meantime so I can survive this period. As you know,

b6

[b6] I know you have also treated patients with vaccine reactions with [b6] How successful was the treatments? Would you recommend it for me? Would you recommend [b6]

Lastly, I want to call urgency to the situation. Many of us are now reaching a year after our vaccines and that is too long to suffer like this. I lost my [b6] to these side effects. It has been a very long year of pain, suffering and torture. My job performance suffered for the first time in my life, my body no longer has muscle even though I used to be incredibly athletic, I am deeply depressed and my family is in ruins. Several people in my support group have committed suicide. We cannot keep bouncing from doctor to doctor, only to be told they don't know or it's not their area of expertise. These doctors are looking at the NIH for guidance. Only you can help us.

Thank you,

b6

On Fri, Mar 11, 2022 at 4:10 PM Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

REL0000229520

Dear [b6]

I am terribly sorry to hear of your ongoing illness. We are at a loss to know how to help. The symptoms below are more systemic and not neurological so probably now out of our area of expertise. All the tests that we had done did not suggest anything treatable. We can send you copies of the results if you have not received them yet.

With best wishes.

Avi

From: [b6]
Date: Friday, March 11, 2022 at 12:20 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6] Nath, Avindra (NIH/NINDS) [E]
[b6]
Cc: Fouanta, Ladifatou (NIH/NINDS) [E] [b6]
Subject: [EXTERNAL] Vaccine Side Effects Root Cause and 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.

Hi Dr. Safavi and Dr. Nath,

It has now been almost a year since I received the Pfizer vaccines and 6 months since we started working together. However, I am no closer to understanding the root cause of my debilitating symptoms nor a treatment plan that will address it. I have seen a plethora of specialists none of whom are equipped to handle complex and severe reactions to this new vaccine. The best they can offer are harsh drugs to address my symptoms that come with big risks and side effects.

When we first started working together, I sent you a list of my symptoms; they remain the same, if not more severe, as follows:

- Extreme muscle weakness, fatigue and malaise since vaccine
- Elevated temperature [b6]
- Sore throat and tonsils, chest pain, shortness of breath, feeling of inflammation in lungs
- Severe night sweats
- Dizziness and tinnitus
- Joint, muscle and back pain
- Heart palpitations
- Prolonged menstrual periods, change in cycle, bleeding and spotting outside of period (this has not resolved - my previous cycle was the longest I have ever had in my life)
- Rash of small red dots on arms, legs and torso (also not resolved)
- Weight loss and muscle degeneration (have not restored weight to baseline)
- Loss of appetite

- Twitching all over body
- Veins protruding
- Brain fog
- New allergies and constant reactions to food

None of these symptoms have resolved. Following your suggested protocol testing has been extremely stressful for my body and caused me significant setbacks. I am still experiencing [b6] and I will have [b6] for the rest of my life (I still don't have the result from them many months later). Has your research uncovered anything that can help?

Dr. Safavi and Dr. Nath - I am respectfully requesting that given the new and complex nature of reactions to these new vaccines, the extreme nature of my health condition and all the research data you have collected from me, that you continue to spearhead my case [b6] or any other specialist are not focused on vaccine cases like you are. They are not following the latest research. They cannot help.

In the meantime, I am seeing others with my post-vaccine issues develop severe, incurable, devastating medical conditions. Besides the above symptoms and constant inflammation, I am unable to exercise and have been forced to [b6] I still do not understand how a healthy, athletic [b6] that was an avid runner, hiker, biker and swimmer can become so disabled after the vaccine. I have no answers and my life is on hold as my condition is deteriorating. This whole situation has been devastating to me and my family. We had very high hopes for [b6] but it has not resolved my symptoms, while making my tinnitus worse and causing severe headaches, dizziness and blood clots.

I am wondering what else we can do to understand the root cause. Is it autoimmune? Is it Mast Cell Activation Syndrome? Is it the spike protein? Why is my condition so similar to Long COVID?

I am attaching [b6]
[b6]

Now, more than ever, there is a huge urgency to address my condition because I am not getting better and everyday that my body suffers from inflammation and symptoms puts it at risk for developing further complications. This is not a way to live and you are my only hope. Please help any way you can.

Thank you,

[b6]

On Thu, Mar 10, 2022 at 12:24 PM Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

I am out of office with limited access to my email.

It is completely fine to follow [b6] recommendations since she is the neurologist who eventually will follow and provide you with care.

Hope it helps.

Farinaz

From: [b6]
Sent: Thursday, March 3, 2022 10:34:25 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: [EXTERNAL] [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.

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. I have started taking [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] Her recommended treatment plan is [b6]
[b6]
[b6]

I am also seeing the following doctors in March:

March 17: rheumatologist

March 18: functional medicine for gut health, hormonal and nutritional testing

March 24: allergist/immunologist for calming allergies and [b6] advice

April 1: appointment with you!

I would love to hear your thoughts on [b6] in my case and especially if there is hope that giving my body and immune system a break from fighting can help it calm down permanently. I am scared of [b6]
[b6] There is no guarantee that they will be a permanent solution. Lastly, I of course want to run this by you to make sure it does not interfere with anything you have planned or recommend.

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 [b6] by any chance? I don't suspect [b6] but it would be good to know definitely.

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,

[b6]

From: [b6]
Sent: 8/29/2022 10:46:04 PM
To: Gavin, Angelique (NIH/NINDS) [C] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=6e97392e947e4f7ebb17eeb8ac87c5d5 [b6]
Subject: [EXTERNAL] Re: NIH COVID-19 Vaccine Study
Attachments: HIPAA Medical Record Release Blank (1) (1).pdf; [b6].pdf

On Mon, Aug 15, 2022 at 8:59 AM Gavin, Angelique (NIH/NINDS) [C] [b6] wrote:

Hello Andrea:

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

Bethesda, MD 20814-9692

[b6]

(office)

(cell)

(301) 480-5368 (efax)

[b6]

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

REL0000229765

-

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From: Gavin, Angelique (NIH/NINDS) [C] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=6E97392E947E4F7EBB17EEB8AC87C5D5 [b6]
Sent: 2/28/2022 4:24:56 PM
To: [b6]
Subject: NIH COVID-19 Vaccine Study info

Hello [b6]

Thank you for your interest in our COVID-19 vaccine study here at the NIH. I received your information from Dr. Avindra Nath. Our study is not yet underway. If you are interested in participating and being placed on our wait list, it will involve a telephone interview and online questionnaires about your experience. Let me know if you remain interested and I will contact you when the study is approved.

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: Gavin, Angelique (NIH/NINDS) [C] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=6E97392E947E4F7EBB17EEB8AC87C5D5] b6
Sent: 3/7/2022 5:17:00 PM
To: b6
Subject: RE: [EXTERNAL] Re: NIH COVID-19 vaccine study info

Thank you b6 for your quick reply! You will be contacted when the study is ready to accept participants. All my best to you in your recovery.

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, March 7, 2022 12:14 PM
To: Gavin, Angelique (NIH/NINDS) [C] b6
Subject: [EXTERNAL] Re: NIH COVID-19 vaccine study info

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Yes, I would be interested. Here is my contact information:

b6

On Mar 7, 2022, at 12:11 PM, Gavin, Angelique (NIH/NINDS) [C] b6 wrote:

Thank you b6 for your interest in our COVID-19 vaccine study here at the NIH. 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. The study is still in development. 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. I am looking forward to your reply.

Sincerely,

REL0000229918

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
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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: 3/31/2022 5:22:35 PM
To: [b6]
Subject: RE: NIH COVID-19 vaccine study info

Thank you [b6] This study will not be looking at neurological conditions associated with the vaccine immune response. Unfortunately, we are not involved with [b6] I recommend you sign up for <https://www.researchmatch.org>. This is a great site for studies all over the USA that [b6] may qualify for.

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, March 31, 2022 1:01 PM
To: Gavin, Angelique (NIH/NINDS) [C] [b6]
Cc: [b6]
Subject: [EXTERNAL] Re: NIH COVID-19 vaccine study info

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Angelique,

Thanks so much for reaching out. I will have [b6] contact you directly.

Will this study also be looking at neurological conditions associated with an immune response post-vaccine? Additionally, are there any [b6] you team is participating in? Dr. Nath connected us with [b6] but I have not yet heard from him.

Thanks,

[b6]

From: "Gavin, Angelique (NIH/NINDS) [C]" [b6]
Date: Thursday, March 31, 2022 at 11:54 AM

REL0000229919

To: [b6]

Subject: NIH COVID-19 vaccine study info

Hello: [b6]

I received your inquiry from Dr. Avindra Nath. I have a few resources for you and [b6]

NIH Begins Study of Allergic Reactions to Moderna, Pfizer-BioNTech COVID-19 Vaccines | NIH: National Institute of Allergy and Infectious Diseases
Vaccine Research Center | NIH: National Institute of Allergy and Infectious Diseases

My team is preparing a vaccine study but it is not yet underway. We will be doing telephone interviews and online questionnaires in order to collect as much information as we can from vaccine recipients who have had some form of reaction. If [b6] is interested in being on our wait list, please have him contact me directly. All my best to you and [b6]

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: Gavin, Angelique (NIH/NINDS) [C] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=6E97392E947E4F7EBB17EEB8AC87C5D5 [b6]
Sent: 4/1/2022 4:54:34 PM
To: [b6]
Subject: RE: [EXTERNAL] COVID-19 Vaccine Study

Thank you [b6] for your willingness to volunteer for our vaccine study. The study is not yet underway but should be approved soon. You will be contacted as soon as recruitment begins. 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, March 31, 2022 2:14 PM
To: Gavin, Angelique (NIH/NINDS) [C] [b6]
Cc: [b6]
Subject: [EXTERNAL] COVID-19 Vaccine Study

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.

Angelique,

Hello, my name is [b6] has been in communication with you regarding a developing study for people who experienced an adverse reaction after receiving the COVID-19 vaccine.

I am writing to you to express interest in this study. I am a [b6] male who suffered a neurological injury after receiving the vaccine and was given [b6] diagnosis that was confirmed by three separate neurologists.

I would love to share my story with you in further detail, and have listed my contact information below. Thank you so much for your time and consideration in this matter.

[b6]

From: Gavin, Angelique (NIH/NINDS) [C] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=6E97392E947E4F7EBB17EEB8AC87C5D5] [b6]
Sent: 8/31/2022 6:57:42 PM
To: [b6]
Subject: RE: [EXTERNAL] Re: NIH COVID-19 Vaccine Study

Thank you! I look forward to speaking with you then!

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, August 31, 2022 2:55 PM
To: Gavin, Angelique (NIH/NINDS) [C] [b6]
Subject: Re: [EXTERNAL] Re: NIH COVID-19 Vaccine Study

Yes, that works for me.

On Wed, Aug 31, 2022 at 11:50 AM Gavin, Angelique (NIH/NINDS) [C] [b6] wrote:

Thank you [b6] Would Monday, September 26 at 1:00 pm Eastern Standard Time work for you?

Angelique

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

REL0000229965

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: Wednesday, August 31, 2022 2:28 PM
To: Gavin, Angelique (NIH/NINDS) [C] **b6**
Subject: Re: [EXTERNAL] Re: NIH COVID-19 Vaccine Study

Hello,

I am available any of those days except the 29th from 3-4pm.

On Wed, Aug 31, 2022 at 7:43 AM Gavin, Angelique (NIH/NINDS) [C] **b6** wrote:

Hello **b6** I hope all is well. We have reviewed the medical records and would like to schedule your next interview which should take approximately 45 minutes to one hour of your time. I will be away on vacation so if you can provide some days and times starting from 9/21-30, I will respond with something that is best for us both. I am looking forward to speaking with you soon.

Sincerely,

Angelique

Angelique Gavin, MS (Contractor)

REL0000229965

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]

Sent: Tuesday, August 30, 2022 9:35 AM

To: **b6**

Subject: RE: [EXTERNAL] Re: NIH COVID-19 Vaccine Study

Thank you **b6** I was able to open your attachments. We will review your records and I'll get back to you soon.

Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

10 Center Drive

REL0000229965

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, August 29, 2022 6:46 PM
To: Gavin, Angelique (NIH/NINDS) [C]; **b6**
Subject: [EXTERNAL] Re: NIH COVID-19 Vaccine Study

On Mon, Aug 15, 2022 at 8:59 AM Gavin, Angelique (NIH/NINDS) [C]; **b6** wrote:

Hello **b6**

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

REL0000229965

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

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From: Gavin, Angelique (NIH/NINDS) [C] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=6E97392E947E4F7EBB17EEB8AC87C5D5] b6
Sent: 8/23/2022 7:59:06 PM
To: b6
Subject: RE: [EXTERNAL] Re: NIH COVID-19 Vaccine Study

Thank you! I will get back to you soon after we review. 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: Tuesday, August 23, 2022 3:24 PM
To: Gavin, Angelique (NIH/NINDS) [C] b6
Subject: [EXTERNAL] Re: NIH COVID-19 Vaccine Study

Hello,

Sorry for the delayed response. Here is the picture with the time stamp.

b6

On Mon, Aug 15, 2022 at 8:59 AM Gavin, Angelique (NIH/NINDS) [C] [b6] wrote:

Hello [b6]

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

Bethesda, MD 20814-9692

b6

(office)

(cell)

(301) 480-5368 (efax)

[b6]

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

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REL0000229973

From: Gavin, Angelique (NIH/NINDS) [C] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=6E97392E947E4F7EBB17EEB8AC87C5D5 [b6]
Sent: 11/4/2022 1:28:30 PM
To: [b6]
Subject: RE: [EXTERNAL] Re: NIH Vaccine Study

Hi [b6] A PDF attachment should suffice.

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: [b6]
Sent: Friday, November 4, 2022 12:14 AM
To: Gavin, Angelique (NIH/NINDS) [C] [b6]
Subject: [EXTERNAL] Re: NIH Vaccine Study

Hi Angelique,

I understand your email is encrypted, but how do I send the form back? Just as a regular PDF attachment or is there another step I need to take?

On Oct 27, 2022, at 1:43 PM, Gavin, Angelique (NIH/NINDS) [C] [b6] wrote:

<Mail Attachment.png>

Gavin, Angelique (NIH/NINDS) [C] [b6] has sent you an encrypted email.
Please verify your identity at the link below to access the encrypted email.



View encrypted email

REL0000229977

You have been sent an email that has been encrypted. You will need to validate your identity in order to access the content of the message.

By clicking, 'View encrypted email', you understand and agree to the following: You are accessing a U.S. Government system hosted by Microsoft; NO EXPECTATION OF PRIVACY - System use indicates consent to monitoring, recording, and auditing of activity; and Unauthorized use is prohibited and subject to criminal, civil, security, or administrative proceedings and/or penalties. For more information on the NIH Web Policies and Notices, please visit: <https://www.nih.gov/web-policies-notices> For the Microsoft privacy statement, please click below:

[Privacy Statement](#)

[Learn More](#) on email encryption.

Microsoft Corporation, One Microsoft Way, Redmond, WA 98052

<message_v4.rpmsg>

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From: [b6]
Sent: 5/18/2021 1:05:27 PM
To: Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540 [b6]
Subject: Re: [b6]

Thank you Amanda's

Sent from my iPhone

On May 18, 2021, at 8:15 AM, Wiebold, Amanda (NIH/NINDS) [E] [b6] wrote:

Hello [b6]

I can request [b6] be sent to you.

Thanks,
Amanda

From: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Sent: Monday, May 17, 2021 7:02 PM
To: [b6] Wiebold, Amanda (NIH/NINDS) [E]
[b6]
Subject: Re: [b6]

Hi [b6]
I really do not know answer of your question. I cc Amanda who may be able to help.
Thanks

Farinaz

From: [b6]
Sent: Monday, May 17, 2021 2:05:17 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Re: [b6]

Hi Dr. Safavi,

I asked [b6] if there was anything to be concerned with with the information I sent you - which he said he spoke to you about. It sounds like I should touch base with an [b6] in order to do so, he had said I should bring a copy of my scans. Is this something you can provide to me? As it is not on the scans I am obtaining for you guys on the [b6]

Please let me know.
Thanks

[b6]

On Wed, May 12, 2021 at 10:55 AM [b6] wrote:

REL0000230004

Hi Dr. Safavi,

Doing well, no new symptoms or weird things happening. I did notice on the results: [REDACTED] b6

[REDACTED] b6

[REDACTED] b6

[REDACTED] b6

Wondering if you think there is anything I should do about that? Any testing I should get done or anything to worry about? Will let you know when I have more intel on when to expect my scans! Sorry it is taking so long to get them.

Thanks,

[REDACTED] b6

On Tue, May 11, 2021 at 5:25 PM Safavi, Farinaz (NIH/NINDS) [E] [REDACTED] b6 wrote:

Hi [REDACTED] b6

How are you doing?

Thank you very much for following up about it. Really appreciate it.

Farinaz

From: [REDACTED] b6

Sent: Tuesday, May 11, 2021 2:17:19 PM

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

Subject: Re: [REDACTED] b6

Hi Dr. Safavi,

I wanted to let you know I had called both [REDACTED] b6 locations and have sent in the documents to retrieve my files. I am not getting anywhere with the phone numbers, so I am going to try to go to each location and see if I can confirm they have received my request and will send through as soon as I have them.

Just wanted to keep you updated.

Thanks,

[REDACTED] b6

On Thu, Apr 29, 2021 at 10:22 AM Safavi, Farinaz (NIH/NINDS) [E] [REDACTED] b6 wrote:

No Dear,

We are good. Can wait for original CD. We also see [REDACTED] b6

[REDACTED] b6

Best

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: [b6]
Sent: Thursday, April 29, 2021 10:20 AM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: [b6]

Hi Dr. Safavi,

Would it be helpful if I took screen shots of any of [b6] images that I have access to? Is there a way I can give you my log in to MyChart so you could view everything yourself? The other thing is I can send the notes from all of the reports and then if you want specific pictures ahead of the discs finally getting to me and then to you -- I am happy to share those as well. Let me know if these are helpful or if there are other images I can send ahead of the discs coming?

Best,

[b6]

[b6]

[b6]

b6

b6

b6

From: [b6]
Sent: 5/24/2021 1:43:03 PM
To: Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540 [b6]
Subject: Re: MRI/CT ahead of CDs

No problemo, I will eventually get it, I am sure! Thanks

On Mon, May 24, 2021 at 9:36 AM Wiebold, Amanda (NIH/NINDS) [E] [b6] wrote:

Oh that is terrible. It is just annoying to have to deal with those types of hassles on top of everything else! I wish you luck!

From: [b6]
Sent: Monday, May 24, 2021 9:28 AM
To: Wiebold, Amanda (NIH/NINDS) [E] [b6]
Subject: Re: [b6]

Haha, well your department is wonderful. I have been trying to figure out [b6] system... I call and no one picks up, or I get bounced around... I filled out a form that doesn't go anywhere and I am about to go to 2 different hospitals to get [b6] but the one time I did get someone they said if I just show up I will have to go a few times to actually get them haha. Though, they make it super easy for me to access online but no way to forward them!

Happy Monday!

[b6]

On Mon, May 24, 2021 at 8:44 AM Wiebold, Amanda (NIH/NINDS) [E] [b6] wrote:

Hahaha. I take no credit. I just request them. The medical records department does all the work! I am glad you got it quickly!

Thanks,

Amanda

REL0000230012

From: [b6]
Sent: Sunday, May 23, 2021 9:36 PM
To: Wiebold, Amanda (NIH/NINDS) [E] [b6]
Subject: Re: [b6]

Hi [b6]

I received [b6] thank you! Do you have any tips how I can get mine to you guys quicker? I have called [b6] and filled out forms for them to get them to you. I will physically go to each hospital this week if I can get them on the phone and that will help, but you were so quick I wondered if you had any hot tips for me!

Thanks again,

[b6]

Sent from my iPhone

On May 18, 2021, at 8:15 AM, Wiebold, Amanda (NIH/NINDS) [E]
[b6] wrote:

Hello [b6]

I can request [b6] be sent to you.

Thanks,

Amanda

From: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Sent: Monday, May 17, 2021 7:02 PM
To: [b6] Wiebold, Amanda (NIH/NINDS) [E]
[b6]
Subject: Re: [b6]

Hi [b6]

I really do not know answer of your question. I cc Amanda who may be able to help.

Thanks

Farinaz

From: [b6]
Sent: Monday, May 17, 2021 2:05:17 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Re: [b6]

Hi Dr. Safavi,

I asked [b6] if there was anything to be concerned with with the information I sent you - which he said he spoke to you about. It sounds like I should touch base with an [b6] In order to do so, he had said I should bring a copy of my scans. Is this something you can provide to me? As it is not on the scans I am obtaining for you guys on the [b6]

Please let me know.

Thanks

[b6]

On Wed, May 12, 2021 at 10:55 AM [b6] wrote:

Hi Dr. Safavi,

Doing well, no new symptoms or weird things happening. I did notice on the results **b6**

b6

b6

b6

Wondering if you think there is anything I should do about that? Any testing I should get done or anything to worry about? Will let you know when I have more intel on when to expect my scans! Sorry it is taking so long to get them.

Thanks,

b6

On Tue, May 11, 2021 at 5:25 PM Safavi, Farinaz (NIH/NINDS) [E]

b6

wrote:

Hi **b6**

How are you doing?

Thank you very much for following up about it. Really appreciate it.

Farinaz

From: [b6]
Sent: Tuesday, May 11, 2021 2:17:19 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Re: [b6]

Hi Dr. Safavi,

I wanted to let you know I had called both [b6] locations and have sent in the documents to retrieve my files. I am not getting anywhere with the phone numbers, so I am going to try to go to each location and see if I can confirm they have received my request and will send through as soon as I have them.

Just wanted to keep you updated.

Thanks,

[b6]

On Thu, Apr 29, 2021 at 10:22 AM Safavi, Farinaz (NIH/NINDS) [E]

[b6]

wrote:

No Dear,

We are good. Can wait for original CD. We also see

[b6]

[b6]

Best

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: [b6]
Sent: Thursday, April 29, 2021 10:20 AM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: [b6]

Hi Dr. Safavi,

Would it be helpful if I took screen shots of any of [b6] images that I have access to? Is there a way I can give you my log in to MyChart so you could view everything yourself? The other thing is I can send the notes from all of the reports and then if you want specific pictures ahead of the discs finally getting to me and then to you -- I am happy to share those as well. Let me know if these are helpful or if there are other images I can send ahead of the discs coming?

Best,
[b6]

[b6]

b6

b6

b6

From: [b6]
Sent: 9/30/2021 8:06:08 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
CC: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6] Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540 [b6]
Subject: Re: Forgot to mention

Thank you!

Sent from my iPhone

On Sep 30, 2021, at 2:54 PM, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

Thank you for reaching out.

We do not have any data to suggest for or against booster shot but the consensus among our team is not to take if patient develop significant neurological complications post vaccine.

I highly suggest that you discuss with your physicians [b6] and make a decision in this case.

Hope it helps

Farinaz

From: [b6]
Sent: Thursday, September 30, 2021 2:50 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Re: Forgot to mention

Hi Dr. Safavi,

Hope you are well. I wanted to touch base since the booster is now becoming available -- do you think when I am eligible I should go ahead and get it?

From my end, nothing has really changed, I think my ears are still off, but I have gotten used to it -- but I haven't had any new symptoms.

Thanks,

[b6]

On Mon, Jun 28, 2021 at 2:12 PM Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

It seems that everyone is out for long weekend. I guess we have to wait until after holiday to even start the process. I will let you know.

Best

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: [b6]
Sent: Thursday, June 24, 2021 11:18 AM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Re: Forgot to mention

Hi Dr. Safavi,

Just wanted to follow up, [b6]
[b6] and I have to follow up in 6
months. Wanted to keep you posted.

Thanks,

[b6]

On Tue, Jun 22, 2021 at 1:56 PM [b6] wrote:

Hey Dr. Safavi,

I forgot to mention - I am going to be in the area from Jun 30th - July 5th visiting [b6]
[b6] I am flying in on the 30th and flying out on the 5th. I could come
down sooner or extend if you wanted. Just figured I would let you know.

Thanks,

[b6]

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246; b6]
Sent: 10/23/2021 8:06:41 PM
To: b6
CC: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6; b6] Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540; b6]
Subject: RE: Forgot to mention

Hi; b6

I spoke with b6 about your case and he would be able to send some tests and based on those test results we can decide how to proceed.
Hope it helps.

Farinaz

From: b6
Sent: Thursday, October 21, 2021 11:14 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
Cc: Nath, Avindra (NIH/NINDS) [E]; Wiebold, Amanda (NIH/NINDS) [E]
Subject: Re: Forgot to mention

Hi Dr. Safavi,

I reached out to b6 today and he said to get in touch with you to see if you had any suggestions as today I had an episode where my eyelid started dropping again, I didn't have any double vision but it was my right eye lid again. I have had some strange ear pain the past few nights which hasn't seemed too alarming but also figured I would mention. I have attached 2 pictures of my eye, 1 looking straight on and 1 trying to lift it up.

Thanks!

b6

b6

b6

Sent from my iPhone

On Sep 30, 2021, at 2:54 PM, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

Thank you for reaching out.

We do not have any data to suggest for or against booster shot but the consensus among our team is not to take if patient develop significant neurological complications post vaccine.

I highly suggest that you discuss with your physicians [b6] and make a decision in this case.

Hope it helps

Farinaz

From: [b6]

Sent: Thursday, September 30, 2021 2:50 PM

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

Subject: Re: Forgot to mention

Hi Dr. Safavi,

Hope you are well. I wanted to touch base since the booster is now becoming available -- do you think when I am eligible I should go ahead and get it?

From my end, nothing has really changed, I think my ears are still off, but I have gotten used to it -- but I haven't had any new symptoms.

Thanks,

[b6]

On Mon, Jun 28, 2021 at 2:12 PM Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

It seems that everyone is out for long weekend. I guess we have to wait until after holiday to even start the process. I will let you know.

Best

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

REL0000230016

From: [REDACTED] b6
Sent: Thursday, June 24, 2021 11:18 AM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Re: Forgot to mention

Hi Dr. Safavi,

Just wanted to follow up, [REDACTED] b6
[REDACTED] b6 and I have to
follow up in 6 months. Wanted to keep you posted.

Thanks,

[REDACTED] b6

On Tue, Jun 22, 2021 at 1:56 PM [REDACTED] b6 wrote:

Hey Dr. Safavi,

I forgot to mention - I am going to be in the area from Jun 30th - July 5th visiting [REDACTED] b6
[REDACTED] b6 I am flying in on the 30th and flying out on the
5th. I could come down sooner or extend if you wanted. Just figured I would let you know.

Thanks,

[REDACTED] b6

From: [REDACTED] b6
Sent: 5/20/2021 3:41:23 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group
(FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [REDACTED] b6
Subject: Consent form [REDACTED] b6
Attachments: Photo.pdf

Sent from my iPhone

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.



From: [b6]
Sent: 3/31/2021 1:16:13 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: Myself

Sorry my whole head is numb right now and I feel terrible. When I get like this, I don't know how to get relief.

Sent from my iPhone

On Mar 30, 2021, at 6:06 PM, [b6] wrote:

That would be great. I will look forward to speaking with you. Sorry, I did not know that you cannot give me medical advice. Is it possible for you to be a treating physician or consultant for me? Unfortunately, my neurologist knows nothing about this and has been completely unhelpful with no recommendations. I will ask her what the outcome was of my case being presented at the CDC grand Rounds last week. She is very slow to respond to me and has had no suggestions for me up until now. It has been impossible to get care in the community as no doctors know about these reactions and think they are all psychogenic. The neurologist that I saw before this one had no ideas as well. Maybe after we speak on Monday, I will ask you to communicate with my current neurologist and try to educate her about this reaction so someone can help me. I feel very alone on this terrible journey.

[b6]

Sent from my iPhone

On Mar 30, 2021, at 5:55 PM, Safavi, Farinaz (NIH/NINDS) [E]
[b6] wrote:

Hi [b6]

As we discussed before, I can not give you any medical advice since we are not your treating physician. I understand your concerns and I believe the best approach here is seeing your neurologist and discuss your concerns with her/him. I would be happy to communicate our understandings about vaccine related side effects with your neurologist as well and share our thoughts. I am quite swamped this week but we can have a short meeting on Monday at 12 noon ET if it works for you.
Best Regards,

Farinaz

From: [b6]
Sent: Tuesday, March 30, 2021 7:03:24 PM

REL0000230290

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

Subject: Re: Myself

Hi Farinaz,

I am continuing to have ups and downs. I am never symptom-free but I have days when my symptoms are mild and I am more functional. Yesterday I had a good day with only mild symptoms. Today, I am having more severe paresthesias in my face, tongue, scalp, eyes and the tight band around my chest. I am in bed because I am very uncomfortable. I am crying. I feel that overall I am getting better but I still have some bad days like today.

I would very much like to have a short visit with you if possible. I know that [b6] [b6] spoke about me and recommend that I [b6] [b6] I am also awaiting a [b6] [b6]

Honestly, if I am going to continue to slowly improve and if there is no downside to waiting, I would prefer to hold off on more tests and treatments with potential risks.

On the other hand, my symptoms fluctuate from day today and I am very worried that I will not recover.

If possible, I would like to talk to you about treatment strategy.

Thank you for all your help,

[b6]

Sent from my iPhone

On Mar 27, 2021, at 8:39 AM, [b6]

[b6] wrote:

Thank you Farinaz. I would love to have a brief visit next week. What would be a good time for you? I will tell the other patient who is confused about what Dr. Fletcher told her to call her for clarification. Maybe she did not understand correctly what Dr. Fletcher told her.

Thank you for everything.

[b6]

Sent from my iPhone

On Mar 27, 2021, at 8:13 AM, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

Thank you for your email. I would be happy to help other patients if I can.

You cc me in [b6] email last time. I understand they bring up the possibility of

b6

[b6] We all are currently learning about COVID infection and vaccines so that I would be cautious to come up with any statement about causality of your symptoms. I understand [b6]

b6

so that I prefer to stick to our evidence based approach until we know more about the condition.

What is clear here that you have developed immediate reaction to the vaccine with some systemic symptoms continued by evolution of neuropathic features [b6] We know as a fact that immune mediated neurological complications can happen post vaccination and post infection. COVID is not an exception either.

What kind of immune reaction lead to neurological complications of COVID vaccines are what we all try to understand. We have some hypothesis but we need to go through an accurate process to first define the disease and gather all clinical information that can help us to recognized the cause and pave the path to suggest a treatment.

Being symptom free for several days is a good news. Based on our knowledge from the past we usually expect the immune mediated reactions fade away by time but I believe if you still experience bothersome symptoms you should be seen by a neueologist and discuss further work up [b6] and consider further treatments. In our experience, [b6]

b6

I also would like to emphasize one point here. Not everyone with vaccine reaction has the same disease. As physicians, we all know variety of illnesses can present with similar symptoms but they do not end up to be similar diseases and we all need to be very vigilant about this fact. Unfortunately I can not share other patients information with you due to patient privacy policies but we would be happy to communicate with anyone contacted us directly.

We can quickly e-meet next week and chat if you think that helps you understand the process better.

Please let me know if you have any concerns or questions.
Best Regards,
Farinaz

From: [REDACTED] b6
Sent: Friday, March 26, 2021 9:38:20 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
[REDACTED] b6
Subject: Myself

Hi Farinaz,

Thank you so much for seeing so many people that I have collected over the last few weeks who have had similar reactions to mine.

I thought I was feeling better and had four or five good days in a row with only mild symptoms. Late yesterday, the symptoms became severe again with severe paresthesias in my face and scalp and tongue and chest band tightness. It was quite miserable and lasted all afternoon and evening. I had severe muscle spasms in my scalp and jaw and even my gums and teeth hurt. I feel better today. I am [REDACTED] b6

b6

b6

b6 And **b6**
spoke and recommended that I **b6**
b6

My case was Supposedly presented to the CDC grand Rounds this week but I have not heard anything from my private neurologist who asked for the consultation.

One of the patients in our group **b6** saw Anita Fletcher in your group who did not feel the vaccine caused her reaction but thought that she had **b6** Maybe the patient is confused. She asked me to ask you if you could speak to Dr. Fletcher to clarify. It sounds like she had a vaccine reaction.

Thanks so much for everything Farinaz. I am so sorry I have sent so many people your way. Hopefully you're going to figure out what is going on with all of us.

Sincerely,

b6

Sent from my iPhone

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246; [b6]
Sent: 5/25/2021 12:34:47 AM
To: [b6]
Subject: Re: post vaccine adverse events

[b6]

I spoke to her. She is a fantastic physician and she will help you to get a proper treatment.
Im sure we are on the right track.
Have a good night
please send me the consent form that we can send you the kit for blood draw before you get any further treatment.

Farinaz

From: [b6]
Sent: Monday, May 24, 2021 8:00:08 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Re: post vaccine adverse events

No not until [b6]

Sent from my iPhone

On May 24, 2021, at 4:41 PM, Safavi, Farinaz (NIH/NINDS) [E] [b6]
wrote:

Thats a great progress. Have you done [b6]

Farinaz

From: [b6]
Sent: Monday, May 24, 2021 7:39:44 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Re: post vaccine adverse events

Waiting for [b6] but that's it.

Sent from my iPhone

On May 24, 2021, at 4:35 PM, Safavi, Farinaz (NIH/NINDS) [E]
[b6] wrote:

No rush! one more question
what tests she plans to do?

Farinaz

From: [b6]
Sent: Monday, May 24, 2021 7:34:24 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Re: post vaccine adverse events

I can when I get home. I'm still out. Hopefully you can use the photo until I get it to you

Sent from my iPhone

On May 24, 2021, at 4:30 PM, Safavi, Farinaz (NIH/NINDS) [E]
[b6] wrote:

Can you scan and send me the signed consent form instead of photo ?

Farinaz

From: [b6]
Sent: Monday, May 24, 2021 7:18:23 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Re: post vaccine adverse events

I only have the office number. She is at the [b6] location today

[b6]

Her asst name is [b6]

They are there today for another 45 min.

Sent from my iPhone

On May 24, 2021, at 4:13 PM, Safavi, Farinaz
(NIH/NINDS) [E] [b6] wrote:

please send me her name and phone number

Farinaz

From: [b6]
Sent: Monday, May 24, 2021 7:12:14 PM

REL0000230666

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

[b6]

Subject: Re: post vaccine adverse events

Yes I have her your contact info and told her you would like to speak w her. I'm hoping she reaches out soon but she didn't tell me when.

Sent from my iPhone

On May 24, 2021, at 4:10 PM,
Safavi, Farinaz (NIH/NINDS) [E]
[b6] wrote:

Can you connect me with your
neurologist?

Farinaz

From: [b6]
[b6]
Sent: Monday, May 24, 2021 7:05:00 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
[b6]
Subject: Re: post vaccine adverse events

Hi Dr Safavi,

I just got out of my neurology appointment and she seems to think I [b6] that I need to go see a rheumatologist to look further into it. My left arm falling asleep while not being compressed is also a mystery. I'm working on getting the other labs for you [b6] I'm not sure what kit you are referring to but I'm open to help the research in any way that I can.

Thanks

[b6]

[Get Outlook for iOS](#)

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

[b6]

Sent: Monday, May 24, 2021 3:56:13 PM

To: [b6]

[b6]

Cc: Gustafson, Lindsey (NIH/NINDS) [E]

[b6]

Nath, Avindra (NIH/NINDS) [E]

[b6]

Subject: Re: post vaccine adverse events

Dear [b6]

Lee informed me about your trigeminal neuralgia pain. I am really sorry that you have been experiencing worsening of your symptoms.

We had a discussion in our team regarding how we would like to proceed and unfortunately we do not have active clinical trial protocol to be able to bring patients here and treat them at this point.

I would be more than happy to speak with your neurologist and share our understanding about your symptoms which may help you receive proper treatments. Since Amanda went through the consent form, I will sign the page you already sent it and put it in your file. We can arrange to send you a kit and you can send us [b6] if you are interested in participating in our research.

Please do not hesitate to share my email address with your neurologist and I would be more than happy to speak with them.

Best Regards,

Farinaz

From: [b6]

[b6]

Sent: Thursday, May 20, 2021,
11:42 AM
To: Safavi, Farinaz (NIH/NINDS)
[E]
Subject: Consent form [b6]
[b6]

Sent from my iPhone

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246; [b6]
Sent: 5/25/2021 12:02:58 AM
To: [b6]
Subject: Re: post vaccine adverse events

Its ok,I will do my best to speak with her.try to see a Rheum if you can to exclude other possibilities however

[b6]

Farinaz

From: [b6]
Sent: Monday, May 24, 2021 8:00:08 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Re: post vaccine adverse events

No not until [b6]

Sent from my iPhone

On May 24, 2021, at 4:41 PM, Safavi, Farinaz (NIH/NINDS) [E] [b6]
wrote:

Thats a great progress.Have you done [b6]

Farinaz

From: [b6]
Sent: Monday, May 24, 2021 7:39:44 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Re: post vaccine adverse events

Waiting for [b6] but that's it.

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[b6] wrote:

No rush!one more question
what tests she plans to do?

Farinaz

From: [b6]
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From: [b6]
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Subject: Re: post vaccine adverse events

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[b6]

Her asst name is [b6]

They are there today for another 45 min.

Sent from my iPhone

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Farinaz

From: [b6]
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To: Safavi, Farinaz (NIH/NINDS) [E]
[b6]
Subject: Re: post vaccine adverse events

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Sent from my iPhone

On May 24, 2021, at 4:10 PM,
Safavi, Farinaz (NIH/NINDS) [E]
[b6] wrote:

Can you connect me with your
neurologist?

Farinaz

From: [b6]
[b6]
Sent: Monday, May 24, 2021 7:05:00
PM
To: Safavi, Farinaz (NIH/NINDS) [E]
[b6]
Subject: Re: post vaccine adverse
events

Hi Dr Safavi,

I just got out of my neurology
appointment and she seems to think I
[b6] and
that I need to go see a rheumatologist
to look further into it. My left arm
falling asleep while not being
compressed is also a mystery. I'm
working on getting the other labs for
you from [b6] I'm not sure what
kit you are referring to but I'm open
to help the research in any way that I
can.

Thanks

[b6]

Get Outlook for iOS

From: Safavi, Farinaz (NIH/NINDS) [E]
[b6]
Sent: Monday, May 24, 2021 3:56:13
PM

To: [b6]
[b6]
Cc: Gustafson, Lindsey (NIH/NINDS) [E]
[b6] Nath,
Avindra (NIH/NINDS) [E]
[b6]
Subject: Re: post vaccine adverse events

Dear [b6]
Lee informed me about your trigeminal neuralgia pain. I am really sorry that you have been experiencing worsening of your symptoms.

We had a discussion in our team regarding how we would like to proceed and unfortunately we do not have active clinical trial protocol to be able to bring patients here and treat them at this point.

I would be more than happy to speak with your neurologist and share our understanding about your symptoms which may help you receive proper treatments. Since Amanda went through the consent form, I will sign the page you already sent it and put it in your file. We can arrange to send you a kit and you can send us your [b6] if you are interested in participating in our research.

Please do not hesitate to share my email address with your neurologist and I would be more than happy to speak with them.

Best Regards,

Farinaz

From: [b6]
[b6]
Sent: Thursday, May 20, 2021, 11:42 AM
To: Safavi, Farinaz (NIH/NINDS) [E]

Subject: Consent form: **b6**
b6

Sent from my iPhone

From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246] b6
Sent: 5/24/2021 11:27:06 PM
To: b6
Subject: Re: post vaccine adverse events

I spoke with b6 and left my cell phone number. I will do my best to speak with her.

Is she neuromuscular specialist?

Farinaz

From: b6
Sent: Monday, May 24, 2021 7:18:23 PM
To: Safavi, Farinaz (NIH/NINDS) [E] b6
Subject: Re: post vaccine adverse events

I only have the office number. She is at the b6 location today .

b6

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please send me her name and phone number

Farinaz

From: b6
Sent: Monday, May 24, 2021 7:12:14 PM
To: Safavi, Farinaz (NIH/NINDS) [E] b6
Subject: Re: post vaccine adverse events

Yes I have her your contact info and told her you would like to speak w her. I'm hoping she reaches out soon but she didn't tell me when.

Sent from my iPhone

On May 24, 2021, at 4:10 PM, Safavi, Farinaz (NIH/NINDS) [E]

[b6] wrote:

Can you connect me with your neurologist?

Farinaz

From: [b6]
Sent: Monday, May 24, 2021 7:05:00 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Re: post vaccine adverse events

Hi Dr Safavi,

I just got out of my neurology appointment and she seems to think I [b6] [b6] and that I need to go see a rheumatologist to look further into it. My left arm falling asleep while not being compressed is also a mystery. I'm working on getting the other labs for you from [b6] I'm not sure what kit you are referring to but I'm open to help the research in any way that I can.

Thanks

[b6]

Get Outlook for iOS

From: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Sent: Monday, May 24, 2021 3:56:13 PM
To: [b6]
Cc: Gustafson, Lindsey (NIH/NINDS) [E] [b6] Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Re: post vaccine adverse events

Dear [b6]

Lee informed me about your trigeminal neuralgia pain. I am really sorry that you have been experiencing worsening of your symptoms.

We had a discussion in our team regarding how we would like to proceed and unfortunately we do not have active clinical trial protocol to be able to bring patients here and treat them at this point.

I would be more than happy to speak with your neurologist and share our understanding about your symptoms which may help you receive proper treatments. Since Amanda went through the consent form, I will sign the page you already sent it and put it in your file. We can arrange to send you a kit and you can send us your [b6] if you are interested in participating in our research.

Please do not hesitate to share my email address with your neurologist and I would be more than happy to speak with them.

Best Regards,

REL0000230701

Farinaz

From: [REDACTED] b6
Sent: Thursday, May 20, 2021, 11:42 AM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Consent form [REDACTED] b6

Sent from my iPhone

From: [b6]
Sent: 5/24/2021 7:37:20 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Covid-19 vaccine reaction set back

Good Afternoon Doctor Safavi,

I am reaching out to you once again to let you know that I am having a very bad set-back in my progress to health. I reached out to a doctor that has been treating covid long haul patients, and he suggested [b6]
[b6] I have taken [b6]

You had reached out to my Neurologist here, with no response back to you or me. He has dismissed my issues since day one, so it wasn't a shocker that when he said he was dismissing me, that he washed his hands of me. If you know of a good neurologist that you could collaborate with-in the [b6] area? I will go!

I would also be more than happy, at this point, to come to Maryland to see you, but I would have to make advanced arrangements for myself to get there, and then for [b6]

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

I'm sorry to whine, but I just need help! I have been reading that this is being recognized by physicians better than it was [b6] when I first started this journey, but I just have very limited resources here in my small town.

I have an appointment with my Allergist/Immunologist June 10th. I am going to see if he can order [b6]
[b6] I have heard that [b6] are really the only tx options at this point, but there has to be an underlying cause. My only underlying cause is still only the vaccine. [b6]
[b6] There has to be an answer, and I have spent [b6] searching.

I would just appreciate some direction again.

Thank you, as always, for your time!

[b6]

From: [b6]
Sent: 5/21/2021 6:25:33 PM
To: Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540 [b6] Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Vaccine Neuro Reaction

Hello,

My name is [b6] I was given your name as I am in a group who have experienced neurological reactions to the vaccine. I'd like to share my story with you and see if you have any recommendations! Thank you in advance.

I am a [b6] female from [b6] with no prior health conditions/issues, not even allergies. I am a former [b6] and current young professional working from home who eats anti-inflammatory and exercises regularly, and have not had Covid-19. I received the Moderna dose #1 on [b6] Hours later the back of my neck went completely stiff, and I felt intense tingling in the back of my head/scalp. My face started burning and felt very stiff like my neck. The next day (and ever since) I've experienced tingling in my face, particularly the left side of my nose. For the next week I had lots of face/scalp tingling, chest tightness, face stiffness, dizziness, brain fog, tiredness, intense back pain, sound sensitivity, sensations in the injection side hand, and plugged ears. Sometimes the back pain would travel from my ribs and down to my glutes/hamstrings. One week after the shot, I had an intense headache on the injection side from the top of my head, down my neck and jaw, and down to my collar bone/shoulder. It was especially bad/sensitive behind my ears. I still experience the behind ear pain, intermittently on the injection side. When I had the left side head pain, I experienced significant tightness in my left side forehead/eyelid - it felt like my eyelid was opening slower than the other after blinking. Intense muscle spasms began Day 7. Day 10 I noticed eye floaters - sometimes appearing like blurry spots but most of the time they are black. Day 15 I also noticed face swelling - big dents on my nose where my glasses rested. On Day 21, buzzing sensations began in my calves and have now moved to my feet. It is also in my right hand. Eye floaters, face tingling, leg/feet buzzing, hand/feet cramping, and random muscle twitching continue now at [b6] The face tingling has reduced significantly and I can tell that hiking/exercising, reducing stress/meditating, and sleeping full 8-9 hours definitely helps my symptoms.

I have seen my primary care, neurologist, and eye specialist, who conducted [b6]

[b6]

I have taken [b6]

[b6]

[b6]

As I read about Covid long-haulers I'm curious about the relationship. I am wondering if [b6]

[b6]

Additionally, I started my period the day after the shot so wondering if a hormone imbalance led me susceptible. [b6]

[b6]

I'm very interested in any thoughts/research as I was completely healthy before this. Thank you in advance if you have any thoughts you could provide or if you'd like to discuss further.

Thank you!!!

[b6]

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 [b6]
Sent: 1/14/2021 11:46:33 PM
To: [b6] Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540 [b6] Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6] Smith, Bryan (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=de7bf3d6ad0046288fd8c35f33de3e57 [b6]
Subject: Re: AZD-1222 adverse reactions

Dear [b6]
That is wonderful! Thanks.

Dear Amanda,
Farinaz and I just spoke with [b6] who developed a constellation of neurological symptoms following the Astra Zeneca vaccine. Would it be possible to consent her on 15-N for samples only. She will send medical records to us. Would it be possible to mail her a kit for collection of a new blood sample as well. They can get the blood drawn at a local clinic.

Thanks.
Avi

From: [b6]
Date: Thursday, January 14, 2021 at 5:56 PM
To: "Nath, Avindra (NIH/NINDS) [E]" [b6]
Subject: Re: AZD-1222 adverse reactions

Dr. Nath,

I have located [b6] I can collect it and send that along with the blood samples in the kit or the lab will send it directly to you if you have a way to pay for shipping.

The latter sample (11-19-2020) was discarded.

Thank you so much for speaking with us today.

b6

On Jan 11, 2021, at 11:26 AM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]
Sorry to hear of [b6] illness. I would be glad to speak to you and [b6] to see how we can help. Warren can help set up a virtual meeting. I will request Drs. Smith and Safavi, Neurologists who works with me to join me.
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 (cell)

b6

From: b6

Date: Monday, January 11, 2021 at 1:13 PM

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

Subject: AZD-1222 adverse reactions

Dr. Nath,

b6 participated in the phase 3 clinical trial of the AstraZeneca AZD1222 covid-19 vaccine. Beginning shortly after vaccination on b6 and continuing to present, she has had serious neurological complications. Double vision, tinnitus, hyperacusis, paresthesias, autonomic problems such as heart palpitations and tachycardia, tremors, leg weakness, trouble walking, numbness, tingling, low-grade fevers and a very pronounced vibration sensation in her brain/head.

b6

b6 She has been denied the second shot and unblinded, she received vaccine.

b6 has been disabled by this, b6

She has also made contact via support forums with another woman in b6 who had the vaccine 10 days later and is experiencing almost every single symptom.

AstraZeneca seems only concerned with a diagnosis that absolves them in these matters.

I read about others in the UK, India and possibly Brasil that have had neurological complaints following the AZD-1222 trial and yet AstraZeneca persists in stating that no serious adverse events have been recorded.

I am concerned that regulators are being deprived of vital information in these studies.

b6

From: [b6]
Sent: 7/21/2021 1:47:51 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246] [b6]
Subject: Re: Neuro Reaction Post-Vaccine

Thank you for your response; I have just submitted!

Thank you,

[b6]

On Tue, Jul 20, 2021 at 8:59 PM Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

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: Tuesday, July 20, 2021 8:34:29 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Neuro Reaction Post-Vaccine

Hello Dr. Safavi,

I write to you in hopes I can educate you on symptoms I am experiencing, and if there's any way I can support research efforts for people like me.

My name is [b6] I will preface this with I am a pro-science, pro-vaccine individual who received the first dose of vaccine and as a result, now experience neurological symptoms extremely similar to long haul Covid. The Mayo Clinic has recently interviewed me and others to publish in medical literature for future research.

I am a [b6] female from [b6] with no prior health conditions/issues, not even allergies. I am a former D1 [b6] and current engineer working from home who eats anti-inflammatory and exercises regularly, and have not had the Covid-19 virus. I received the Moderna dose #1 on [b6] Hours later the back of my neck went completely stiff, and I felt intense tingling in the back of my head/scalp. My face started burning and felt very stiff like my neck. The next day (and ever since) I've experienced tingling in my face, particularly the left side of my nose. For the next week I had lots of face/scalp tingling,

chest tightness, heart palpitations, face stiffness, dizziness, brain fog, tiredness, intense back pain, sound sensitivity, sensations in the injection side hand, headache, swollen lymph nodes, and plugged ears. Within the following two weeks, I also developed intense muscle spasms, eye floaters, and buzzing nerve sensations in my calves/feet.

I am now b6 post-vaccine and still experiencing eye floaters, face tingling, leg/feet buzzing, hand/feet cramping, plugged ears, heart palpitations, random muscle twitching, and swollen lymph nodes. I am also unable to exercise as it increases my symptoms.

I have seen my primary care, neurologist, and eye specialist, who conducted:

b6

b6

I'm very interested in this research as b6 and there are significant similarities between my immune response to the vaccine and the symptoms of long haul Covid sufferers. If there's any research you're aware of where I can help advance studies for people like me, please let me know. Thank you in advance!

Thank you,

b6

From: [b6]
Sent: 8/12/2021 8:00:40 PM
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]

I know this is probably useless for your research but for the lay person like me this was super interesting! Figured you may find this cool too....this was hiding on my apple watch this whole time....

[b6]

[b6]

[b6]

b6

Kinda cool.

But once again, thank you, thank you, thank you.

I am going to wear my apple watch every day now. When I get feeling a tiny bit better, I would like to **b6** here at home (as NOBODY wears masks here in **b6** so going to a facility seems like a terrible idea) **b6**
b6

Also **b6**
b6

Could be why my symptoms flared as well though...another bug. Will keep you posted.

From: [b6]
Sent: 3/30/2021 1:10:00 AM
To: Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540 [b6] Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Side effects from the Covid Vaccine
Attachments: Video.MOV

My name is [b6] and I took the Pfizer vaccine on [b6] I lost the use of my left leg. On [b6] I lost the use of both legs. An hour later, full body convulsions started. I spent 5 days in the hospital with no explanation of what was going on. I have had [b6]
[b6]
[b6] but so am still experiencing full body convulsions, muscle jerks, severe headaches and severe muscle weakness. I have been to numerous doctors including 2 neurologist that has no clue how to treat me. I am currently [b6] but on the bad days, it doesn't help. It only helps with mild tremors. I can be reached at [b6]
I am attaching a video from Friday.

Thanks,

[b6]

Sent from my iPhone

REL0000231080

From: [b6]
Sent: 3/30/2021 9:40:10 PM
To: [b6] Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540 [b6]
Subject: Neurological Vaccine Reaction

Hello,

I received your information from [b6] and I am looking for some help desperately. I received my second dose of Pfizer COVID-19 vaccine [b6] Two weeks following my 2nd vaccination I started to have neurological symptoms of twitching in my legs and arms; numbness, pins and needle feeling in my hands and feet. I've also been experiencing tingling inside my mouth on my tongue, gums and lips like an allergic reaction. I have done [b6]
[b6] My symptoms are now going on for [b6] continuously without an answer and they are starting to get worse. I've been to two neurologists, my primary care doctor, and an allergist to see if they can figure out the issue but nothing.

I am not sure what can be done reaching out but at this point, I am desperate and honestly very scared. Hoping you have some insight working with this I would like to know is there anything that can be done?

[b6]

From: Wiebold, Amanda (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=4491EE2AE9804610899C741100150540] [b6]
Sent: 7/30/2021 6:33:15 PM
To: [b6]
Subject: RE: Follow up visit

Great. I will schedule you for 3:30 PM EDT [b6] on Tuesday, August 10, 2021. You should get a link for the meeting emailed to you by our medical records department.

Thank you,
Amanda

From: [b6]
Sent: Friday, July 30, 2021 1:40 PM
To: Wiebold, Amanda (NIH/NINDS) [E]; [b6]
Subject: Re: Follow up visit

Yep open anytime!

On Jul 30, 2021, at 10:35 AM, Wiebold, Amanda (NIH/NINDS) [E] [b6] wrote:

[b6]

Are you available Tuesday, August 10, 2021, anytime between 3:00 PM EDT and 5:30 PM EDT [b6] for a telehealth visit?

Thanks,
Amanda

From: [b6]
Sent: Friday, July 30, 2021 11:59 AM
To: Nath, Avindra (NIH/NINDS) [E]; [b6]
Cc: Safavi, Farinaz (NIH/NINDS) [E]; [b6] Wiebold, Amanda (NIH/NINDS) [E]
[b6] Nahar, Kymani (NIH/NINDS) [C]; [b6]
Subject: Re: Follow up visit

Yep. That's fine.

Should I try to just get [b6] and whatever else scheduled here for that time?

[b6]

[b6] Suuuuper concerned about getting another vaccine. No real win-win for me in this situation. :(

On Jul 30, 2021, at 7:45 AM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear b6

Hope you are doing well. I understand that you were being scheduled for a follow up visit to NIH. However, due the new risk of breakthrough infection with the delta variant, it might be best for us to do the follow up visit via telehealth etc and not put you at risk by travelling you here. Hope that is OK.

Best wishes.

Avi

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6] b6
Sent: 7/30/2021 4:25:12 PM
To: b6
CC: 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=4491ee2ae9804610899c74110015054d] b6 Nahar, Kymani (NIH/NINDS) [C] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4f432f899337490ea7cbde0a4b52effb] b6
Subject: Re: Follow up visit

b6
Avi

From: b6
Date: Friday, July 30, 2021 at 11:59 AM
To: Nath, Avindra (NIH/NINDS) [E] b6
Cc: Safavi, Farinaz (NIH/NINDS) [E] b6 Wiebold, Amanda (NIH/NINDS) [E] b6 Nahar, Kymani (NIH/NINDS) [C] b6
Subject: Re: Follow up visit

Yep. That's fine.

Should I try to just get b6 and whatever else scheduled here for that time?

b6

b6 Suuuuper concerned about getting another vaccine. No real win-win for me in this situation. :(

On Jul 30, 2021, at 7:45 AM, Nath, Avindra (NIH/NINDS) [E] b6 wrote:

Dear b6

Hope you are doing well. I understand that you were being scheduled for a follow up visit to NIH. However, due the new risk of breakthrough infection with the delta variant, it might be best for us to do the follow up visit via telehealth etc and not put you at risk by travelling you here. Hope that is OK.

Best wishes.

Avi

From: Wiebold, Amanda (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=4491EE2AE9804610899C741100150540] **b6**
Sent: 6/8/2021 11:38:34 AM
To: **b6**
Subject: RE: NIH Consenting for Blood Collection Remotely

Hello **b6**

Yes, we need to speak prior to you signing the consent form. Please let me know when you have some availability.

Thanks,
Amanda

From: **b6**
Sent: Monday, June 7, 2021 3:40 PM
To: Wiebold, Amanda (NIH/NINDS) [E]; **b6**
Subject: Re: NIH Consenting for Blood Collection Remotely

Dear **b6**

Thank you. I will do that.

Also, shall I do the signed consent, or do we need to talk about it? I am very confident in this consent and willing to sign.

Thanks,

b6

b6

b6

b6

b6

b6

On Mon, Jun 7, 2021 at 9:27 AM Wiebold, Amanda (NIH/NINDS) [E] **b6** wrote:

REL0000231158

b6

I would say since **b6** but if your symptoms have a longer history then I would go back to when they started.

Thanks,

Amanda

From: **b6**
Sent: Monday, June 7, 2021 12:21 PM
To: Wiebold, Amanda (NIH/NINDS) [E]; **b6**
Subject: Re: NIH Consenting for Blood Collection Remotely

Dear **b6**

Thank you. I wanted to know what range of dates that you want for my medical records. Do you want since the vaccine issue, or all my records since **b6** or even earlier?

Thanks,

b6

b6

b6

b6

b6

b6

On Mon, Jun 7, 2021 at 4:26 AM Wiebold, Amanda (NIH/NINDS) [E] **b6** wrote:

You have been sent a secure message/file(s).

To access the secure message/file(s), click on the following link or copy and paste the link into the browser.

Sender : Wiebold, Amanda (NIH/NINDS) [E]

Link : <https://medicalsecureemail.nih.gov/bds/Login.do> **b6**

Sent To : **b6**

Expires : 6/12/24, 12:00:00 AM EDT

NIH SecureEmail Service, brought to you by the NIH Central Email Service.

Proven*Trusted

From: [REDACTED] b6
Sent: 7/14/2021 2:44:55 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [REDACTED] b6
Subject: My HPI
Attachments: [REDACTED] b6

Hi I am sending 2 emails for you to review to get some idea.

Sent from my iPhone

[REDACTED] b6

b6

b6

From: [b6]
Sent: 7/20/2021 4:48:33 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: Question

I wanted to know your thoughts on the flu vaccine. [b6]
[b6] I am very scared to get another vaccine. My allergist [b6]
[b6] What are your thoughts? I'm also curious
how they will formulate this year's flu vaccine since there was hardly any flu last year.

From: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Sent: July 19, 2021 2:48 PM
To: [b6]
Subject: RE: functional scale

Hi [b6]
How are you doing? Please update me with your status and your current WHO scale
Thank you
Farinaz
Farinaz Safavi MD, PhD
Division of Neuroimmunology and Neurovirology
NINDS, NIH, Bethesda, MD

From: [b6]
Sent: Tuesday, June 29, 2021 12:47 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: functional scale

Hi Farinaz,

I have attached the questionnaire. I will continue to do it weekly. [b6]
[b6]

Take care,

[b6]

From: [b6]
Sent: June 29, 2021 9:44 AM
To: [b6]
Subject: FW: Transfer file from "Epson Connect Scan to Cloud"

-----Original Message-----

From: [REDACTED] b6
Sent: Tuesday, June 29, 2021 12:43 PM
To: [REDACTED] b6
Subject: Transfer file from "Epson Connect Scan to Cloud"

CAUTION: This Email is from an EXTERNAL source. Ensure you trust this sender before clicking on any links or attachments.

CONFIDENTIALITY NOTICE: This electronic mail transmission has been sent by [REDACTED] b6 It may contain information that is confidential, privileged, proprietary, or otherwise legally exempt from disclosure. If you are not the intended recipient, you are hereby notified that you are not authorized to read, print, retain, copy or disseminate this message, any part of it, or any attachments. If you have received this message in error, please delete this message and any attachments from your system without reading the content and notify the sender immediately of the inadvertent transmission. There is no intent on the part of the sender to waive any privilege.

From: [b6]
Sent: 8/30/2021 11:24:07 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: update

Hi Farinaz,

[b6] I continue to have numbness and tingling in my feet intermittently each day and sometimes it involves my calves, but it isn't overly bothersome. [b6]

[b6] I am functioning at about 90%. [b6]
[b6]

I still have some post-exertional malaise however my endurance is much better and [b6]
[b6] It's still hard to know how much to push myself without risking a setback for a few days. I can go for 2 mile walks and have started some light weight training again which has gone well. I still have some mild dysautonomia symptoms if I do not aggressively hydrate each day. It actually seems to be worse if I sit for a long time versus standing. It is worse if I do not get enough sleep.

I hope you are doing well.

Take care,

[b6]

From: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Sent: August 30, 2021 3:47 PM
To: [b6]
Subject: update

Hi [b6]
How are you doing? please update me with your condition.
I also wanted to update you with [b6]

[b6]

Best

Farinaz

From: [b6]
Sent: 6/20/2021 10:57:17 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: [b6]

Works for me!

Sent from my iPhone

On Jun 20, 2021, at 5:36 PM, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

How about 1pm?

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

From: [b6]
Sent: Sunday, June 20, 2021 8:48 AM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Re: [b6]

Hi Dr. Safavi,

I do, what time works for you?

Thanks,

[b6]

Sent from my iPhone

On Jun 20, 2021, at 7:26 AM, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

Hope all is well. Do you have time to talk on Tuesday in the PM?
Thanks

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

From: [b6]
Sent: Sunday, June 13, 2021 9:22 AM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Re: [b6]

Sounds good, safe travels!

Sent from my iPhone

On Jun 13, 2021, at 6:48 AM, Safavi, Farinaz (NIH/NINDS) [E]
[b6] wrote:

Dear [b6]
I am sorry to hear about new symptoms. I am out of country and will be back next week. [b6] also told me about your new symptoms. I will be in touch when I return to see how we can proceed.
Best

Farinaz

<7490B73CBD4B43428B37D1B3A9FA76B7.png>

From: [b6]
Sent: Monday, June 7, 2021 10:23:42 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Cc: Wiebold, Amanda (NIH/NINDS) [E] [b6]
Subject: Re: [b6]

Hi Dr. Safavi,

2 weeks ago I was having some odd things happening - I reached out to [b6] and let him know, he said none of it seemed to be related to [b6] -- but after talking to my GP she told me to be sure to let you know, as she knows you would like to hear all potential symptoms.

5/17 -- I was very dizzy
5/19 -- I had a stiff neck for 5 days
5/20 -- while working out my ear felt clogged, the ear and area around were numb and I could hear a thumping in it.

I went to the doctor for the ear, and was prescribed [b6] It didn't fix the issue, I still have a bit of muffled hearing in my left ear, but the numbness has resolved. Sometimes there is a bit of ringing or when I speak a bit of a chime sound.

My doctor has given me a referral to an ENT who I am setting up an appointment now to see.

Just wanted to give you all the information. Will keep you posted if any new issues arise.

Thanks,

b6

On Mon, May 17, 2021 at 7:09 PM, b6

b6

wrote:

Thank you!

Sent from my iPhone

On May 17, 2021, at 7:01 PM,
Safavi, Farinaz (NIH/NINDS)
[E] b6
wrote:

Hi b6

I really do not know answer
of your question. I cc Amanda
who may be able to help.
Thanks

Farinaz
<6B6D324B469D411CB75140
39F4F36DE2.png>

From: b6

b6

Sent: Monday, May 17, 2021
2:05:17 PM

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

b6

Subject: Re: b6

b6

Hi Dr. Safavi,

I asked b6 if there
was anything to be concerned
with with the information I
sent you - which he said he
spoke to you about. It sounds

like I should touch base with
an [b6] In order
to do so, he had said I should
bring a copy of my scans. Is
this something you can
provide to me? As it is not on
the scans I am obtaining for
you guys on the [b6]
[b6]

Please let me know.

Thanks

[b6]

On Wed, May 12, 2021 at
10:55 AM [b6]

[b6]

wrote:

Hi Dr. Safavi,

Doing well, no new
symptoms or weird things
happening. I did notice on
the results [b6]

b6

b6

b6

Wondering if you think
there is anything I should
do about that? Any testing I
should get done or
anything to worry
about? Will let you know
when I have more intel on
when to expect my scans!
Sorry it is taking so long to
get them.

Thanks,

b6

On Tue, May 11, 2021 at
5:25 PM Safavi, Farinaz
(NIH/NINDS) [E]

b6

wrote:

Hi b6

How are you doing?

Thank you very much
for following up about
it. Really appreciate it.

Farinaz

<6BC08683C27E4ECDA02
2578EE8383632.png>

From: b6

b6

Sent: Tuesday, May 11,
2021 2:17:19 PM

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

b6

Subject: Re: b6

b6

Hi Dr. Safavi,

I wanted to let you know

I had called both b6

b6 locations and have
sent in the documents to
retrieve my files. I am not
getting anywhere with
the phone numbers, so I
am going to try to go to
each location and see if I
can confirm they have
received my request and
will send through as soon
as I have them.

Just wanted to keep you
updated.

Thanks,

b6

On Thu, Apr 29, 2021 at
10:22 AM Safavi, Farinaz
(NIH/NINDS) [E]

b6

wrote:

No Dear,

We are good. Can wait for original CD

b6

b6

Best

Farinaz Safavi MD, PhD

Division of Neuroimmunology and
Neurovirology

NINDS, NIH, Bethesda, MD

From: b6

Sent: Thursday, April 29, 2021 10:20 AM

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

Subject: b6

Hi Dr. Safavi,

Would it be helpful if I took screen shots of any
of the b6 that I have access to?

Is there a way I can give you my log in to
MyChart so you could view everything
yourself? The other thing is I can send the notes
from all of the reports and then if you want
specific pictures ahead of the discs finally
getting to me and then to you -- I am happy to

share those as well. Let me know if these are helpful or if there are other images I can send ahead of the discs coming?

Best,

b6

b6

b6

b6

b6

From: [b6]
Sent: 5/13/2021 9:08:47 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: Covid vaccine reaction
Flag: Flag for follow up

Dr. Safavi,

Thank you so much for responding. Neuro here can't see me until July the earliest as of right now and I definitely don't want to struggle until then. Is it true that you don't have any more room in your study?

[b6]

On Tue, May 11, 2021 at 5:55 PM Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

Im sorry to hear about your illness. Where do you live. I suggest you see a neurologist in university based hospital and I would be happy to speak with him/her and share our understanding about these adverse events.

Hooe it helps.

Farinaz

From: [b6]
Sent: Monday, May 10, 2021 2:32:22 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Covid vaccine reaction

Hey Dr. Safavi,

It's been really hard for me to get the help that I need with my covid vaccine reaction. I emailed to get into your study but it was already closed. I am hoping you can email my doctor or suggest a local neurologist that can help me navigate this better. It would be super helpful if I could reassure my PCP office that this is not all in my head.

I had my first and only vaccine on [b6] and have been struggling ever since.

I had an immediate adverse reaction with numbness, weakness, dizziness, chest pains and blurred vision. Over the course of weeks the dizziness and weakness persisted. 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. That's when things got way worse.

(Interrupting the story to say that I have never been allergic to any of the foods listed below.)

I thought since I felt mostly better that I must be recovering finally and I ate peanut butter cookie. I went into anaphylaxis (or very near anaphylaxis), and then again the next night. I was so desperately ill that I restricted my food even more and was reacting to even more things, I had a bug reaction to sweet potato, onion, didn't feel right with rice and oatmeal, etc. I am down to chicken and potatoes only for breakfast, lunch and dinner. I have lost 15 lbs in 2 weeks.

I don't have anyone who can help me locally so I have been working HARD to get help in any way since the day of my vaccination. I am desperately hoping that this is a temporary issue and won't stick with me and I

want to make sure I do everything in my power to help it be that way. I am finally to the place where I can stand up again without feeling like I am going to pass out but am still scared to eat for fear of anaphylaxis.

Other health issues, I am

b6

b6

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

b6

b6

b6

From: [b6]
Sent: 3/29/2021 5:58:50 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Paresthesia after 1st Pfizer COVID vaccine
Attachments: Adverse Effects Log [b6].pdf
Flag: Flag for follow up

Good afternoon Dr. Safavi!

I was encouraged to contact you after I joined a support group organized by [b6] for adverse effects from COVID-19 vaccines relating to Paresthesia.

I received my first Pfizer vaccine on [b6] and within 10 minutes began to have paresthesia in both arms (the vaccine was given in my right arm). That evening the paresthesia had spread to my entire left side from scalp to toes, everything including my left teeth, left side of my lip, left eyelid, etc. Today is [b6] and the Paresthesia still remains (although is intermittent in severity), and I now have intermittent pins and needles sensations too, as well as some lower left back pain. I have reported my side effects to VAERS, and Pfizer, and have had a visit with my PCP (he ordered [b6] [b6]). He is puzzled and it was recommended that I contact you for any possible help or guidance with this.

For a more detailed log of my symptoms, as well as more background info about myself (medications, medical history etc) please see the attached PDF.

I appreciate your time and help and hope I may be able to have an appointment with you!

Thank you,

[b6]

b6

b6

From: [b6]
Sent: 6/13/2021 1:21:44 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246- [b6]
Subject: Re: [b6]

Sounds good, safe travels!

Sent from my iPhone

On Jun 13, 2021, at 6:48 AM, Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Dear [b6]
I am sorry to hear about new symptoms. I am out of country and will be back next week [b6] also told me about your new symptoms. I will be in touch when I return to see how we can proceed.
Best

Farinaz

From: [b6]
Sent: Monday, June 7, 2021 10:23:42 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [b6]
Cc: Wiebold, Amanda (NIH/NINDS) [E] [b6]
Subject: Re: [b6]

Hi Dr. Safavi,

2 weeks ago I was having some odd things happening - I reached out to [b6] and let him know, he said none of it seemed to be related to [b6] -- but after talking to my GP she told me to be sure to let you know, as she knows you would like to hear all potential symptoms.

5/17 -- I was very dizzy

5/19 -- I had a stiff neck for 5 days

5/20 -- while working out my ear felt clogged, the ear and area around were numb and I could hear a thumping in it.

I went to the doctor for the ear, and was prescribed [b6] It didn't fix the issue, I still have a bit of muffled hearing in my left ear, but the numbness has resolved. Sometimes there is a bit of ringing or when I speak a bit of a chime sound.

My doctor has given me a referral to an ENT who I am setting up an appointment now to see.

Just wanted to give you all the information. Will keep you posted if any new issues arise.

Thanks,

REL0000231337

b6

On Mon, May 17, 2021 at 7:09 PM: [b6] wrote:
Thank you!

Sent from my iPhone

On May 17, 2021, at 7:01 PM, Safavi, Farinaz (NIH/NINDS) [E]
[b6] wrote:

Hi [b6]

I really do not know answer of your question. I cc Amanda who may be able to help.

Thanks

Farinaz

From: [b6]
Sent: Monday, May 17, 2021 2:05:17 PM
To: Safavi, Farinaz (NIH/NINDS) [E]; [b6]
Subject: Re: [b6]

Hi Dr. Safavi,

I asked [b6] if there was anything to be concerned with with the information I sent you - which he said he spoke to you about. It sounds like [b6] should touch base with an [b6]. In order to do so, he had said I should bring a copy of my scans. Is this something you can provide to me? As it is not on the scans I am obtaining for you guys on the [b6]

Please let me know.

Thanks

[b6]

On Wed, May 12, 2021 at 10:55 AM: [b6]
[b6] wrote:

Hi Dr. Safavi,

Doing well, no new symptoms or weird things happening. I did notice on the results: [b6]

[b6]

[b6]

[b6]

REL0000231337

Wondering if you think there is anything I should do about that? Any testing I should get done or anything to worry about? Will let you know when I have more intel on when to expect my scans! Sorry it is taking so long to get them.

Thanks,

b6

On Tue, May 11, 2021 at 5:25 PM Safavi, Farinaz (NIH/NINDS) [E]

b6

wrote:

Hi

b6

How are you doing?

Thank you very much for following up about it. Really appreciate it.

Farinaz

From:

b6

Sent: Tuesday, May 11, 2021 2:17:19 PM

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

b6

Subject: Re:

b6

Hi Dr. Safavi,

I wanted to let you know I had called both b6 locations and have sent in the documents to retrieve my files. I am not getting anywhere with the phone numbers, so I am going to try to go to each location and see if I can confirm they have received my request and will send through as soon as I have them.

Just wanted to keep you updated.

Thanks,

b6

On Thu, Apr 29, 2021 at 10:22 AM Safavi, Farinaz (NIH/NINDS) [E]

b6

wrote:

No Dear,

We are good. Can wait for original CD

b6

b6

Best

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

REL0000231337

NINDS, NIH, Bethesda, MD

From: [b6]
Sent: Thursday, April 29, 2021 10:20 AM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: [b6]

Hi Dr. Safavi,

Would it be helpful if I took screen shots of any of the [b6] that I have access to? Is there a way I can give you my log in to MyChart so you could view everything yourself? The other thing is I can send the notes from all of the reports and then if you want specific pictures ahead of the discs finally getting to me and then to you -- I am happy to share those as well. Let me know if these are helpful or if there are other images I can send ahead of the discs coming?

Best,

[b6]

[b6]

b6

b6

b6

b6

From: [b6]
Sent: 6/28/2021 6:15:20 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: Forgot to mention

Hi Dr. Safavi,

No worries, just keep me posted. I can be available whenever. Hope you have a nice 4th of July weekend and stay cool... this heat is supposed to be intense!

Thanks,

[b6]

On Mon, Jun 28, 2021 at 2:12 PM Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

Hi [b6]

It seems that everyone is out for long weekend. I guess we have to wait until after holiday to even start the process. I will let you know.

Best

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: [b6]
Sent: Thursday, June 24, 2021 11:18 AM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Re: Forgot to mention

Hi Dr. Safavi,

REL0000231342

Just wanted to follow up,

b6

b6

and I have to follow up in 6 months. Wanted

to keep you posted.

Thanks,

b6

On Tue, Jun 22, 2021 at 1:56 PM

b6

wrote:

Hey Dr. Safavi,

I forgot to mention - I am going to be in the area from Jun 30th - July 5th visiting

b6

b6 I am flying in on the 30th and flying out on the 5th. I could come down sooner or extend if you wanted. Just figured I would let you know.

Thanks,

b6

From: [b6]
Sent: 4/29/2021 6:04:12 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Pfizer vaccine adverse reaction
Flag: Flag for follow up

Hello!

I was told to contact you all from some help.

A quick break down of events: [b6] I was vaccinated and had an immediate adverse reaction with numbness, weakness, dizziness, chest pains and blurred vision. Over the course of weeks the dizziness and weakness persisted. 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. That's when things got way worse.

Interrupting the story to say that I have never been allergic to any of the foods listed below.

I thought since I felt mostly better that I must be recovering finally and I ate peanut butter cookie. I went into anaphylaxis (or very near anaphylaxis), and then again the next night. I was so desperately ill that I restricted my food even more and was reacting to even more things, I had a bug reaction to sweet potato, onion, didn't feel right with rice and oatmeal, etc. I am down to chicken and potatoes only for breakfast, lunch and dinner. I have lost 15 lbs in 2 weeks.

I don't have anyone who can help me locally so I have been working HARD to get help in any way since the day of my vaccination. I reached out to an immunologist [b6] who thinks [b6]

[b6]
[b6] So I am reaching out for second opinions. I would love any help that you can give me and any advice on what I can do. I am desperately hoping that this is a temporary issue and won't stick with me and I want to make sure I do everything in my power to help it be that way. I am finally to the place where I can stand up again without feeling like I am going to pass out but am still scared to eat for fear of anaphylaxis.

Other health issues, I am diagnosed with [b6]

[b6]

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

[b6]

[b6]

From: [REDACTED] b6
Sent: 6/29/2021 4:47:26 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246] b6
Subject: functional scale
Attachments: [REDACTED] b6

Hi Farinaz,

I have attached the questionnaire. I will continue to do it weekly. [REDACTED] b6
[REDACTED] b6

Take care,

[REDACTED] b6

From: [REDACTED] b6
Sent: June 29, 2021 9:44 AM
To: [REDACTED] b6
Subject: FW: Transfer file from "Epson Connect Scan to Cloud"

-----Original Message-----

From: [REDACTED] b6
Sent: Tuesday, June 29, 2021 12:43 PM
To: [REDACTED] b6
Subject: Transfer file from "Epson Connect Scan to Cloud"

CAUTION: This Email is from an EXTERNAL source. Ensure you trust this sender before clicking on any links or attachments.

CONFIDENTIALITY NOTICE: This electronic mail transmission has been sent by [REDACTED] b6. It may contain information that is confidential, privileged, proprietary, or otherwise legally exempt from disclosure. If you are not the intended recipient, you are hereby notified that you are not authorized to read, print, retain, copy or disseminate this message, any part of it, or any attachments. If you have received this message in error, please delete this message and any attachments from your system without reading the content and notify the sender immediately of the inadvertent transmission. There is no intent on the part of the sender to waive any privilege.

b6

From: [b6]
Sent: 10/22/2021 2:46:03 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Vaccine Reaction Question

Dear Dr. Nath,

Please forgive the direct email as I am sure you are overwhelmed.

I am a [b6]
[b6]

I understand that there may be a study in the works for people who may have had an adverse reaction to the Covid vaccines. I would be very interested to participate, if such a study exists or were to launch.

Sadly, [b6] I received two doses of Pfizer/BioNtech [b6]
[b6] which resulted in severe adverse reaction with ongoing sequelae.

After Dose 1, I developed paresthesia reaction almost immediately - affecting the right arm/face/eye/ear, which subsided after about 10 days. Upon the advice of a neurologist [b6] it was suggested to proceed with Dose 2.

I proceeded to Dose 2 and within 4 days. I developed severe tinnitus, tachycardia, hypertension, headache, right eye irritation, mild facial tingle and flushed, hot ear. I contacted the neurologist, and I was instructed to "wait it out". I ended up in the ED on [b6] with worsening symptoms including mesenteric inflammation. A vaccine correlation was dismissed despite my suggestion.

Over the course of the next [b6] I sought experts all over [b6] but few knew how to treat. I continued to develop severe dysautonomia, worsening tinnitus, severe insomnia, adrenal dumps, and muscle fasciculations and prickly skin sensations. Course of treatments included [b6]
[b6]

By [b6] I finally found a neurologist [b6] who suspected vaccine induced [b6]
[b6] She was the first neurologist to identify my issue and consider [b6]
[b6]

By [b6] I continued to worsen with the progression of severe, acute neuropathies involving my entire body: burning/stinging feet and hands, tingle right side face, prickly painful throat, stabbing pain in hands, ulnar nerve pain in right hand and severe dull right-side headaches. I had a [b6]
[b6]

I should note I was a very healthy [b6] male prior to vaccine, with no significant medical history or medications.

I recently had a cross-consult (recommended by [b6] with the neuropathy specialist [b6]
[b6] I saw him a few weeks ago, but he was skeptical of the vaccine correlation, despite my well
documented history. At that time, he did not offer much in terms of treatment, but said he would research
it. He recommended I contact my PCP for [b6]
[b6] I continue to
see the neurologist [b6]
[b6]

I am almost [b6] now struggling to understand the disease process, identify a knowledgeable
neurologist in such vaccine issues, and hopefully find an effective therapy. I am scheduled for [b6]
[b6] but I am not yet convinced of this therapeutic approach.

I fully understand you are not able to offer medical advice, but if you should know of any studies or experts
worth contacting that may be able to aid me in my quest, please keep me in mind.

I am willing to travel anywhere at any cost due to the worsening symptoms and the impact this has had on my
life and [b6]

I am more than happy to take part in any research to help as much as possible to contribute to the
advancement of science and assist in better understanding this reaction.

Thank you for your time,

[b6]

b6

From: [b6]
Sent: 9/1/2021 4:49:15 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Vaccine Reaction

I read the article in <https://www.c19vaxreactions.com/in-the-news> , disturbing and alarming. I am [b6] received first shot [b6] and second on [b6] I was extremely active before the shots, after number one my neck started to "pop and crack" after number two, forget it. The 24-hour nausea, I could handle but I was unable to get out of bed without crying, the pain was so severe (and I have a high tolerance to pain). Four days later I ended up in an ER. The care was TERRIBLE!! The Dr swore I had COVID-19 or Pneumonia, didn't have either one (MY OWN PCP even stated she had absolutely NO WORDS for what that Dr did) Just sent me on my way, no answer, nothing. I cried all the way home. Had an appt with my PCP, [b6] [b6] Meanwhile the pain is worsening, no relief, I end up at a different ER. They proceed to give me [b6] Still NOTHING, send me on my way again! [b6] I am thinking "how are these people so dumb?" I could just barely walk! [b6] [b6] I never had a neck issue, I am active, energetic, now could not do anything, including my JOB. I could NOT sit for 8 hours.

After having enough, I drove MYSELF to [b6] In severe pain, crying, no one to take me because [b6] [b6] I go! Of course, due to the Opioid epidemic, NO ONE wants to order anything for PAIN! I had to wait for [b6] The ONLY thing different was the VACCINE! The sad part, there are others with issues, and NO ONE LISTENS!! This is one thing that needs to be addressed, funny I do NOT have 1 antibody from the vaccine.

How are they pushing this on others?!

C19 VAX REACTIONS - In The News

SOURCE: 2KUTV SALT LAKE CITY (KUTV) --Utah's senior senator is throwing the weight of his office behind a push to get the CDC to recognize and help people injured by the COVID-19 vaccines, even if those injuries are rare.Two weeks ago, Sen. Mike Lee (R-UT) announced his effort to help a Utah woman who's suffering neurological trauma after receiving a COVID-19 vaccine.

www.c19vaxreactions.com

From: [b6]
Sent: 6/14/2021 5:46:17 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: Covid 19 Pfizer vaccine myelitis??

Thank you.

Just FYI!

[b6] So I will have to plan next step sooner than later and prevent another event. [b6]
[b6]

Sent from my iPhone

[b6]
[b6]

On Jun 13, 2021, at 8:59 PM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

[b6]

From: [b6]
Date: Sunday, June 13, 2021 at 9:57 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Re: Covid 19 Pfizer vaccine myelitis??

Hi

I understand.

However I noted it takes longer to reach them directly to discuss Case.

Is there anyway I can get email address.

I will call the number on internet tomorrow in the meantime.

Sent from my iPhone

[b6]
[b6]

On Jun 1, 2021, at 9:17 PM, b6 wrote:

b6

From: [b6]
Sent: 5/14/2021 4:31:31 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: COVID vaccine reaction

Hello Dr. Nath,

I could use some help so I am reaching out. I am not getting the help that I need locally so I'm hoping you can help me with that somehow.

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 an arrhythmia and tachycardia. I felt ignored when they told me it was likely stress and anxiety. 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 4/13 I ate a peanut butter cookie, and went into anaphylaxis, then again the next night. 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, and [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, higher than normal and lower than normal BP readings, 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 [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]

[b6]

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.

REL0000231473

b6

From: [REDACTED] b6
Sent: 12/15/2021 1:42:20 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6] b6
Subject: [EXTERNAL] Automatic reply: Post Covid19 Vaccine reaction Research

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 will be out of the office from [REDACTED] b6

b6

b6

b6

b6

b6

b6

b6

From: [b6]
Sent: 9/19/2022 4:38:43 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [EXTERNAL] Research - COVID and Vaccine

Hi! I recently came across an article published earlier this year where you were mentioned. I will provide more information below, but I was wondering if you knew of any current studies being done around the high autoantibodies seen in patients after receiving the COVID-19 vaccine or after they got COVID? Or, are you aware of any studies for someone suffering long-term health issues could connect to (from both COVID vaccine and COVID)? I know the below is extremely rare but just reaching out again to those in the field. Thanks!

More info:

First COVID vaccine, [b6] did fine. Just tired from vaccine.

[b6] - second COVID vaccine. Following day, in urgent care with chest pain, neuropathy, etc. Later that week, sent to the ER. Over next several months, Dr after Dr, specialist after specialist, no one could figure things out (just ruled out different things)

Symptoms: chest pain, nerve pain, neuropathy, body/joint pain, rashes that bruised (face to upper legs), brain fog, migraines, ocular migraines (with decreased vision), incontinence issues, fall/fall down stairs due to legs just giving out, fatigue, physically unable to walk up stairs, stomach issues. Some days in so much pain that I couldn't even get him out of bed. Some days he could physically not walk up stairs and had to crawl. [b6]

[b6]

Dr's treated with [b6] Diagnosed with [b6]
[b6]

One dr. said [b6] Another said perhaps in 6 months, research will be out to help. Either way, no one knew how to help him. For [b6] post vaccine, the symptoms persisted.

Spring 2022, saw new rheumatologist [b6]
[b6]
[b6] He was also getting [b6]
[b6] However, I'm now reading research or an article that says perhaps autoantibodies and immune response die down after 6 months, so that may be why symptoms weren't as severe.

[b6] 3 days of being extremely tired. No other major [b6] symptoms. Since then, symptoms similar to what happened after his COVID vaccine are back in full force. [b6]
[b6] Rashes all over his body that bruised, severe joint pain and neuropathy, brain fog is worse, stomach/digestive issues worse, migraines back more often, many days it hurts to walk.

I have been reading some articles about newer-ish research around autoantibodies as well as some people experiencing weird symptoms after the vaccine and COVID itself.

We've been searching for answers for a while. Some dr's write him off (one said [b6] while others take it very seriously. But, none of them know how to really help. One neurologist had mentioned a [b6] He's been told obviously he can't get the COVID vaccine again. I'd just love to find research, perhaps there is a study recruiting people like him, I'd love more information on how immune suppressing medication could potentially help, etc. Would love if there are any true research we can point his doctors to.

Do you know where we might be able to turn? Sorry for the novel, but I'm sure you understand how desperate people can be when all they want is to feel somewhat normal again.

Thanks!

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: 10/1/2022 5:13:59 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [EXTERNAL] Odd symptoms post Moderna Bivalent Vaccine

Hello Dr. Nath,

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.

I have [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 [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 [b6]. [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] [b6] 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

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: 2/24/2022 10:44:33 PM
To: b6 NINDS Public Inquiries [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b8a11837b5244c2395ed81bb7c0a65d7-NINDS Publi]
Subject: Re: [EXTERNAL] Studies/Research

Sorry, I am not aware of any, but am copying other officials at NIH who can guide you.
Avi

From: b6
Date: Thursday, February 24, 2022 at 5:28 PM
To: Nath, Avindra (NIH/NINDS) [E] b6
Subject: [EXTERNAL] Studies/Research

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! I found your name online in an article and was hoping I could ask a quick question.

Are there any current studies being done or do you know of any completed around adverse reactions to COVID vaccines?

b6 had an adverse reaction to his second vaccine. Er, urgent cares, many drs, tons of specialists. First thought b6 b6 b6

Anyways just thought I'd check to see if you knew of any current, upcoming, or completed studies around long term side effects from vaccine? Pfizer/2nd dose was b6

Thank you!

b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6] [b6]
Sent: 8/4/2021 4:14:14 PM
To: [b6]
Subject: Re: Strong immune response to Covid vaccine

Call

From: [b6]
Date: Wednesday, August 4, 2021 at 12:10 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Re: Strong immune response to Covid vaccine

Just dropped you a line on [b6] Please let me know if this the best # to reach you on.

Regards,

[b6]

On Tue, Aug 3, 2021 at 11:57 AM [b6] wrote:

Ok, let's do that. Will send a calendar invite.

Sent from my iPhone

On Aug 3, 2021, at 4:15 PM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Tomorrow at 12 noon would be better

Avi

From: [b6]
Date: Tuesday, August 3, 2021 at 10:33 AM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Re: Strong immune response to Covid vaccine

Can we talk @ 12pm your time? I'm currently in the UK.

Sent from my iPhone

On Aug 3, 2021, at 1:42 PM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

REL0000231569

Dear [b6]

Sorry about your symptoms. Not sure what I can do to help. But can talk to you. When would be a good time.

Avi

Avindra Nath MD

Chief, Section of Infections of the Nervous System

Clinical Director,

National Institute of Neurological Disorders and Stroke

National Institutes of Health, Bethesda, MD

[b6] (Office)

[b6]

From: [b6]

Date: Tuesday, August 3, 2021 at 8:33 AM

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

Subject: Strong immune response to Covid vaccine

Avindra -

Apologies for the cold email. I believe you spoke to my neurologist, [b6] not too long ago about some abnormal reactions/strong immunological responses to the vaccine. It would be great to talk to you for 10 mins when your schedule permits.

Regards,

[b6]

Sent from my iPhone

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 [b6]
Sent: 8/26/2022 12:44:04 AM
To: [b6]
Subject: Re: [EXTERNAL] update

Dear [b6]

Thanks for the update and for sharing this article with me. [b6]

Unfortunately no new insights. [b6]

Best
Avi

On Aug 25, 2022, at 6:35 PM, [b6] wrote:

Hi Dr. Nath,

I wanted to follow up with you and your team since we checked-in on a telehealth appointment.

After [b6] I had a brief remission of neurological symptoms from [b6]
[b6] Severe tinnitus persisted but some reduction in volume after [b6]
[b6] This seemed promising at the time.

However, on [b6] I began a rapid decline. A repeat of [b6]
did not have as profound an effect as the first. This was a puzzling disappointment. I was
started on [b6]

Despite these new interventions, my muscle fasciculations continue with increased frequency and intensity (worse after activity) and the neuropathies have worsened. They are now full body including eyes, mouth, and genitals. The rapid spread is concerning. The positional tachycardia has also worsened in frequency and intensity.

My neurologist and I decided [b6]
[b6]

[b6]

<https://onlinelibrary.wiley.com/doi/10.1002/mus.27696>



Post-COVID-19 Vaccine Small-Fiber Neuropathy
and Tinnitus Treated with Plasma Exchange -
Schelke - Muscle & Nerve - Wiley Online Library

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record.

onlinelibrary.wiley.com

I reviewed the pre-print paper on these reactions, but it seems to offer more questions than answers aside from the C4d finding. As you can imagine, I am pushing the medical system as hard as possible. b6

b6 Are there been any new insights into the underlying pathophysiology or any planned research?

All the best,

b6

b6

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From: Gavin, Angelique (NIH/NINDS) [C] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=6E97392E947E4F7EBB17EEB8AC87C5D5] b6
Sent: 9/21/2021 8:46:06 PM
To: b6
Subject: RE: NIH COVID-19 Vaccine Study

Thank you b6

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 4:05 PM
To: Gavin, Angelique (NIH/NINDS) [C] b6
Subject: Re: NIH COVID-19 Vaccine Study

Hello Angelique ,

I would be willing to share my story.

b6

Kind Regards,

b6

On Tue, Sep 21, 2021 at 1:08 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

REL0000231633

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: 10/22/2021 3:51:28 PM
To: b6
Subject: RE: Query C19 studies

Thank you b6 You will be contacted as soon as the study is approved and under way. All my best to you.

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
301-402-0880-phone
301-451-7352-fax

From: b6
Sent: Friday, October 22, 2021 11:40 AM
To: Gavin, Angelique (NIH/NINDS) [C] b6
Subject: Re: Query C19 studies

Hi,

Yes, please add me to your list. I am very interested to contribute to research. Here are my personal contact details:

b6

All the best,

b6

b6

b6

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

b6

Sent: Friday, October 22, 2021 11:32 AM

To: **b6**

Subject: [EXTERNAL] RE: Query C19 studies

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.

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: **b6**

Sent: Friday, October 22, 2021 9:52 AM

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

b6

Subject: Query C19 studies

Dear Angelique,

I am a **b6** I understand that there may be a study in the works for people who may have had an adverse reaction to one of the Covid vaccines.

I would be very interested to participate, if such a study were to launch. I received two doses of Pfizer/BioNTech **b6** I developed paresthesia reaction almost immediately in the right arm/face/eye/ear after dose 1, which subsided after about 10 days upon the advice of a neurologist, I proceeded to Dose 2. Within 4 days. I developed severe tinnitus, tachycardia, hypertension, headache, right eye irritation, mild facial tingle. I contacted the neurologist, and I was instructed to "wait it

REL0000231636

out". Over the course of the next **b6** I continued to worsen: developing severe dysautonomia, worsening tinnitus, severe insomnia, adrenal dumps, and muscle fasciculations.

I saw many doctors and had hundreds of tests without any diagnosis. I was given **b6**
b6

By mid-June I finally found a neurologist **b6** who suspected **b6**
b6 I continued to worsen with the progression of severe, acute neuropathies involving my entire body. I have burning/stinging feet, tingle right side face, prickly painful throat, stabbing pain in hands, ulnar nerve pain in right hand and severe dull right-side headaches. I had **b6**

I should note I was a very healthy **b6** prior to vaccine, with no significant medical history or medications.

I have not been able to function, and I try to continue to work as much as possible from home. I continue to see a neurologist **b6** So far this has not prevented the progression. I am almost **b6** now struggling to understand the disease process, identify a knowledgeable neurologist in such vaccine issues, and hopefully find an effective therapy.

If you should know of any studies or persons worth contacting that may be able to aid, please keep me in mind. I am more than happy to take part in any research to help as much as possible to contribute to the advancement of science.

Thank you,

b6

b6

b6

From: Gavin, Angelique (NIH/NINDS) [C] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=6E97392E947E4F7EBB17EEB8AC87C5D5 [b6]
Sent: 2/21/2022 11:42:30 PM
To: [b6]
Subject: RE: [EXTERNAL] Re: Problems with Zoom

Hello: [b6]

I am sorry for any confusion this has caused. It seems I accidentally sent you an invitation to a meeting that has nothing to do with your inquiry. Our vaccine study is not yet underway but it seems that you remain on our wait list. Please note that this study involves a telephone interview and online questionnaires. There is no treatment associated with the study at this time. Let me know if you remain interested and we will contact you as soon as we are able to proceed.

Sincerely,
Angelique

Angelique Gavin, MS
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, February 21, 2022 10:38 AM
To: Gavin, Angelique (NIH/NINDS) [C] [b6]
Cc: Stussman, Barbara (NIH/NCCIH) [E] [b6] Horan, Sean (NIH/NINDS) [F]
[b6] Calco, Brice (NIH/NINDS) [F] [b6] Vetter, Courtney (NIH/NINDS) [F]
[b6] Jones, Melina (NIH/NINDS) [C] [b6] Amin, Niranjana (NIH/NINDS) [E]
[b6] Espinoza, Claudia (NIH/NINDS) [C] [b6] Singh, Komudi (NIH/NHLBI) [E]
Subject: [EXTERNAL] Re: Problems with Zoom

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Hi Angelique,

Dr. Nath told me I would be contacted by a research team that was being put together to find out what was going on in cases like mine. However, I could not find the email with the information about the meeting you mentioned.

I would very much like to participate in the meeting. I have been down a very long road and would very much like to get to the end.

REL0000231638

Please let me know when this meeting is scheduled so I can plan accordingly.

Kind regards,

b6

On Thu, Feb 17, 2022, 12:08 PM Gavin, Angelique (NIH/NINDS) [C] **b6** wrote:

Hello! We are having problems with the link to zoom. A new meeting invitation is coming shortly.

Thank you,

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: 10/21/2022 4:43:04 PM
To: Gavin, Angelique (NIH/NINDS) [C] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=6e97392e947e4f7ebb17eeb8ac87c5d5; [b6]
Subject: Re: [EXTERNAL] Covid Vaccine Reaction Study

Much appreciated. Thanks again!

On Fri, Oct 21, 2022 at 12:39 PM Gavin, Angelique (NIH/NINDS) [C] [b6] wrote:

Thanks [b6] for your reply! I will place you on our waiting list. Fingers crossed!

All my best to 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: [REDACTED] **b6**
Sent: Friday, October 21, 2022 12:38 PM
To: Gavin, Angelique (NIH/NINDS) [C] [REDACTED] **b6**
Subject: Re: [EXTERNAL] Covid Vaccine Reaction Study

Hi Angelique,

Thanks for your response! I'm happy to share my information in case you need another participant down the road.

[REDACTED] **b6**

Best of luck with your research.

Thanks,

[REDACTED] **b6**

On Fri, Oct 21, 2022 at 12:11 PM Gavin, Angelique (NIH/NINDS) [C] [REDACTED] **b6** wrote:

Thank you [REDACTED] **b6** for your interest in our research. We have developed an online survey system to collect stories about people's complications after receiving COVID vaccines. At this time, we have already received the maximum number of persons for recruitment. If you are willing, we can take your name and contact information. We will reach back out to you if someone drops out or if we make changes to the study that would allow us to include more persons. I look forward to your reply.

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: **b6**
Sent: Thursday, October 20, 2022 12:55 PM
To: NINDSPostCovid19 <nindspostcovid19@ninds.nih.gov>
Subject: [EXTERNAL] Covid Vaccine Reaction Study

Hello,

I received your email contact from someone that mentioned you are looking for participants for a Covid vaccine reaction study.

I personally had a severe reaction to the Moderna vaccine and would be interested in participating in the study.

If you are looking for participants, please let me know more information regarding qualifications and process.

REL0000231672

Best regards,

b6

--

b6

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--

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.

--

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: 2/22/2021 6:35:44 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [b6]

Dr. Nath,

We have sent your contact information to [b6]

A question, what is your opinion on [b6]
[b6]

On Feb 22, 2021, at 11:00 AM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Thanks for the update. Glad to know that there is some improvement. Yes, I would be glad to talk to [b6] [b6] to see how we can help. You can share my contact information with him.

Avi

Avindra Nath MD

Chief, Section of Infections of the Nervous System

Clinical Director,

National Institute of Neurological Disorders and Stroke

National Institutes of Health, Bethesda, MD

[b6] (Office)
[b6] (cell)

[b6]

From: [b6]
Date: Monday, February 22, 2021 at 12:54 PM
To: "Nath, Avindra (NIH/NINDS) [E]" [b6]
Subject: [b6]

Dr. Nath,

An update: [b6] sensitivities to sound, light and touch are slowly improving. She still has; fatigue, brain fog, paresthesias, anxiety, and the most debilitating symptom, the brain vibration or "wobbly brain". She is still unable to work [b6] drive or do anything other than simple self-care (bathe, clothes, move around the house.) Still a lot of suffering.

We are struggling to know what the next steps are. Her doctor [b6]

[b6]

[b6] Are you interested in any more samples, or do you have any guidance as to what testing he should be doing on these samples? We have [b6] open to us.

We feel as though our help has stagnated and are desperate to help [b6] feel better. We also feel like her condition may help contribute to finding the cause and then treatments for the Long Covid syndrome that is poised to continue to decimate the economy, as her symptoms mirror those reported so closely.

She continues to find reports in support forums of very similar adverse reactions to the Astra Zeneca vaccine, mostly out of the UK, as it is being given to the population there.

We look to you to help guide the next steps with [b6] as well as others.

Thank you for listening,

[b6]

Sorry for the double send, I sent it from the wrong address before.

From: [b6]
Sent: 1/14/2022 7:46:48 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [EXTERNAL] info

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.

Hey hearing things through the grapevine... I thought you should know...

Yes, your team told research participants who were injured by the covid vaccines to not to talk about what was going on = there at the NIH. We were told not to talk about it. I know this because Safavi herself told me this, point blank, the final day I was there...no misunderstanding it. Several other people were told the same thing. Also, over the summer someone else from your team directly called my fellow injured who had been there for examination. The call was to specifically tell her to NOT talk about it, or else they would restrict her access to the NIH. Enough of us were told this same thing, that we intentionally erased each and every comment and post from our small facebook group of 180 people... that mentioned the NIH... because we were that afraid of research being halted because we were talking to each other, and we didn't want to ever be the reason that the only lifeline there was for the injured to be cut off.

I will always be indebted to you and what you did for me. The ONLY reason I am alive, is because of [b6] [b6] unyielding advocacy and because of you. I hope that you do realize the monumental impact you have on the injured... I know this first-hand with my own home physicians. They would not give me the time of day, they slapped [b6] label on me and left me to suffer on my own through something that still to this day I am surprised I survived... it wasn't until after YOU brought me in, YOU advocated for me with my doctors...only then did things change for me. Completely changed the trajectory of my recovery. I would still be trapped in a bed or worse right now if it weren't for you. You are in an extremely unfortunate position where you hold the keys to the doors for healing, yet many times you are unable to open that door for people due to circumstances I do not understand.

Why do I say this? Because I have repeatedly seen the difference in the injured's ability to get basic medical care just by one simple phone call you have made to their physicians. I sent hundreds your way, quietly. One simple email to their medical team. Without it, these people [b6] are merely urban legends, are not real, irrelevant, unworthy of care. The difference is seriously night and day...life-changing. Yes the list is very very long of those you have helped, in person or remotely. But the list is also equally long or much longer of those who were turned away because there wasn't enough room in the study, or whatever the reason was... those people are still not well. Their recovery, months later looks dramatically different than mine and others who were lucky enough to be selected for help. Even to this day, some people email your team and get a telehealth visit, their life changes... others get nothing.

I understand you are just one person, in a system that obviously is broken...But also at the same time your impact is monumental. From my myopic perspective, it is extremely hard to understand why the now 12,000 injured Americans (and others with similar numbers) [b6] must remain suffering in silence. Why has the net not been cast out? Guidance for further investigation? Advocacy? Researchers can't find what they aren't looking for. I absolutely do believe that someone, somewhere at a level of authority needs to actively pursue and examine what is happening. I also know this is possible at the

government level. We have seen this in action with long-haulers...yes, open discussions can happen as the research progresses, yes directives and guidance can be provided.

Yes vaccine injured are fewer in numbers, but this is being heavily mandated and everyone is expected to do their part and take the risk. With this high expectation for all to partake, there needs to be the high expectation that there will be help for those who fall through the cracks. Those who are injured are so broken down now that they really don't even need a cure at this point...they just need someone to tell their doctor to actually engage with them and not gaslight them...just recognize them as a person worthy of medical care...not cast them aside and hope that months after their lives have been altered that they can quietly find their way through a complicated medical system totally on their own...good luck to them. The scrutiny is extremely high to vaccinate, so the flip of that coin is the harms must be meticulously examined.

Dr. Safavi left a vaccine injured chat last September, something strange was going on. The active engagement from the spring and summer was replaced with distance and vague responses, then nothing. But then some people get telehealth visits, and vague responses...and others are told "there is no research" and that's it for them.

I am sure you would understand now why the hundreds+ who were turned down for any assistance are now extremely upset after waiting for so long...many feel very betrayed. They have been waiting and waiting, all while suffering every single day. Those of us who got the help (their friends), had been telling them that the promised published lit will then help them too. But the problem is, the lit isn't coming soon enough for many. The conversation isn't happening. They are dying. 😊 Their doctors don't know what to do, or don't want to help...and why would they help? Not a single mention of someone from authority/trust has yet mentioned this to the med community.

I guess my greatest fear now is the risk that we all took by going out there...that trip wasn't entirely for us individually. It was for everyone else. For that data to be gathered and compiled and open the door for everyone else. I am afraid at this point, especially after seeing the minimizing that was done with the NIH post-vax menstrual report (which the NIH actually cast out the net for, solicited for input...AND released their findings in shorter time than this study). But the report minimized the issue, it was hurtful, damaging even...for those who literally are passing blood clots and tissue for months and months, that isn't minor. What is the purpose of doing any examination if the worst gets word-smithed into "nothing to worry about". I got dozens of photos of passed tissue and clots from injured people after that report was released... (which I would prefer not to get), because it was their way of expressing to someone, anyone...that their physical ailment that keeps them confined to their home is in-fact real.

Please tell me that we are not minimized, that our data, however confounding it is, is not going to be manipulated into something like what that menstrual report was... that's not looking at the hard truths. The sad reality is I see those "hard truths" every single day, by the hundreds each day. It is horrible, it is dark, it is ugly, thousands of people who have no one, and they're all just waiting for a light to pierce the darkness to show a way out.

I guess all this to say... this will be the last email I will send. My heart is shattered tonight. I am more confused now than ever about what my active and willing engagement in the scientific process actually meant, or has led to.

b6

From: [b6]
Sent: 1/15/2022 1:30:02 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [b6]
Re: [EXTERNAL] Re: <no subject>

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Will speak next week. Thanks avi

[Get Outlook for iOS](#)

From: Nath, Avindra (NIH/NINDS) [E] [b6]
Sent: Friday, January 14, 2022 7:58:00 PM
To: [b6]
Subject: Re: [EXTERNAL] Re: <no subject>

External Email - Use Caution

Yes, that would be perfectly fine.
Avi

From: [b6]
Date: Friday, January 14, 2022 at 7:17 PM
To: "Nath, Avindra (NIH/NINDS) [E]" [b6]
Subject: [EXTERNAL] Re: <no subject>

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, Avi. I think it best if you have a virtual visit with him confidentially without me as to maintain his privacy. Is that possible? If it is helpful to you, I can organize this for you. Whatever you think is best.

With appreciation,

[b6]

From: "Nath, Avindra (NIH/NINDS) [E]" [b6]
Date: Friday, January 14, 2022 at 6:26 PM
To: [b6]
[b6]
Subject: Re: <no subject>

External Email - Use Caution

Sorry, to hear that. Yes, I will be glad to talk to you and visit with [b6]
Avi

REL0000231730

From: [REDACTED] b6

Date: Friday, January 14, 2022 at 4:19 PM

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

Subject: [EXTERNAL] <no subject>

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 Avi and [REDACTED] b6

Sorry to bother you. I am writing about [REDACTED] b6

[REDACTED] b6

[REDACTED] b6 Is there a possibility we could speak together about this and whether Avi in particular could have a virtual visit with him ?

I know that there are many unknowns here but any help you can offer is appreciated.

Best wishes,

[REDACTED] b6

b6

The information in this e-mail is intended only for the person to whom it is addressed. If you believe this e-mail was sent to you in error and the e-mail contains patient information, please contact the [REDACTED] b6

[REDACTED] b6 If the e-mail was sent to you in error but does not contain patient information, please contact the sender and properly dispose of the e-mail.

Please note that this e-mail is not secure (encrypted). If you do not wish to continue communication over unencrypted e-mail, please notify the sender of this message immediately. Continuing to send or respond to e-mail after receiving this message means you understand and accept this risk and wish to continue to communicate over unencrypted e-mail.

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[REDACTED] b6 If the e-mail was sent to you in error but does not contain patient information, please contact the sender and properly dispose of the e-mail.

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From: Marks, Peter [b6]
Sent: 1/24/2022 2:58:48 PM
To: [b6] Woodcock, Janet (FDA/OC) [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=9bc3fc3ebfcf48879f92169bd7644e29 [b6] Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: RE: [EXTERNAL] Impromptu Meetup

Dear [b6]

Thanks for being in touch about this. Obviously, we have connected with Dr. Nath and we are also working through contacting other physicians as well. I have sent a note to our pharmacovigilance group to see if they can free up time today or tomorrow. However, they would not be in a position to be able to meet in person in any case, so setting up a virtual meeting at some point in the near future when there is more time to plan participants and the agenda may make sense.

Best Regards,
Peter

-----Original Message-----

From: [b6]
Sent: Monday, January 24, 2022 9:38 AM
To: Woodcock, Janet [b6] Marks, Peter [b6] Nath, Avi (NIH) [b6]
Subject: [EXTERNAL] Impromptu Meetup

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

Good Morning Drs.
I hope you are all doing well. We are in DC the remainder of today and tomorrow. Some of our epidemiologists happen to be in town as well and would like to have the opportunity to review with you the scientific data they have.

Also checking in to see what progress has been made with our researchers?

[b6]

From: Woodcock, Janet [b6]
Sent: 1/24/2022 2:58:30 PM
To: [b6] Marks, Peter (FDA/CBER) [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b2e527dbda2b4a86b8d72f06b813d471; [b6] Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6; [b6]
Subject: RE: [EXTERNAL] Impromptu Meetup

FDA is not having in person meetings right now. I think something could be set up for a discussion between the scientists but it would need to be scheduled to ensure the right people attend.

We are evaluating the data and analyses that have been done on adverse events after vaccination, particularly neurologic AE's. Janet Woodcock

-----Original Message-----

From: [b6]
Sent: Monday, January 24, 2022 9:38 AM
To: Woodcock, Janet [b6] Marks, Peter [b6] Nath, Avi (NIH) [b6]
Subject: [EXTERNAL] Impromptu Meetup

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

Good Morning Drs.
I hope you are all doing well. We are in DC the remainder of today and tomorrow. Some of our epidemiologists happen to be in town as well and would like to have the opportunity to review with you the scientific data they have.

Also checking in to see what progress has been made with our researchers?

[b6]

From: [b6]
Sent: 4/5/2022 6:50:06 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
CC: NINDSPostCovid19 [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=7288bc48d86f4f5fb796620bda298e7f-nindspostco]
Subject: Re: [EXTERNAL] Symptoms post Moderna reaction

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Thank you so much !

It's more the inflammation and up and down blood pressure, I have been noticing concentration and word mix up.

I notice I'll skip a word? Like instead of saying "hand work" I'll say "work."

I have [b6] and I want so say we really look up to people like you!!!

Have a great day and appreciate it!

On Tue, Apr 5, 2022 at 9:37 AM Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

Thanks for sharing your experience with me. Sounds like you are receiving excellent care from your cardiologist. Currently we do not have any specific studies on myocarditis. I have copied our research team in case you are willing to share more details about you symptoms

Best

Avi

On Apr 5, 2022, at 9:15 AM, [b6] wrote:

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I developed severe Myocarditis [b6] after my second dose and was hospitalized for a week [b6]

I have had intense inflammation attacks when I get a slight colds. Muscle pain and soreness. I had an intense head pain that I thought was a aneurysm, that sent me to hospital.

My blood pressure that was normal before, [b6]
[b6]

If there are any studies that would help figure out any solutions or help add light to what I have and many others have been going through I'd gladly sign up.

REL0000231745

My GP has been good, doing

b6

b6

My cardiologist

b6

Thanks for your work!!! It's appreciated. That Science article really reached me and it made me feel a lot less isolated in what I have been going through!

Have a great day!!!

b6

b6

From: [b6]
Sent: 4/25/2022 11:40:03 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [EXTERNAL] Significant Adverse Reaction to Covid Vaccination Need 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.

Hi, Dr. Nath. I am writing to you because I have become desperate. I was vaccinated [b6] with the Pfizer Covid vaccine. I did not have an immediate reaction, but weeks later became overwhelmed by debilitating fatigue that I had never before experienced. Subsequent to that, I had severe diarrhea and experienced a burning pain in my feet and lower legs which spread quickly to full limbs, hands and feet. I sought medical help. I underwent an extensive work-up over the span of months. Initially doctors thought [b6]
[b6]

As I waited for tests and appointments, my condition worsened. In addition to the fatigue, brain fog, and peripheral paresthesia, I experienced heart palpitation, vertigo, dizziness. I developed very loud tonal tinnitus and intermittent pulsatile tinnitus. I have internal vibrations, extreme venous pooling, orthostatic intolerance, heat intolerance, very dry skin on my legs and arms, rashes, new allergies, extreme constipation and more.

b6

Through [b6] I believed I was improving. I traveled to see a doctor [b6] and when I returned had a horrible flare. All my symptoms returned, stronger than ever. (That doctor, rheumatologist believes [b6]

I am now sicker than I have ever been and I am receiving no medical treatment. I suddenly feel that I am deteriorating badly. It has become hard for me to walk due to pain and the blood pooling and bulging veins have become severe. The skin on my arms and legs has become severely dry. My toes are becoming deformed.

I wrote to my neurologist and asked him if [b6]
[b6]

I am still waiting to see [b6] I can't even make an appointment because [b6]

I thought about going to the ER this weekend because I am becoming frightened.

I am writing to you out of desperation.

I know you treated some people like me with [b6] and the report is that they improved and are healing. I studied what my insurance will cover [b6] for and I do not know if any doctor will make a case for me. I don't really have time to find new doctors and travel to see them because I feel my condition is rapidly deteriorating. I need help now or soon.

Please, Dr. Nath. I am not alone. I know there are others like me and many of us have been sick for a year now. Some people, like me, felt we were improving and then relapsed. After [b6] I can see that (even though I

have had a few good months) the trendline for me is downward. It feels to me that there is autoimmune process and unless that is interrupted, I will continue the downward spiral.

Can you please reinstate the program of treating post-vaccine patients? Or at least give guidance so that our local doctors will know what to do? If the FDA gave emergency approval for **b6** for refractory post-vax, our insurers would have to pay for it.

Please, can you help me? I am worried that I will become crippled. Please.

Kind regards,

b6

From: [b6]
Sent: 4/29/2022 2:51:25 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [EXTERNAL] Post-vaccine illness Need Help

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Hi, Dr. Nath. I am writing to you because I have become desperate. I was vaccinated [b6] with the Pfizer Covid vaccine. I did not have an immediate reaction, but weeks later became overwhelmed by debilitating fatigue that I had never before experienced. Subsequent to that, I had severe diarrhea and experienced a burning pain in my feet and lower legs which spread quickly to full limbs, hands and feet. I sought medical help. I underwent an extensive work-up over the span of months. [b6]

As I waited for tests and appointments, my condition worsened. In addition to the fatigue, brain fog, and peripheral paresthesia, I experienced heart palpitation, vertigo, dizziness. I developed very loud tonal tinnitus and intermittent pulsatile tinnitus. I have internal vibrations, extreme venous pooling, orthostatic intolerance, heat intolerance, very dry skin on my legs and arms, rashes, new allergies, extreme constipation and more.

[b6]

Through [b6] I believed I was improving. I traveled to see a doctor [b6] and when I returned had a horrible flare. All my symptoms returned, stronger than ever. (That doctor, rheumatologist believes [b6])

I am now sicker than I have ever been and I am receiving no medical treatment. I suddenly feel that I am deteriorating badly. It has become hard for me to walk due to pain and the blood pooling and bulging veins have become severe. The skin on my arms and legs has become severely dry. My toes are becoming deformed.

I wrote to my neurologist and asked him if [b6]

I am still waiting to see [b6] I can't even make an appointment because [b6]

I thought about going to the ER this weekend because I am becoming frightened.

I am writing to you out of desperation.

I know you treated some people like me with [b6] and the report is that they improved and are healing. I studied what my insurance will cover [b6] for and I do not know if any doctor will make a case for me. I don't really have time to find new doctors and travel to see them because I feel my condition is rapidly deteriorating. I need help now or soon.

Please, Dr. Nath. I am not alone. I know there are others like me and many of us have been sick for a year now. Some people, like me, felt we were improving and then relapsed. After [b6] I can see that (even though I

REL0000231750

have had a few good months) the trendline for me is downward. It feels to me that there is autoimmune process and unless that is interrupted, I will continue the downward spiral.

Can you please reinstate the program of treating post-vaccine patients? Or at least give guidance so that our local doctors will know what to do? If the FDA gave emergency approval for [b6] for refractory post-vax, our insurers would have to pay for it.

Please, can you help me? I am worried that I will become crippled. Please.

Kind regards,

[b6]

Sent with ProtonMail secure email.

From: [b6]
Sent: 4/2/2021 4:55:15 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: Update and Inquiry

Thank you.

[b6]

Regarding [b6] my neurologist still does not believe [b6]
He doesn't think this is [b6] has not listened to any of my symptoms (my internist and myself firmly know that it is, as it started shortly after [b6]
As of today, I am trying to find another neurologist, as the neurologist at [b6] has not helped me whatsoever since the vaccine reaction began [b6]
I was hoping to get well. Trying not to be discouraged.

I will update when I can. Hoping the immediate need I have for [b6] to be treated will happen. Will just take longer as I try to get scheduled with a different doctor.

On Mar 30, 2021, at 1:47 PM, [b6] wrote:

Thank you Dr Nath.

This neurologist, [b6] has said [b6] however I am hoping to get in with an interventional radiologist to [b6]

Is there possible theories on the rash and fever and neuro inflammation after [b6] It is such a strange sensation in my head after the shot.

I was talking with a colleague who was [b6]

[b6]

[b6]

On Mar 29, 2021, at 7:45 PM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

Sorry to hear about all that you are going through. Hard to practice medicine via email, but [b6]

[b6] Happy to talk to your neurologist if it would help. You may share my contact information with them.

Avi
Avindra Nath MD

REL0000231765

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, March 29, 2021 at 9:14 PM
To: Nath, Avindra (NIH/NINDS) [E] **b6** Safavi, Farinaz
(NIH/NINDS) [E] **b6**
Subject: Update and Inquiry

Here is an update from **b6**
I was given **b6**
b6

I had a strange inflammatory response to **b6** felt just like I did in
b6 lots of neuro inflammatory issues identical to post covid. Low fever, super
weak, very delirious and had a hard time sticking in reality. Strange pains and vibrations,
nausea, dizziness.
It was actually kinda scary. Walking was strange again, trying to work on that again. I
also got a rash all over my neck, and stomach and back. It still hasn't gone away.

I also (before **b6**) started getting this strange vascularization where I
get occasional super dark small unexplained bruises about 2mm in diameter. Just
sometimes on my legs sometimes on my arms.
I also started losing my hair at about **b6**

Neurologist: **b6**
b6

My internist: **b6** has been spending a lot of time this month trying to sort
through my condition and help. Are there any words of guidance for me and this
doctor? Any word on lab results that we sent **b6** Still suffering in a lot of neuro pain,
occasional "buzzing" still in my head and body. Massive brain fog, pots symptoms. I
experience what I can only describe as neuro inflammation extremely easy.

b6
b6 Been trying everything I can to reduce stress, and rest,
and heal, and recuperate. Been eating super healthy. I don't know what else I can do.
The neurology team at **b6**
b6 have not been helpful. They have been the gatekeepers of me
being able to access care all this time. Hoping **b6** will be more amenable to
helping me.

b6 wants to **b6**
b6

And he wants to

b6

b6 Seeing how physically weak I am now compared to before the vaccine, I am concerned it may cause another strange inflammatory reaction, making me weaker or causing a relapse in my cognitive function again.

Any suggestions or help?

b6

From: [b6]
Sent: 4/24/2021 6:08:53 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Covid Vaccine Reactions

Dr. Nath,

Curious if any results have started to come back from

[b6]

[b6]

AstraZeneca covid vaccine injury.

From: [b6]
Sent: 1/15/2021 7:14:59 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: AZD-1222 adverse reactions

RE: Symptoms

This is [b6]

I forgot to mention yesterday regarding symptoms. I have initial strong tinnitus and also pulsatile tinnitus occurred within the first three days. The tinnitus has since reduced a bit (or I have become used to it so it's not as loud), but the pulsatile tinnitus is still there and definitely can feel it swooshing almost in my head...the sensation is worse with the head pain.

(I do have a prior history of [b6]
[b6]
[b6]

On Jan 15, 2021, at 11:26 AM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

I have now discussed your symptoms with our group. Some of us are wondering if we should consider bringing you to NIH to study you here. It does pose some challenges since [b6] Do you think that might be possible?
Avi

From: [b6]
Date: Thursday, January 14, 2021 at 5:56 PM
To: "Nath, Avindra (NIH/NINDS) [E]" [b6]
Subject: Re: AZD-1222 adverse reactions

Dr. Nath,

I have located [b6] I can collect it and send that along with the blood samples in the kit or the lab will send it directly to you if you have a way to pay for shipping.

[b6]

Thank you so much for speaking with us today.

[b6]

On Jan 11, 2021, at 11:26 AM, Nath, Avindra (NIH/NINDS) [E] [b6]
wrote:

Dear [b6]
Sorry to hear of [b6] illness. I would be glad to speak to you and [b6] to see
how we can help. Warren can help set up a virtual meeting. I will request Drs. Smith and
Safavi, Neurologists who works with me to join me.

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] (cell)
[b6]

From: [b6]
Date: Monday, January 11, 2021 at 1:13 PM
To: "Nath, Avindra (NIH/NINDS) [E]" [b6]
Subject: AZD-1222 adverse reactions

Dr. Nath,

[b6] participated in the phase 3 clinical trial of the
AstraZeneca AZD1222 covid-19 vaccine. Beginning shortly
after vaccination on [b6] and continuing to present,
she has had serious neurological complications. Double
vision, tinnitus, hyperacusis, paresthesias, autonomic
problems such as heart palpitations and tachycardia, tremors,
leg weakness, trouble walking, numbness, tingling, low-grade
fevers and a very pronounced vibration sensation in her
brain/head.

[b6]
[b6] She has been denied
the second shot and unblinded, she received vaccine.

[b6] has been disabled by this, [b6]
[b6]

She has also made contact via support forums with another woman in [b6] who had
the vaccine 10 days later and is experiencing almost every single symptom.

AstraZeneca seems only concerned with a diagnosis that absolves them in these matters.

I read about others in the UK, India and possibly Brasil that have had neurological
complaints following the AZD-1222 trial and yet AstraZeneca persists in stating that no
serious adverse events have been recorded.

I am concerned that regulators are being deprived of vital information in these studies.

b6

b6

From: [b6]
Sent: 5/29/2021 1:24:33 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: Mental Health of Vaccine Victims

I really appreciate you taking the time to reply.

Best wishes.

On May 28, 2021, at 7:13 PM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

We are very saddened to hear of [b6] death. We are well aware of the psychiatric manifestations in patients with post-COVID syndrome. There are a number of manuscripts in the published literature describing the phenomenon. While the underlying reasons might be many and are not fully understood, recognizing it and getting help is critical to prevent these kinds of events. Yes we do have a psychiatrist at NIH who is interested in these issues, but the situation is much beyond the capacity of a single individual. Local help and long-term care is vital to managing depression and other mental health illnesses.

With best wishes.

Avi

From: [b6]
Date: Thursday, May 27, 2021 at 6:57 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6] Safavi, Farinaz (NIH/NINDS) [E]
[b6]
Subject: Mental Health of Vaccine Victims

Dr Nath and Safavi.

I have been in touch with [b6] she had become a dear friend to me. He told me the sad news of [b6] and has tasked me with trying to get others like her help.

I opened up the topic to our group (350-400) about the mental health aspect of this. I was shocked to see that the vast majority of these individuals (me included) have had this strange overpowering brain fog that caused deep depression/derealization [b6]

[b6] Some of whom I know have been to visit you at the NIH.

I previously knew there were a few...but I had no idea that this was happening on a bigger scale and so many were afraid to talk about it.

So, through tears rolling down my face thinking of [b6]
[b6]

Is there anything that can be offered to these vaccine injured for mental health? Someone mentioned something about a neuro-inflammation psychiatrist?

I have never heard of anything like this. Would you be able to redirect me to someone who would be able to help me get these people to the correct professionals??

I know you are extremely busy. I just have no idea who else to turn to...there is nobody else out there that is helping us. We are all struggling in silence.

I really appreciate your time. I just have no idea where to start when it comes to finding the resources specific to help with this important issue.

Ps... I am thrilled at the opportunity to be able to meet you later this month. Counting down the days.

b6

From: [b6]
Sent: 12/1/2021 5:51:03 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
[b6]
Subject: [b6]

Good morning Dr Nath.

I would like to introduce you to [b6] who is conducting some remarkable research on covid and long-haulers through her research in immunobiology.

She is looking into examining possible auto-antibodies (which are turning up positive in a subset of the neuro vaccine injured, via specific testing done at Washington University).

Dr Nath is a lead researcher in long-covid and as an extension of that work, he has collected a bank of samples from a subset of of those suffering persistent neurological symptoms post vaccine.

I really appreciate both of your time, and will let you take it from here.

[b6]

From: [b6]
Sent: 1/15/2021 7:15:13 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: AZD-1222 adverse reactions

[b6]

[b6]

On Jan 15, 2021, at 12:04 PM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

OK. Lets not change current plans, which is shipping samples and sending us records. Amanda and Keymani will be in touch with you reading travel arrangements. I will also discuss with you what to expect in terms of tests etc when you come here. The current political climate is another aspect that we need to keep an eye on. [b6]

Avi

From: [b6]
Date: Friday, January 15, 2021 at 1:55 PM
To: "Nath, Avindra (NIH/NINDS) [E]" [b6]
Subject: Re: AZD-1222 adverse reactions

Dr. Nath,

That is something that we would make every effort to do if you and your team thought it was best. She would be unable to travel alone, however.

Best, [b6]

On Jan 15, 2021, at 11:26 AM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

I have now discussed your symptoms with our group. Some of us are wondering if we should consider bringing you to NIH to study you here. It does pose some challenges since [b6] Do you think that might be possible?

Avi

From: [b6]
Date: Thursday, January 14, 2021 at 5:56 PM
To: "Nath, Avindra (NIH/NINDS) [E]" [b6]
Subject: Re: AZD-1222 adverse reactions

Dr. Nath,

REL0000231797

I have located [b6] I can collect it and send that along with the blood samples in the kit or the lab will send it directly to you if you have a way to pay for shipping.

[b6]

Thank you so much for speaking with us today.

[b6]

On Jan 11, 2021, at 11:26 AM, Nath, Avindra (NIH/NINDS) [E]

[b6] wrote:

Dear [b6]

Sorry to hear of [b6] illness. I would be glad to speak to you and [b6] to see how we can help. Warren can help set up a virtual meeting. I will request Drs. Smith and Safavi, Neurologists who works with me to join me.

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] (cell)

[b6]

From: [b6]

Date: Monday, January 11, 2021 at 1:13 PM

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

Subject: AZD-1222 adverse reactions

Dr. Nath,

[b6] participated in the phase 3 clinical trial of the AstraZeneca AZD1222 covid-19 vaccine. Beginning shortly after vaccination on [b6] and continuing to present, she has had serious neurological complications. Double vision, tinnitus, hyperacusis, paresthesias, autonomic problems such as heart palpitations and tachycardia, tremors, leg weakness, trouble

walking, numbness, tingling, low-grade fevers and a very pronounced vibration sensation in her brain/head.

b6

b6 She has been denied the second shot and unblinded, she received vaccine.

b6 has been disabled by this,

b6

b6

She has also made contact via support forums with another woman in Georgia who had the vaccine 10 days later and is experiencing almost every single symptom.

AstraZeneca seems only concerned with a diagnosis that absolves them in these matters.

I read about others in the UK, India and possibly Brasil that have had neurological complaints following the AZD-1222 trial and yet AstraZeneca persists in stating that no serious adverse events have been recorded.

I am concerned that regulators are being deprived of vital information in these studies.

b6

From: [b6]
Sent: 11/4/2021 12:01:10 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6-[b6]
CC: NINDSPostCovid19 [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=7288bc48d86f4f5fb796620bda298e7f-nindspostco]
Subject: Re: Vaccine Reaction - 3rd opinion

Good morning Dr. Nath,

Thank you very much for touching base with me. I certainly do appreciate it. I would love to be apart of the online study. I currently reside in [b6] but would be happy to travel. Thanks again.

[b6]

On Nov 4, 2021, at 12:32 AM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Sorry to hear of your symptoms. Currently, we are in the process of learning about these side effects. I have copied our research team and will be appreciative if you would be willing to participate in this online study. We do not have any treatment protocols at the moment. But what city do you live in? Maybe we can recommend someone to see you.

Avi

Avindra Nath MD

Chief, Section of Infections of the Nervous System

Clinical Director,

National Institute of Neurological Disorders and Stroke

National Institutes of Health, Bethesda, MD

[b6] (Office)

[b6]

From: [b6]
Date: Tuesday, November 2, 2021 at 10:41 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Vaccine Reaction - 3rd opinion

Good Evening Dr. Nath,

I truly hope this email finds you well. A patient of yours passed along your info to me as we both are experiencing the same issue following our COVID Vaccine. I am very hopeful that maybe you would be able to lead me in the right direction as the doctors I have seen at [b6] are lost as to what is going on and are recommending a 3rd opinion.

My Symptoms Are As Follows:

- Difficulty walking and weakness within the legs
- Vertigo

- Blurry vision
- Depth perception was very off visually - background moving backwards
- Trouble forming sentences and beginning to stutter
- Severe brain fog
- Short term memory loss
- Dystonic/Seizure Like Episodes
- Anxiety/Panic Attacks
- Insomnia
- Feeling out of body / Depersonalization
- Tinnitus
- Lack of sensation throughout the body
- Tics
- Vocal utterances
- Involuntary eye movements - shifting to the right
- Comprehension issues - understanding what's being said during a convo and reading
- Sensitive to sounds, light, movement, long conversations - too much stimulation
- Blank stares where I'm unable to talk but can hear everything around me
- Extreme Paranoia / Hallucinations

I've had several tests come back

b6

b6

b6 I have been seen by a Movement Disorder Specialist, 2 Rheumatologists, ENT Doctor and 4 Neuro-Immunologists; not including the 4 trips I've taken to the ED and trips to see my PCP. I am so very desperate for help and don't know where to turn at this point b6 Thank you for your time.

b6

From: [REDACTED] b6
Sent: 11/13/2021 6:02:30 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6] b6
Subject: FYI
Attachments: POST COVID-19 VACCINE SMALL FIBER NEUROPATHY.pdf

The information in this e-mail is intended only for the person to whom it is addressed. If you believe this e-mail was sent to you in error and the e-mail contains patient information, please contact the [REDACTED] b6 [REDACTED] b6. If the e-mail was sent to you in error but does not contain patient information, please contact the sender and properly dispose of the e-mail.

Please note that this e-mail is not secure (encrypted). If you do not wish to continue communication over unencrypted e-mail, please notify the sender of this message immediately. Continuing to send or respond to e-mail after receiving this message means you understand and accept this risk and wish to continue to communicate over unencrypted e-mail.

Post COVID-19 vaccine small fiber neuropathy

We describe the case of a 57-y-old female who presented 1 week after receiving the second dose of the Pfizer coronavirus disease 2019 (COVID-19) vaccine with subacute onset of intense burning dysesthesias in the feet, gradually spreading to the calves and minimally into the hands, unaccompanied by other neurological or constitutional symptoms. There was no known prior COVID-19 exposure; a COVID-19 reverse-transcriptase-polymerase-chain-reaction test 9 mo before this presentation was negative. She was not on any medications and denied the use of alcohol. Besides the distal loss of pinprick and cold sensations in the feet, her examination was unremarkable.

An electrodiagnostic study performed on the day of presentation (including left median, peroneal, and tibial motor nerves with F-waves; left median, sural, and superficial peroneal sensory nerves; and needle examination of the left tibialis anterior, gastrocnemius, vastus medialis, iliopsoas, and lower lumbar paraspinal muscles), was normal. Skin biopsies showed multifocal involvement¹ (Figure 1). Hematoxylin and eosin and CD3 staining showed no histologic abnormalities.

The following laboratory tests were normal or negative: complete blood count, comprehensive metabolic profile, thyroid-stimulating hormone, methylmalonic acid, folic acid, thiamine, pyridoxine, hemoglobin A1c, serum and urine electrophoresis with immunofixation, serum-free light chains, HIV antibody, Lyme antibody, sedimentation rate, anti-double-stranded DNA antibody, rheumatoid factor, anti-Smith antibody, antineutrophil cytoplasmic antibodies, anti-SSA/SSB antibodies, complement levels, and a serum paraneoplastic antibody profile. The severe acute respiratory

syndrome coronavirus 2 (SARS-CoV-2) antibody profile was consistent with a post-vaccination state and ruled out previous asymptomatic COVID-19 exposure.

Treatment with gabapentin provided symptomatic improvement. At 2 wk follow-up, she reported complete resolution of neuropathic pain and successfully discontinued gabapentin therapy, although stocking-type small fiber modality loss persisted on examination.

We have identified a case of biopsy-proven small fiber neuropathy as a post-vaccination complication. The SARS-CoV-2 antibody profile was consistent with a post-vaccination state but ruled out previous asymptomatic COVID-19 exposure, which could have resulted in a robust immune response. The development of our patient's presentation soon after the vaccination, and exclusion of other known etiologies, support a possible causal association. A proposed pathophysiologic mechanism for vaccine-associated polyneuropathy is an immune-mediated hypersensitivity to the solvent/adjuvant (polyethylene glycol).²

Concerns regarding neurologic complications of vaccination are not new and include the development of Guillain-Barré syndrome (GBS); however, the associated risk is minute – on the scale of one to two GBS cases per million doses of influenza vaccine administered, favoring a recommendation for flu vaccination.³ Although rare, a small number of case reports of small fiber neuropathy have been described in the literature following various vaccinations.³

With regard to SARS-CoV-2, a recent study from the United Kingdom found no association between COVID-19 and GBS.⁴ Furthermore, the lack of significant homology between any SARS-CoV-2 genetic or linear protein structure and human linear protein

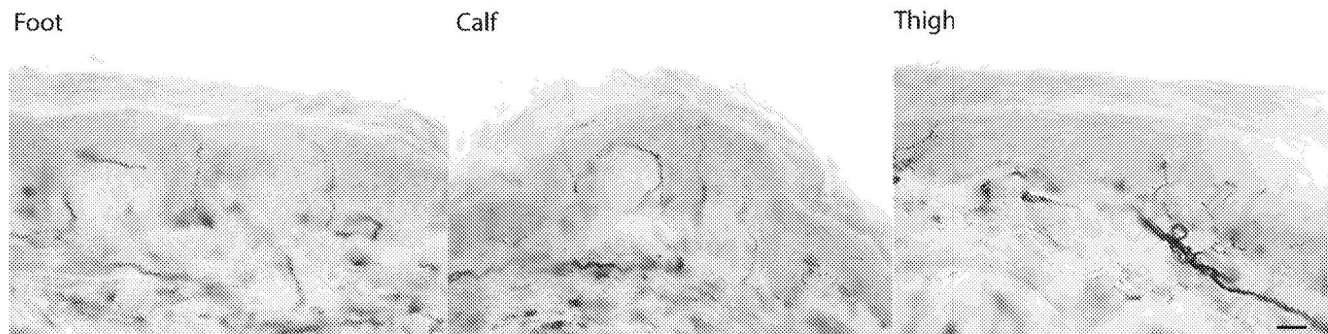


FIGURE 1 Three mm punch biopsies of skin undertaken confirmed multifocal small fiber neuropathy, suggested by loss of protein gene product 9.5 immunolabeled nerve fibers in the dorsum of left foot, over the extensor digitorum brevis muscle (2.1 fibers/mm of skin; normal >3.0) and left upper thigh at the level of ischial tuberosity (3.8 fibers/mm of skin; normal >6.0), and low normal intra-epidermal nerve fiber density (IENFD) in the calf segment, 10 cm above the lateral malleolus (4.7 fibers/mm of skin; normal >4.3). Scale bar represents 20 μ m. Interpretation of IENFD was done by Corinthian Reference Laboratory, Benbrook, TX

structures in this study make molecular mimicry as a cause less likely, thus minimizing the concerns for COVID-19 vaccination-associated GBS.⁴

Rare cases of Bell palsy were noted in phase III trials with both COVID-19 vaccines (Moderna: three in the vaccine and one in the placebo group; Pfizer: four in the vaccine and zero in the placebo group); however, the observed frequency rates did not exceed the background rate found in the general population.⁵

A temporary pause after rare reports of transverse myelitis in other COVID-19 vaccination trials, by AstraZeneca and Sinopharm, was removed after documentation of safety and lack of causal relationship.⁶

Adverse neuromuscular events following immunization against SARS-CoV-2 were not seen in the pivotal vaccine trials; however, vaccine safety monitoring is an ongoing process. As of February 19, 2021, 28 cases of GBS and no case of Bell palsy have been reported to the Vaccine Adverse Event Reporting System (VAERS) following the COVID-19 vaccination.⁷ In addition to our biopsy-proven report of small fiber neuropathy, VAERS has received additional reports: 2 of acute motor-sensory axonal neuropathy, 27 of peripheral neuropathy, 1 of mononeuropathy, 1 of peripheral sensorimotor neuropathy, and 3 of polyneuropathy. New-onset neuropathies following inoculation against SARS-CoV-2 remain rare, with incidence rates between 0.01% and 0.13%.⁷

In summary, rare occurrences of COVID-19 vaccine-related neuromuscular complications are indeed possible. Although infrequent, any serious adverse reaction to vaccines must be sought, reported, and rigorously investigated to facilitate ongoing safety evaluation and to minimize vaccine hesitancy among the general population. Further studies are warranted to better understand the spectrum of neurological complications after COVID-19 vaccination and to determine whether a causal relationship exists between these vaccines and neurological sequelae, including small fiber neuropathy.

ACKNOWLEDGMENTS

We thank Ms. Molly Partelow for manuscript formatting, figure editing, and proofreading of the article. The authors are grateful for the insightful comments and assistance with obtaining the skin biopsy figures by Todd D. Levine, MD.

CONFLICT OF INTEREST

None of the authors have any conflicts of interest to disclose.

DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study

ETHICAL PUBLICATION STATEMENT

We confirm that we have read the Journals' position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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Email: waqar.waheed@uvmhealth.org

Present address

Sarah R. Tandan FNP, Community Health Centers of Burlington, Burlington, Vermont

Abbreviations: COVID-19, coronavirus disease 2019; GBS, Guillain-Barré syndrome; IENFD, intra-epidermal nerve fiber density; S1, Subunit 1; SARS-CoV-2, severe acute respiratory syndrome coronavirus 2; VAERS, Vaccine Adverse Event Reporting System.

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- US Centers for Disease Control and Prevention Vaccine Adverse Event Reporting System, <https://wonder.cdc.gov/vaers.html>

From: [b6]
Sent: 9/17/2021 2:22:24 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: Update

b6

Also on the "spike protein" front... the researchers re-did all their tests on finding the spike in the non-classical monocytes and got the same result. They're working on their pre-print now detailing their methods, in an effort to make the data iron-clad. (As you have seen, anything that is published in this arena gets ripped apart unless it's from big entities - like the Harvard study which went well.)

Kind of interesting that a similar immune dysfunction may be found in both symptomatic long-haulers and those symptomatic post vaccine. Also would be interesting if they are truly able to definitively identify biomarkers for both groups.

And EXCELLENT point! The follow-up with the drug companies has been concerning.

My case (irrelevant of the bigger picture because it was AZ.) We literally begged them for anything...at all. Help, follow-up, offering updates on records, etc. I haven't heard from them since [b6] Early on I called them in tears asking for help because I thought I was gonna die. The test clinic has been surprised and sad that nothing has come back from AZ.

Follow-up on VAERS reports is less than 10% from the group. The follow-up from the companies is less than that. BUT people have not been instructed to notify the companies. Everyone has been instructed to file to vaers, and VAERS sends a reply saying they should be following up.

Of those who have received follow-up from the drug companies (usually 6 months later). The followup form is centered around allergic reactions, very generalized...not designed to catch other issues. Sometimes in rare cases the person is asked for their medical records.

It's amazing how much \$ is available to these companies but the responsibility and liability has been stripped away by US law. These vaccines are not on the right compensation funds and the current bill drafted to add the vaccines to these funds only includes those who have issues after the FDA approval, so the vast majority of us will remain completely on our own without recourse of any kind.

[b6]

On Sep 16, 2021, at 10:54 PM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Terribly sorry, I agree that [b6]

[b6]

Ordinarily when any drug is released it is the manufacturers responsibility to investigate and treat the side effects. Where are the vaccine manufacturers in all of this? Have you tried to contacting them? It cannot be the government's responsibility to pick up after them. They are a profit company and they should be the ones taking change. Don't you think?

Avi

REL0000231810

From: [b6]

Date: Thursday, September 16, 2021 at 11:42 PM

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

Subject: Update

I am feeling suuuuper sick. [b6] I have an appointment monday with my internist. Going to ask him to try to start the paperwork with my insurance for [b6] if that's ok with you. I know it will take a while for them to process it.

Trying to hang onto hope. I had to write a eulogy for my injured sweet friend [b6]
[b6] to read at her memorial. My dear friends :(

I have NO IDEA how you navigate the world you have found yourself in. You deal with this intense stuff all the time.
The tiny part I experience is definitely crushing me under the heavy weight.

In follow-up with our meeting with the FDA a few weeks back, Peter Marks emailed me saying something about safety signals are not occurring for this reaction... after reviewing submitted medical records from several people, in-depth conversations with us, even meeting with our injured MDs and me.
He then talked about how well the system works...even picked up 6 myocarditis cases (which is ironic to me because they met with 6 of us).

Then he proceeded to say that he met with the NIH and that we need to defer to you guys for medical treatment and intervention and research. He's washing his hands of it and passing us on to you. You and I both know that it isn't fair to your small team there to take on all of these people.
So I asked him for clarification on his recommended direction that we need to take...Just stating I am unsure if I am understanding him correctly. I also told him I know there are good people at these agencies that really are dedicating themselves to helping everyone in these unprecedented times and that they must have the weight of the world on their shoulders.

Is there something I am missing with this? Or someone I should be appealing to there at the NIH to encourage further research? Funding for care? Or?

(The irony is I was on the phone for an hour with his colleague Paul Richards who is always so kind and said that this is a priority for them and it is important for them to figure out, and even went so far as to say I should be commended for my efforts to help for the greater good... at the same time Marks drafted that email telling me that we are the NIH's problem. 😞 Bureaucrats hard at work. Lol)

[b6]

From: [b6]
Sent: 9/2/2021 3:32:30 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
CC: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Update and WHO Scale
Attachments: [b6]

Good morning.
I hope you are faring well.

I was able to get [b6]
[b6]

I felt like my body wasn't constantly fighting itself. Felt calm even. The burning and tingling disappeared and by body really just felt relieved to have a break from the constant struggle. It was amazing. I could think clearly as well.

I am [b6] and I definitely had a hard turn backwards. Yesterday and last night were horrible. Sky high HR, tingling and vibrations back, bad heartburn again. Unable to think clearly. Super dizzy. Hoping it settles down, levels out. Will see what this week brings.

Attached find my updated scores.

We did a symptoms survey in our "vetted" group of Americans experiencing this specific type of reaction.

Wanted to share it with you :)

I am sure your data you have there is WAY better than this (this will look like a high school book report to you

I am sure. Lol)

if there are other items or questions you would be curious about we would be happy to help.

On Aug 24, 2021, at 8:45 PM, [b6] wrote:

Thank you :)

On Aug 24, 2021, at 8:04 PM, Nath, Avindra (NIH/NINDS) [E]
[b6] wrote:

Yes, I talked to him earlier today.

Best wishes.

Avi

From: [b6]

Date: Tuesday, August 24, 2021 at 1:19 PM

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

Subject: Neurologist

My new neurologist just called asking if one of you would be willing to contact him,
regarding my follow-up care plan. [b6]

Would you mind reaching out to him? His name is [b6]
His email is

[b6]

Hope you all are safe and doing well.

Thanks again.

[b6]

b6

b6

From: [b6]
Sent: 8/25/2021 2:44:44 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
CC: NINDSPostCovid19 [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=7288bc48d86f4f5fb796620bda298e7f-nindspostco]
Subject: Re: Covid 19 - Pfizer Vaccine severe reaction

Hello Dr. Nath,

Thank you for copying the research time. I am more than happy to provide any and all information to help with understanding some of these side effects a few of us have experienced.

I am going to speak with my doctor on Thursday, and will see if [b6]
[b6]

I appreciate you responding so very quickly.

Best regards,

Thank you,

[b6]

On Tue, Aug 24, 2021 at 7:39 PM Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

Sorry to hear of your illness. Thanks for your willingness to participate in our research study. I have copied our research team who can guide you on how to get us the information.

With regards to getting the second dose, no one really knows what is the right thing to do. As you mention if you get the vaccine, you will for sure develop significant side effects and if you do not, you risk getting the infection which will have even worse effects on you. I guess you could take all the preventive measures to avoid an infection or you could talk to your doctors to see if they might consider [b6]

[b6] But it would have to be their decision, and they would need to weight in the pros and cons. Hard for me to give medical advice over the internet.

Best

Avi

From: [b6]
Date: Tuesday, August 24, 2021 at 10:26 PM

REL0000231831

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

Subject: Covid 19 - Pfizer Vaccine severe reaction

Hello Dr. Nath,

I came across a New York Times article about the Pfizer vaccine and neurological issues, to which your name was mentioned on the article.

I received a Covid vaccine on [b6] and immediately experienced tightness of the throat and rapid heart racing.

Fast forward, I experienced fatigue, brain fog and dizziness. To this day, I still am experiencing balance issues.

I have [b6]

[b6]

I was perfectly healthy with no issues prior to my vaccine. I haven't received the 2nd dose due to my ongoing issues. Is there any way you could use my medical notes or guide me in the right direction? I am terribly afraid of getting Covid 19, but just as afraid of getting another shot and becoming severely ill.

I was in bed for weeks filling the vaccine, with extreme body pain, hand and feet tingling, fluttering heart, and felt as if my head was tight and wrapped in Saran Wrap. I'm at a loss of what to do next in this pandemic. I am more than happy to provide you with medical records and doctors notes. Any information or advice will be helpful.

Thank you for your time.

[b6]

--

Thank you,

[b6]

From: [b6]
Sent: 7/8/2021 5:41:48 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
CC: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: Consult

Thanks for letting me know.

I will send him the list of current publications we have and go from there.

On Jul 8, 2021, at 11:30 AM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

Thanks for all your efforts in getting the word out. I think the best way for us to communicate is via peer reviewed publications even though it takes time to get them out. That is the only thing that will have any credibility.

With best wishes.

Avi

From: [b6]
Date: Thursday, July 8, 2021 at 1:25 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Cc: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Consult

Good Afternoon.

I hope you are doing well! I am still surprised at the progress I have been making. Really been profound actually. I forgot about how the body should function and what that feels like.

I just got off the phone with my state health department's immunization director. It was a great conversation. I requested his help in spreading awareness of these reactions to community physicians, to help remove obstacles to patient care. We both agreed that yes, the vaccines are saving lives and should continue to do so.

I did mention that I know of 5 here locally that have experienced the same reaction and issues with their local medical care teams. That we all knew there would be some that would draw the short straw with the vaccines, and that we should care for those who drew the short straw...even though it is rare.

Anyway, he is asking if there are any basic concepts that can help with this conversation with the hospitals [b6]... that it is rare, and to be mindful and recognize this when it happens.

I was wondering if either of you would be willing to talk to him, as you are way more capable of illustrating the unique issue at hand?

Here is his info...

b6

From: [b6]
Sent: 6/27/2021 1:41:22 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: Re: Random Update

Thank you so much. I value your opinion on this matter above anyone else.

[b6] shares your sentiment on the macrophages with [b6] It is just one person they have looked at so far, and obviously they're gonna run with it as sound science... in my own opinion, preying on those of us who are desperate for help and answers.

And yes! On the emerging case studies, [b6] and those like [b6] have been slowly collecting these as they emerge, so people can share these with their physicians.

I absolutely agree that we likely would have fared far worse had we gotten actual covid. I am unsure if I will have enough time to relay that, but I hope I will be able to.

Thank you for the reply about this being treatable, early treatment, research for clinical trial...I will add this to my comment notes.

[b6]

On Jun 27, 2021, at 7:30 AM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

Glad that you are doing better.

Interesting that spike protein would be found in macrophages. I have not seen the data so it is hard for me to comment upon it. But one has to be very careful in interpretation of these findings, since many of the antibodies used to detect spike protein are non-specific and often bind to a subset of macrophages. The only way to be certain is to pull down the protein and then sequence it.

Good that you are getting the word out. But the way I look at it is that if the vaccine which is a small amount of spike protein can cause these symptoms, just imagine what could have happened if an infection would have occurred.

Maybe the issue has not received the deserved attention, but there now an increasing number of publications in the literature documenting the complications. It always takes a while to get papers through from collection of data, writing them up and then getting them published. Considering over a billion doses administered, the complications are still rare. From my stand point the important message to get out is that they are treatable, so should treat early or do it in the context of a clinical trial.

Keep me posted.

All the best.

Avi

From: [b6]
Date: Sunday, June 27, 2021 at 8:38 AM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Random Update

Dr Nath.

I wanted to say thank you again for your compassion and your team's willingness to take me on in your study. I already have noticed some good changes that have honestly taken me by surprise!

I just wanted you to know some non study related things that may or may not be relevant to you [b6] [b6] said to not bother you with this stuff) but you have been so good to me I wanted to for sure share what is going on.

[b6] last night on a clubhouse call with post vax injured people said that they have specifically found the spike protein in macrophages of a patient who had no prior covid infection (negative nucleocapsid). In 25% of her macrophages. The patient is several months post vax. Then of course they went on hailing the cure and plugging his website.

On a personal front... Last May I had sent a large group signed letter to the CDC and FDA detailing our plight as a group, lack of understanding from our medical teams, and asking them to communicate this to the medical community.

Of course no substantive response was made, and more and more sick and scared people started asking ME for help which I am NOT able to do nor am I qualified.

I reached out to my home senator asking him for help with the CDC to which he agreed. He is sending a very strongly worded letter on our behalf Monday afternoon.

So I am boarding a plane today to attend and speak press conference, where we are describing the situation, urging an open dialogue surrounding the issue and to request and end to the stigma surrounding the term "vaccine injury". [b6] and a few others. We are going to ask for the cdc to finally say something, but also to ask for help and direction for more research and funding.

Those of us speaking have all very much agreed to not discuss the current limited research happening...these institutions and individuals can speak for themselves when they are ready. I have just given a heads up to the few I know that are researching this. We also are NOT going in this as anti-vax and will not discuss whether or not to vaccinate.

And honestly, the fact that this issue is so taboo, I am pretty sure the media won't pick it up.

Thanks again for all you and your team is doing. You are saving lives, making great strides, and have made a huge impact on me and many more.

Best,

[b6]

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 b6]
Sent: 2/27/2021 9:07:52 PM
To: b6
Subject: b6

How about tomorrow (Sun) 11 am EST?

Avi

My cell is: b6

From: b6
Date: Saturday, February 27, 2021 at 3:59 PM
To: "Nath, Avindra (NIH/NINDS) [E]" b6
Subject: b6

Is there a time that works for you?

On Feb 26, 2021, at 8:50 AM, b6 wrote:

I have no plans this weekend so whenever is convenient for you. I am very much appreciative of your time.

On Feb 26, 2021, at 8:35 AM, Nath, Avindra (NIH/NINDS) [E] b6 wrote:

Maybe sometime this weekend anytime after 10 am EST. Let me know what might be best.

Avi

From: b6
Date: Friday, February 26, 2021 at 10:21 AM
To: "Nath, Avindra (NIH/NINDS) [E]" b6
Subject: b6

Good morning Dr Nath. This is: b6 I am curious if you would be willing to call me just sometime before my appointment with my neurologist on Tuesday morning. It appears he is my gatekeeper to testing and possible treatment, and symptomatic relief. I am somewhat concerned as his interest in helping me in our initial appointment didn't appear to be very substantial. So I am just wondering if you would have any insight for me as to the right questions to ask him or how I could encourage him to possibly look outside old established issues like b6

b6

On Feb 22, 2021, at 11:00 AM, Nath, Avindra (NIH/NINDS) [E]

b6 wrote:

Thanks for the update. Glad to know that there is some improvement. Yes, I would be glad to talk to **b6** to see how we can help. You can share my contact information with him.

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, February 22, 2021 at 12:54 PM

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

Subject: **b6**

Dr. Nath,

An update: **b6** sensitivities to sound, light and touch are slowly improving. She still has; fatigue, brain fog, paresthesias, anxiety, and the most debilitating symptom, the brain vibration or "wobbly brain". She is still unable to work **b6** drive or do anything other than simple self-care (bathe, clothes, move around the house.) Still a lot of suffering.

We are struggling to know what the next steps are. Her doctor **b6**

b6

b6 Are you interested in any more samples, or do you have any guidance as to what testing he should be doing on these samples? We have **b6** open to us.

We feel as though our help has stagnated and are desperate to help **b6** feel better. We also feel like her condition may help contribute to finding the cause and then treatments for the Long Covid syndrome that is poised to continue to decimate the economy, as her symptoms mirror those reported so closely.

She continues to find reports in support forums of very similar adverse reactions to the Astra Zeneca vaccine, mostly out of the UK, as it is being given to the population there.

We look to you to help guide the next steps with **b6** as well as others.

Thank you for listening,

b6

Sorry for the double send, I sent it from the wrong address before.

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 b6]
Sent: 8/19/2021 12:25:44 AM
To: b6
Subject: Re: Covid Vaccine reaction: potential participant in study/evaluation

Dear b6

Sorry to hear about your illness, Thanks for reaching out. I have now heard from several individuals from this facebook group who have similar symptoms. This is all new to us and am not sure how to investigate. We do not have anything more to offer than what your neurologist can do. Some patients have b6

b6 Best to continue to work with your neurologists and other physicians.

Best wishes

Avi

From: b6
Date: Wednesday, August 18, 2021 at 4:14 PM
To: Nath, Avindra (NIH/NINDS) [E] b6
Subject: Covid Vaccine reaction: potential participant in study/evaluation

Dear Dr. Nath,

Your name appeared in an article about rare covid vaccine reactions. Unfortunately, I've had a moderate case of this vaccine "longhailer type" reaction. (J and J shot on b6) I am now in one of the same FB groups as b6 with whom I understand you've been in touch.

Since I live and work in b6 I could potentially volunteer to come by NIH to participate in any study or evaluations you might be conducting without it being a huge burden. The article mentioned that you had no cases available to study among NIH staff, which doesn't surprise me- since we all know the cases are relatively rare. So if my participation would be useful for your efforts, please let me know.

Relative to some members of the FB group, my case has been moderate in severity. So far I can still generally function, though I've burned up a lot of sick leave the last few months. But since I work at b6 b6 it wouldn't be that hard for me to come by for testing, etc. when that was appropriate.

Most of my symptoms have been neurological- burning and tingling sensations. I'm not sure if these are correctly described as paraesthesia or not, because the sensations now feel mostly like a sunburn- but no longer feel like these are right on the surface.

Although I have some occasional twitches and buzzing type sensations, most of the effect seems to be primarily on sensory rather than motor function. I've also experienced much greater fatigue, exercise intolerance, and almost constant headache/pressure, but intensity has varied greatly from mild to severe.

My symptoms don't seem to be exclusively neurological, though, because I also notice easier bruising and more small petechiae than I used to have. b6

FYI - I've been to a neurologist and b6 b6

If you think that your research into this effect could benefit from my participation, please let me know.

Regards,

b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 [b6]
Sent: 8/28/2021 11:13:41 PM
To: [b6]
Subject: Re: Random Updates

Hi [b6]

Glad to know you are feeling better. That is great news. Navigation of the US healthcare system is no easy task even for those who are well versed with it. Yes, Dr. Woodcock did talk to me. She is very smart and asked very good questions. Keep me posted
All the best
Avi

On Aug 28, 2021, at 5:26 PM, [b6] wrote:

Oh man...

Long-Hauler Alliance voted us out, the holdout was Dysautonomia International (which to me this seems like the one obvious group that really should be willing to work with us.) But rather they were very very aggressive against it. They said that they can't risk their reputation working with us, because we have no credibility.

Our injured MDs and I sent an email to them a couple months back and they didn't reply...now I know why. After seeing just HOW MUCH they hate us on the conference call...like yelling and leaving the call early. We are irrelevant nobodies.

FDA meeting...

After discussing this with Janet Woodcock for the last couple months, they agreed with a meeting with our injured MDs. We were solid, kept it clean and inviting...vaccines are essential, but we need acknowledgment of some sort because absolutely nothing can happen for us (state health depts, medical orgs, physicians, medical communities, research, no early intervention, disability claims, we don't even qualify for the CICP injury fund).

No commitments from that meeting, once again, they just asked for the same information we have already provided. She said she has discussed this with the researchers provided, including you. But when I follow up with the few researchers we have provided, the researchers haven't heard from them.

I am a terrible at this (lol) was a discouraging week, losing hope, and this definitely is not conducive to healing. I am way more effective at [b6] would say "you're sick? Well people should help you."

So once again, thanks for helping. It is very very rare indeed. My life would be dramatically different right now had you not been so kind and concerned...and for that I will forever be grateful.

[b6]

PS... HOLY COW you guys know what you're doing! I am [b6] I feel great. The vibrations are gone and tingling in my hands is way less. (I was not expecting this!) The weakness, fatigue, the brain fog is gone again. My short term memory/concentration is better. I feel like a person again. Hoping this lasts. will find out in a few days!
...my immune system obviously has problems. Lol

REL0000231890

On Aug 18, 2021, at 10:42 AM, Nath, Avindra (NIH/NINDS) [E]: [b6]
wrote:

Thanks for all your efforts and for keeping me updated.
Avi

From: [b6]
Date: Wednesday, August 18, 2021 at 12:01 PM
To: Nath, Avindra (NIH/NINDS) [E]: [b6]
Subject: Random Updates

Our "injured" MDs and I are meeting with peter marks and paul richards at the FDA Monday morning. I have discussed this with Janet Woodcock and Paul for the last few weeks.

Hopeful they will be willing to help us "nobodies" in our quest to get medical help for people, or any sort of acknowledgement so people are able to begin dialogue with their home physicians.

We have written letters to clinics nationwide asking them to accept the very few of us in their clinics. No responses back.

I haven't heard back from my local new neurologist yet about next steps with [b6] I went downhill pretty bad after seeing you and Dr Safavi. Was back to not being able to drive or even cook some eggs.

[b6] had me start up [b6] and I stopped eating corn, which I was surprised to see that really has helped.

I hope you all stay safe there. You are very good people who are on the side of humanity, which is more rare than I realized.

I am concerned with the complete lack of urgency here locally to mitigate spread.

[b6]

b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6 [b6]
Sent: 9/18/2021 2:09:40 AM
To: [b6]
Subject: Re: Inquiry

[b6]

Avi

From: [b6]
Date: Friday, September 17, 2021 at 5:22 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Subject: Re: Inquiry

[b6]

Thanks so much for your help - is there any pertinent literature on this?

On Fri, Sep 17, 2021 at 4:29 PM Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

[b6]

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: Friday, September 17, 2021 at 3:18 PM
To: Nath, Avindra (NIH/NINDS) [E] [b6]
Cc: [b6]
Subject: Inquiry

Hi Dr. Nath,

My name is [b6] We had spoken a few weeks ago by way of introduction by [b6] I had discussed with you my patient [b6] from his vaccine reaction and continues to be symptomatic. He had a cold sore after the vaccine, followed by possible pericarditis then multiple symptoms such as internal vibrations, neck pain and headache, feeling like he is walking on springs, exercise intolerance, organic anxiety. While his symptoms have improved somewhat they are still persistent and problematic.

[b6]

I know we discussed that you had some patients with similar profiles that you [b6] I wanted to know the implications of this re immunity to COVID and generally speaking how this is being managed. I have seen some patient [b6] As we enter this uncharted territory I am eager for your help and guidance as you are at the forefront of managing the neurimmunological developments and I want to do what is right by my patients, especially those who have real symptoms and [b6]

Best,

[b6]

Sent from Mail for Windows

b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6] b6
Sent: 11/7/2021 1:12:36 AM
To: b6
Subject: Re: Neurological reaction to covid vaccine

Dear b6

Sorry to hear of your ongoing symptoms and difficulty navigating the health care system. I wish I had some new information to share. Unfortunately, research is a very slow process.

Best wishes.

Avi

From: b6
Date: Saturday, November 6, 2021 at 8:21 PM
To: Nath, Avindra (NIH/NINDS) [E] b6
Subject: Re: Neurological reaction to covid vaccine

Hello Dr. Nath,

I am writing to follow up regarding any further information you have encountered in response to the neurological reactions to the covid vaccines. b6 I am still having issues, and doctors are not equipped to determine the causes. Do you have any new information that might guide those of us trying to find relief with medical staff that is completely unprepared to help the vaccine injured? Anything at this point would be greatly appreciated.

Thank you

b6

On Sat, Aug 28, 2021 at 6:43 AM Nath, Avindra (NIH/NINDS) [E] b6 wrote:

Dear b6

Sorry to hear of your illness. Thanks for your interest in contributing towards research. Currently we are collecting data from patients who have side effects from vaccines. I have copied our research team who can guide you on how to participate. This is all new to us, so we do not have any specific treatment to offer. It seems that some physicians have treated their patients with b6

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

REL0000231903

b6

(Office)

b6

From:

b6

Date: Saturday, August 28, 2021 at 1:27 AM

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

b6

Subject: Neurological reaction to covid vaccine

Hello Dr. Nath,

I read an article today mentioning that you have been looking at neurological adverse effects to the Covid-19 vaccines. I am reaching out to you as I am one of the rare adverse neurological reactions, and am in the midst of trying to figure out how to find the appropriate care, and ideally identify the cause. As this is not common, I am wondering if you might be able to point me in the right direction of resources, or even what things to check for. I also would be willing to be a part of your research if this helps come closer to finding help for those of us that have suffered from this vaccine.

I received my first dose of Pfizer's covid vaccine on [b6] I have been dealing with tremors in my arms and hands, the sensation of my body vibrating, weakness, mind fog, and fatigue ever since. Trying to find anyone who will even explore answers has been a challenge, and the medical system I am in offers little more than a "good luck, we hope it goes away". I am desperate to find someone who will try to find real answers. I am [b6] was healthy prior to my vaccine, and have been on a roller coaster ever since. Any information you have found would be immensely helpful.

I realize that in your work you are immensely busy, but when I saw that someone is taking this seriously I knew I needed to reach out and at least try to connect. This has had serious impacts on my life, and I just want to feel like myself again!

Thank you for your time.

Sincerely,

b6

REL0000231903

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6] b6
Sent: 3/6/2022 12:59:37 PM
To: b6 NINDSPostCovid19 [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=7288bc48d86f4f5fb796620bda298e7f-nindspostco]
Subject: Re: [EXTERNAL] Symptoms of Long Covid without having had COVID-19
Attachments: Vaccination fatigue.pdf

We are developing a study to systematically collect information of this sort. I have copied our research team who can guide you
Best
Avi

On Mar 6, 2022, at 2:14 AM, b6 wrote:

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

We have not had previous contact. I found reference to some of your work that would suggest that you might have a possible interest in my case.

The attached PDF has details.

I would be grateful if you could share this information with anyone who might be interested.

With kind regards.

b6

b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6] b6
Sent: 4/18/2022 6:17:56 PM
To: b6
Subject: Re: post covid neurological manifestations

Dear b6
I am terribly sorry to hear of b6 illness. We have seen several patients with b6
b6
b6

At this point it sounds like she is very affected by the symptoms so might be worth a try. Most vaccine related complications are immune mediated and I suspect the many of the post-COVID symptoms are too. Please do not hesitate to let me know if I can be of any further help.

Avi

From: b6
Date: Monday, April 18, 2022 at 1:42 PM
To: Nath, Avindra (NIH/NINDS) [E] b6
Subject: [EXTERNAL] post covid neurological manifestations

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 Nath
I have b6 who most likely developed a COVID like illness in b6 however without a need for hospitalisation and no test was done. Following the acute illness she developed symptoms of b6
b6
She was treated with b6
b6
She first did not want to be COVID vaccinated because she feared that if the neuropathy caused by an auto-immune reaction, vaccination could worsen her situation. b6
b6
She had frequent anxiety attacks, extremely afraid of reinfection with COVID. b6
b6 She finally was vaccinated twice with the Pfizer vaccine. Initially without too many problems but since she received the Pfizer booster she claims her post covid symptoms increased and now she present an extreme form of allodynia: every touch is painful, taking the pulse or blood pressure is painful, she refuses to wash her body or hair, brush her teeth, cut her finger nails, eating can also trigger pain and she has lost a lot of weight (BMI 16). She is clearly depressed, thinks she will never recover.
b6 Her memory is good and she b6
b6 She claims to feel "immune storms" in her body. She still can walk but cannot do anything in the household with her hands. There is certainly a psychiatric component but it is unclear how much this extreme form of allodynia and the other pains she feels in her body are related to the neuropathy. She refuses hospitalisation and is very reluctant to take psychiatric medication. She would accept immune therapy. Have you seen such a severe form of allodynia in post covid? What is the proportion of persons with similar severe neurological manifestations that recover?
Which blood test could we do to determine whether indeed there is an auto immune phenomenon ongoing, whether the severe "intolerable pain according to her", allodynia and obsessional thinking about her illness (also influenced by information on the internet) are really caused by an organic neurological/brain problem.
Kind regards

b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6] b6
Sent: 2/10/2021 9:44:35 PM
To: b6
Subject: Re: AZD-1222 adverse reactions

Thanks. I will check and see. I do not think they have been analyzed yet. Due to the increase in COVID cases in the community, very few people have been allowed to come to the lab, so have a big back log of experiments. Sorry.
Avi

From: b6
Date: Wednesday, February 10, 2021 at 3:44 PM
To: "Nath, Avindra (NIH/NINDS) [E]" b6
Subject: Re: AZD-1222 adverse reactions

Dr. Nath,

Checking in. The samples were sent. We are trying to work with the provider at b6
b6

Anything you suggest we need to be doing or pushing for at this time?

b6

On Jan 15, 2021, at 12:04 PM, Nath, Avindra (NIH/NINDS) [E] b6 wrote:

OK. Lets not change current plans, which is shipping samples and sending us records. Amanda and Keymani will be in touch with you reading travel arrangements. I will also discuss with you what to expect in terms of tests etc when you come here. The current political climate is another aspect that we need to keep an eye on. b6
Avi

From: b6
Date: Friday, January 15, 2021 at 1:55 PM
To: "Nath, Avindra (NIH/NINDS) [E]" b6
Subject: Re: AZD-1222 adverse reactions

Dr. Nath,

That is something that we would make every effort to do if you and your team thought it was best. She would be unable to travel alone, however.

Best, b6

On Jan 15, 2021, at 11:26 AM, Nath, Avindra (NIH/NINDS) [E] b6 wrote:

Dear [b6]

I have now discussed your symptoms with our group. Some of us are wondering if we should consider bringing you to NIH to study you here. It does pose some challenges since [b6] Do you think that might be possible?
Avi

From: [b6]

Date: Thursday, January 14, 2021 at 5:56 PM

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

Subject: Re: AZD-1222 adverse reactions

Dr. Nath,

I have located [b6] I can collect it and send that along with the blood samples in the kit or the lab will send it directly to you if you have a way to pay for shipping.

[b6]

Thank you so much for speaking with us today.

b6

On Jan 11, 2021, at 11:26 AM, Nath, Avindra (NIH/NINDS) [E]

[b6] wrote:

Dear [b6]

Sorry to hear of [b6] illness. I would be glad to speak to you and [b6] to see how we can help. Warren can help set up a virtual meeting. I will request Drs. Smith and Safavi, Neurologists who works with me to join me.

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] (cell)

[b6]

From: [b6]

Date: Monday, January 11, 2021 at 1:13 PM

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

b6

Subject: AZD-1222 adverse reactions

Dr. Nath,

b6 participated in the phase 3 clinical trial of the AstraZeneca AZD1222 covid-19 vaccine. Beginning shortly after vaccination on b6 and continuing to present, she has had serious neurological complications. Double vision, tinnitus, hyperacusis, paresthesias, autonomic problems such as heart palpitations and tachycardia, tremors, leg weakness, trouble walking, numbness, tingling, low-grade fevers and a very pronounced vibration sensation in her brain/head.

b6

b6 She has been denied the second shot and unblinded, she received vaccine.

b6 has been disabled by this,

b6

b6

She has also made contact via support forums with another woman in Georgia who had the vaccine 10 days later and is experiencing almost every single symptom.

AstraZeneca seems only concerned with a diagnosis that absolves them in these matters.

I read about others in the UK, India and possibly Brasil that have had neurological complaints following the AZD-1222 trial and yet AstraZeneca persists in stating that no serious adverse events have been recorded.

I am concerned that regulators are being deprived of vital information in these studies.

b6

From: Nath, Avindra (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=B81CA051950B4D458D74037A6A86EAD6] b6
Sent: 8/28/2021 1:38:44 PM
To: b6
Subject: Re: Neurological reaction to covid vaccine

From: b6
Date: Saturday, August 28, 2021 at 1:27 AM
To: Nath, Avindra (NIH/NINDS) [E] b6
Subject: Neurological reaction to covid vaccine

Hello Dr. Nath,

I read an article today mentioning that you have been looking at neurological adverse effects to the Covid-19 vaccines. I am reaching out to you as I am one of the rare adverse neurological reactions, and am in the midst of trying to figure out how to find the appropriate care, and ideally identify the cause. As this is not common, I am wondering if you might be able to point me in the right direction of resources, or even what things to check for. I also would be willing to be a part of your research if this helps come closer to finding help for those of us that have suffered from this vaccine.

I received my first dose of Pfizer's covid vaccine on b6 I have been dealing with tremors in my arms and hands, the sensation of my body vibrating, weakness, mind fog, and fatigue ever since. Trying to find anyone who will even explore answers has been a challenge, and the medical system I am in offers little more than a "good luck, we hope it goes away". I am desperate to find someone who will try to find real answers. I am b6 was healthy prior to my vaccine, and have been on a roller coaster ever since. Any information you have found would be immensely helpful.

I realize that in your work you are immensely busy, but when I saw that someone is taking this seriously I knew I needed to reach out and at least try to connect. This has had serious impacts on my life, and I just want to feel like myself again!

Thank you for your time.

Sincerely,

b6

From: [b6]
Sent: 1/11/2021 6:28:29 PM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
CC: Smith, Bryan (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=de7bf3d6ad0046288fd8c35f33de3e57 [b6] Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6] Brown, Warren (NIH/NINDS) [C] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=bef0730648434bb69542199fca79f67e [b6]
Subject: Re: AZD-1222 adverse reactions

Dr. Nath,

That sounds wonderful. Look forward to it.

[b6]

On Jan 11, 2021, at 11:26 AM, Nath, Avindra (NIH/NINDS) [E] [b6] wrote:

Dear [b6]

Sorry to hear of [b6] illness. I would be glad to speak to you and [b6] to see how we can help. Warren can help set up a virtual meeting. I will request Drs. Smith and Safavi, Neurologists who works with me to join me.

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] (cell)

[b6]

From: [b6]

Date: Monday, January 11, 2021 at 1:13 PM

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

Subject: AZD-1222 adverse reactions

Dr. Nath,

[b6] participated in the phase 3 clinical trial of the AstraZeneca AZD1222 covid-19 vaccine. Beginning shortly after vaccination on [b6] and continuing to present, she has had serious neurological complications. Double vision, tinnitus, hyperacusis, paresthesias, autonomic problems such as heart palpitations and tachycardia, tremors, leg weakness, trouble walking, numbness, tingling, low-grade fevers and a very pronounced vibration

sensation in her brain/head.

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She has also made contact via support forums with another woman in Georgia who had the vaccine 10 days later and is experiencing almost every single symptom.

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I read about others in the UK, India and possibly Brasil that have had neurological complaints following the AZD-1222 trial and yet AstraZeneca persists in stating that no serious adverse events have been recorded.

I am concerned that regulators are being deprived of vital information in these studies.

b6

From: [b6]
Sent: 1/21/2022 12:22:16 AM
To: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
Subject: [EXTERNAL] Adverse Covid vaccine reaction

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Hi Dr. Nath

I read the article in science.org regarding adverse covid reactions and am reaching out as we are desperately seeking answers for [b6]

[b6] received her first dose of the moderna vaccine and on [b6] she received her 2nd dose. After her first dose her right arm began to feel funny. Immediately after her second dose she began to experience respiratory symptoms including coughing, nasal congestion, choking episodes, and a lot of phlegm. In addition she began to experience additional weakness in her right hand which is no longer in use (she cannot write, grasp objects, lift objects, open bottles, drive a car, etc.) Weakness has now progressed to her right leg and she is no longer able to walk independently. Her speech and swallowing have also been effected and she has slurred speech and difficulty eating. She is 100% dependent upon [b6] to help her complete daily activities including eating and drinking, personal hygiene, walking, etc.

She has no prior medical history. Prior to the vaccine she was walking 5-6 miles a day, lifted weights, maintained a healthy diet, [b6] enjoyed road trips in her jeep, and simply enjoyed every day life. All of which have been robbed from her in the days and weeks following her vaccination.

She has gone to countless doctors appointments for months and months searching for answers. She has seen neurologists at [b6]

[b6] After further testing all have agreed that her symptoms are due to the vaccine and

[b6]

I am writing in hopes of finding answers and a treatment for this tragic reaction. How can something not be treated when we know the root cause? Is there a way to counteract the vaccine, detox her body of it, etc. Are there alternative treatments available?

We are desperately seeking answers in hopes of somehow reversing this and are hoping you can help in some way.

Thank you

[b6]

Sent from my iPhone

From: [b6]
Sent: 9/8/2022 1:45:27 PM
To: Walitt, Brian (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=5b9339ab4cd1422aaf4669c64ca85914; [b6]
Subject: [EXTERNAL] Re: Post vaccine neuropathic symptoms

Hi Dr. Walitt,

Thank you for reaching out. My case is most unfortunate [b6]
[b6]
[b6] It is a terrible
and lonely place to be.

I am familiar with the paper and have circulated it to my doctors [b6] They are struggling
with how best to investigate and treat such cases. [b6]
[b6] I have been reaching out to experts across the globe to better understand my situation. My
symptoms cross many disciplines, so it has been a challenge to research as well as coordinate care. I do my
best to educate my doctors on what I learn through my research, which has helped direct my care.

b6

If new information comes to light, please keep me updated.

All the best,

[b6]

<https://onlinelibrary.wiley.com/doi/10.1002/mus.27696>

Post-COVID-19 Vaccine Small-Fiber Neuropathy
and Tinnitus Treated with Plasma Exchange -
Schelke - Muscle & Nerve - Wiley Online Library

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record.

onlinelibrary.wiley.com

From: Walitt, Brian (NIH/NINDS) [E] [b6]

Sent: Wednesday, September 7, 2022 12:12 PM

To: [b6]

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

Subject: Post vaccine neuropathic symptoms

[b6]

Hope this email finds you well. Angelique has recently shared information about your post-vaccine issues with me. While we are not currently evaluating or treating post-vaccine neuropathy cases, I thought I would share this link to a paper based on our prior experiences with persons developing neuropathic issues following SARS-CoV-2 vaccination and the (limited) experience using IVIg in such cases: [Neuropathic symptoms with SARS-CoV-2 vaccination | medRxiv](#)

Please take a look and feel free to share with your care providers as they consider your treatment. Let me know if you have questions or concerns.

Thanks,

Brian

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