

To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
From: Wiebold, Amanda (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=4491EE2AE9804610899C741100150540- (b) (6)]
Sent: Wed 3/31/2021 4:38:24 AM (UTC-05:00)
Subject: RE: Referral from (b) (6) neurological vaccine reaction

Good morning.

I emailed you yesterday (b) (6). All the documents you will need have been sent to you through secure email along with instructions. As I mentioned in my email yesterday, I am very flexible on Thursday for a phone call.

Thank you,

Amanda

From: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Sent: Tuesday, March 30, 2021 7:46 PM
To: (b) (6) Wiebold, Amanda (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Referral from (b) (6) neurological vaccine reaction

Sure, I cc her in this email. Hope it helps.

We will request your medical records and imaging files but it seems that if you can get them and send us by fax or email, it will be way faster.

Please let me know if you have any questions and I would contact you if I have any update.

Amanda, can you please consent (b) (6) for sample only?

Thank you

Farinaz

From: (b) (6)
Sent: Tuesday, March 30, 2021 7:38:56 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Referral from (b) (6) neurological vaccine reaction

I tried reaching Amanda and it came back as an undeliverable address. Can you have her contact me?

Thanks

Sent from my iPhone

On Mar 30, 2021, at 1:09 PM, (b) (6) wrote:

I was waiting to hear from you guys. I just sent her an email and would love to get you a sample. My symptoms remain the same. Still feel like an overall burning sensation and my feet and fingertips still bug me. It seems so vascular.

Lots of praying on my side for some answers.

Thanks

(b) (6)

Sent from my iPhone

On Mar 30, 2021, at 10:18 AM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

REL0000228970

Hi (b) (6)

How is everything? Hope your symptoms have improved.

Our research nurse did not receive any call from you for consent. Can you please contact her and schedule the consent which helps us to complete our paperwork. (her email address is

(b) (6)

I also think at this moment bringing you to NIH is not easily possible but if you give us the consent we can send you a kit and information to send us your serum sample.

Please let me know if you have any questions/concerns

Thank you

Farinaz

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: (b) (6)

Sent: Tuesday, March 23, 2021 11:28 PM

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

Subject: Re: Potential SPAM:Re: Referral from (b) (6) neurological vaccine reaction

I started (b) (6). I continued to take (b) (6)

My (b) (6)

My (b) (6)

(b) (6)

I was exposed to people with covid. I was tested 4 or 5 times when I was and I always came back negative.

(b) (6)

Do you have an email address or somewhere where I can send my records?!

Thanks again for talking to me today. I am hoping and praying that I will recover and get back to my old ways!!

Oh by the way (b) (6)

Just so there isn't any confusion down the road!

Thanks again

(b) (6)

On Mar 23, 2021, at 6:05 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
wrote:

(b) (6)

I have a few questions for you.

Can you tell me the exact dates you (b) (6)

The date your (b) (6)

and the dates your (b) (6)

two more questions

have you had or guess you may have COVID in last year?

do you have any family members with autoimmune diseases?

Thank you

Farinaz

<C76A02588DDD431EAF8BF19485CEA4EE.png>

From: (b) (6)

Sent: Tuesday, March 23, 2021 1:52:06 PM

To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>

Subject: Re: Potential SPAM:Re: Referral from (b) (6) neurological vaccine reaction

Hello

I want to apologize about the confusion with the time zones. I had it at 1pm pacific standard time. I got on the meeting at 10:20 but it was too late. I have the day off from work and my kids arranged to do this meeting. Can we still do it? I am available anytime today and would love to talk to you. My phone number is (b) (6) and I will be refreshing my emails also.

Thanks

(b) (6)

Sent from my iPhone

On Mar 23, 2021, at 10:26 AM, (b) (6)
wrote:

I am trying now, please can we still do it? You said 1 and I thought that meant 1 my time

Sent from my iPhone

On Mar 23, 2021, at 10:12 AM, Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)> wrote:

Hello (b) (6)

I and my NP joined to meet with you through MS teams at 1pm and unfortunately you did not join. Did the link work for you? If not we can reschedule.

Thanks

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

From: (b) (6)
Sent: Sunday, March 21, 2021 10:02 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Potential SPAM:Re: Referral from (b) (6)
neurological vaccine reaction

Yes ma'am. Let me know how we proceed!!! Thank you!!!

Sent from my iPhone

On Mar 21, 2021, at 6:32 PM, Safavi, Farinaz
(NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)
I am sorry to hear about your illness. We definitely
can discuss your issues through televisit. I have
availability on Tuesday. Does 1pm work for you?
Please let me know

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

From: (b) (6)
Sent: Sunday, March 21, 2021 3:08 AM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#); [Wiebold, Amanda \(NIH/NINDS\) \[E\]](#)
Subject: Referral from (b) (6)
neurological vaccine reaction

Hello! I was told to reach out to you
and see if you could help me. My
story is below. I currently live in
(b) (6)
My phone number is (b) (6).
Thanks for your time!

My story:

I am a (b) (6)
(b) (6) I am a (b) (6)

(b) (6)
I was healthy and fit before
getting vaccinated. In 2020 I did

(b) (6)
On (b) (6) I got my first first and
only Moderna shot in my left
arm..No symptoms besides a sore
arm for 2-3 days. On the 8th day I
noticed some lymphadenopathy
while I was at work. And then my
neck started to feel hot. After that
anytime I would eat my entire body
felt a hot/burning sensation and
accompanied by a rash that would
migrate. This came and went for
about a week. And then on the 14th
day, I noticed my feet felt tingly. I
had just taken my kids to (b) (6) to
play in the snow that morning and
thought it had something to do with
that. On the 15th day, (b) (6) the
tingling had gotten worse. It was
now in both feet and ankles. It felt
like icicles in my veins. I went to my
primary and she insisted it couldn't
be from the vaccine and prescribe
me (b) (6) for the full body
flushing. And gave me a referral to
an allergist to give me a peace of
mind that I could do the 2nd dose of
vaccine. About an hour later it was
worse so I went back the Dr but she
said just to sent her pics via email. I
told her my knees looked purple and
the tingling was getting worse and
traveling to my knees. She said if I
was that concerned to go to the ER. I
finished my day at the office and
tried to go workout but it was
persistent. I decided to go to (b) (6)
(b) (6). They ran (b) (6)
(b) (6). The Dr. said he
thought (b) (6)
(b) (6)
They gave me (b) (6)
(b) (6)
That seemed to help with the
full body flushing. The tingling in my
feet persisted and also began in my
hands. I went and saw the allergist
and he had no idea. He gave me a
prescription for (b) (6)

(b) (6)
He ordered a bunch of bloodwork, (b) (6)
He then referred me to (b) (6) for a 2nd opinion and also a neuro referral. I saw (b) (6) he said not to get the 2nd shot same thing the first allergist said. He order (b) (6)

The following Monday (b) (6)
I went back to the ER my blood pressure I took after work was (b) (6) I got to the ER and it had come down to (b) (6) or something like that. They did (b) (6). They ran some more labs. My (b) (6)
The ER doctor had no idea, but said I should see a neurologist. He knew I was scared and he said I could help jump start the process and he ordered (b) (6)

I got in with the nurse practitioner at the primary. She ordered more labs and told me to (b) (6)

I remained tingly and my muscles aches, random twitching and electrical impulses in my right quad and my upper right shoulder/back area was randomly numb/tingly. I was exhausted and I lost 13 pounds in 2 weeks, hard to do when you are relatively healthy. My BP started to go down and stay around (b) (6)

Now the low blood pressure was a new thing. I became very vascular and complained of my veins hurting. I went to neuro. He ordered (b) (6)

(b) (6)

Finally I made a follow up appointment with him to discuss (b) (6)

Grrr. I have not lost my strength in all of this nor my balance. I did lose a little strength in the beginning because of the rapid weight loss but I have since regained that back. I am still down 8 or 9 lbs but maintaining that very well with a good diet, staying as low histamine as I can, most of the time.

I went back to see my nurse practitioner on Friday (b) (6) because my veins in my wrists were hurting, almost like they were going to explode. The moment I would raise my hand the blood would rapidly disappear and my veins would sink in. I have videos of it happening. She denied me a vascular referral and prescribe me

(b) (6) I filled the prescription and never took any. I did see a rheumatologist and she ordered a gamet of testing. She took me serious because she she also had numbness in her arm for an hour or two after her shot. (b) (6)

(b) (6) She said to follow up in 4 weeks in the meantime she was going to contact some colleagues at (b) (6) and see if they had heard of anything and she was going to check in with the NIH. She seems genuinely concerned. She wanted me to get a 2nd opinion from another neurologist. She thinks (b) (6)

(b) (6) She said that way we can rule things out. And so I just got approved for that on Friday and I am waiting for them to call me back to schedule.

My current symptoms are random burning sensations in my neck, hands, feet, and face. My tingling has subsided. But I notice if my shoes or socks are too tight it will start again. My hands and knuckles will get red and feel like they are hot. I had bad headaches, pulsing around my ears but those have subsided. My feet feel like they don't get good circulation and the color of them changes. My veins change all the time, Super vascular and then barely there and then will bring on different sensory feelings. My hands/fingers fall asleep at night when I am sleeping and the tingling/ will also start in my feet when I lay down. My heels of my feet feel like they are burning as I type this! My energy is better and I think my BP has stabled more, or I am just not taking it as much at this point. If I am texting on my phone my fingers will tingle as if they are falling asleep. I used to get this cold feeling (icicles in my veins) in my forehead but that subsided and that feeling is now just randomly on the front side of my ankles. I don't seem to respond well to the cold.

I think that is all. I am sure I have left something out . But it has been a very busy (b) (6) since I had my first ER visit and the tests and bloodwork started! It has been (b) (6) since my shot. I would say things have improved since the beginning, especially when it comes to the intensity.

Interested on hearing your thoughts!

Thanks

(b) (6)

Cc: Safavi, Farinaz (NIH/NINDS) [E] (b) (6)
To: Nath, Avindra (NIH/NINDS) [E] (b) (6)
From: (b) (6)
Sent: Tue 7/27/2021 9:31:57 PM (UTC-05:00)
Subject: Re: Myself

Thank you so much. I pray a solution will be found.

Sent from my iPhone

On Jul 27, 2021, at 7:04 PM, Nath, Avindra (NIH/NINDS) [E] <(b) (6)> wrote:

Dear (b) (6)

I am so very sorry to hear of these continuous symptoms. I wish I had some answers to provide. But if we discover anything or hear of anything that may be of help to you, we will definitely let you know.

Avi

From: (b) (6)
Date: Tuesday, July 27, 2021 at 9:52 PM
To: Nath, Avindra (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Myself

Thank you Dr. Nath. I am still very symptomatic after (b) (6). I do have some better days. Today was a bad day. My entire head including my eyes, mouth and teeth were numb and painful, radiating into my esophagus and chest. I had burning pain from head to toe. All I could do was lie still, cry and ask myself how much longer can I endure this. Unfortunately, no doctor that I have seen including 4 neurologists have any idea of what is wrong with me or how to help me. They just say I will eventually get better. I am on my own, praying that this will eventually resolve. I am hoping (b) (6) and (b) (6) will help me with (b) (6) and make other recommendations regarding (b) (6). It is very interesting to me that several other women in our group have almost the identical symptoms to mine. There must be an explanation for these very specific and unusual symptoms. If you have any other ideas that may help me, I would be most appreciative.

Sincerely,

(b) (6)

Sent from my iPhone

On Jul 27, 2021, at 5:52 PM, Nath, Avindra (NIH/NINDS) [E] <(b) (6)> wrote:

Dear (b) (6)

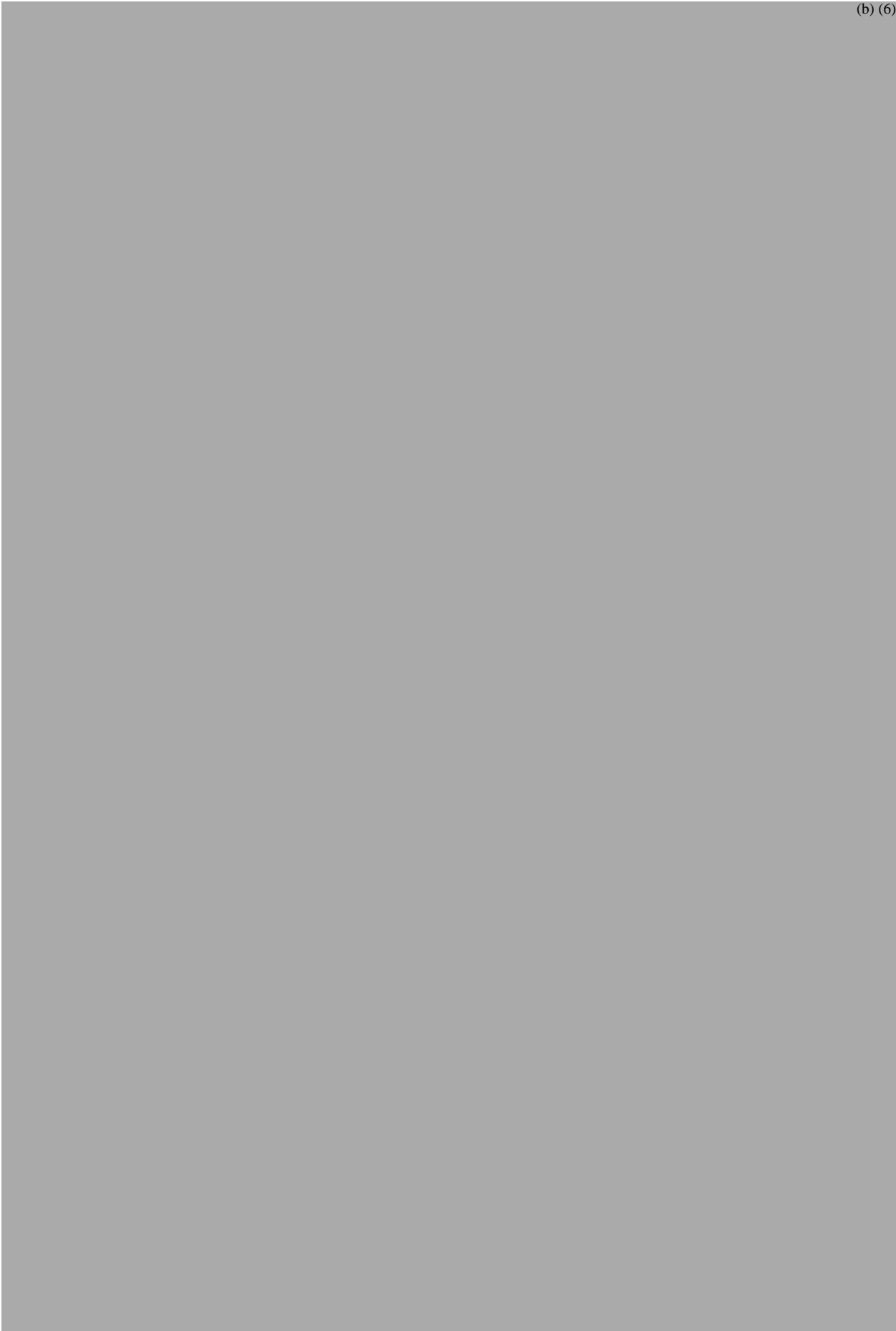
Thanks for sending me the reports. (b) (6) With regards to the (b) (6) We were looking for (b) (6). We have now tested a pool of sera from several patients with similar symptoms but have not been able to find any (b) (6). So we have now stopped testing them.

My suggestion would be to continue to follow up with your local neurologists.

Best wishes.

Avi

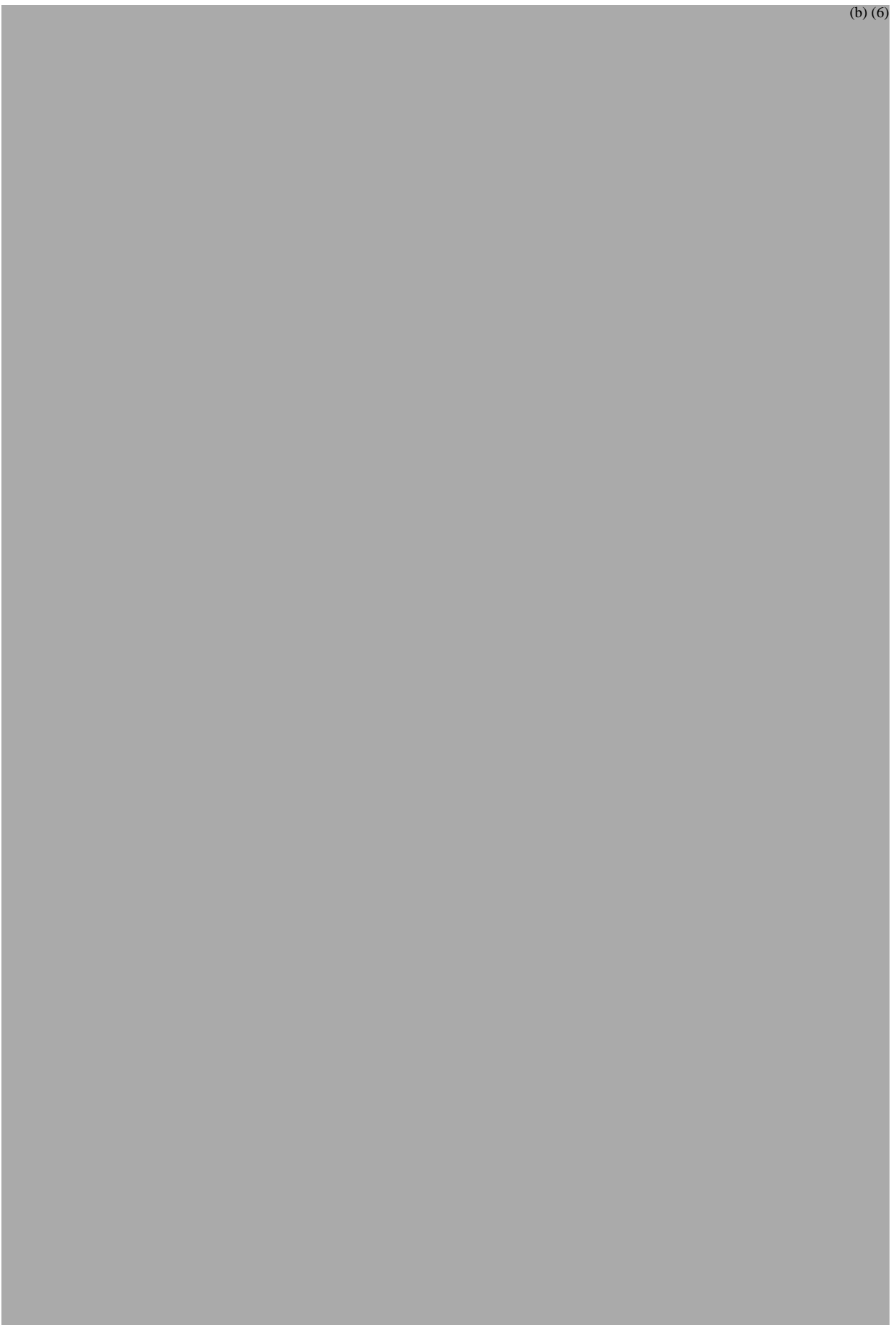
From: (b) (6)
Date: Tuesday, July 27, 2021 at 4:15 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Cc: Nath, Avindra (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Myself











Sent from my iPhone

On Jul 27, 2021, at 1:12 PM, [REDACTED] wrote:

Here are the results of my [REDACTED] (b) (6). Whenever you have time, please let me know what you found [REDACTED] (b) (6). Thank you for your help and for all you are doing to help people like me.

[REDACTED] (b) (6)

Sent from my iPhone

On Jul 27, 2021, at 11:37 AM, (b) (6) wrote:

Thank you Dr. Nath. I have been suffering with unbearable pain and do not know if I will ever recover. To read such things is very distressing. Speaking for myself and many many other people, we need to know what has happened to us and how we can recover. I hope you find the answers for us. Thank you.

Sent from my iPhone

On Jul 27, 2021, at 11:20 AM, Nath, Avindra (NIH/NINDS) [E]

<(b) (6)> wrote:

Dear (b) (6)

Sorry, to learn of your continued symptoms. We believe the symptoms to be real. That is the reason we have been treating patients. I will ask Farinaz via this email to go over all your results with you. I would be glad to address any other concerns. 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

(b) (6) (Office)

(b) (6)

From: (b) (6)

Date: Tuesday, July 27, 2021 at 2:13 PM

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

<(b) (6)>

Cc: Nath, Avindra (NIH/NINDS) [E] <(b) (6)>

Subject: Re: Myself

Thank you for your kind reply. Yes I would like to know what my (b) (6) showed. Also, I saw your recent article in Journal of Neuropsychiatry regarding functional neurological disorder after the covid Vaccine. I was surprised to read in this abstract that you feel there are no neurological adverse reactions to the vaccines. Does your research point to our illnesses being functional? Having suffered with incapacitating illness for (b) (6) now, the last thing I would want to be labeled with having is functional neurological disease.

Thank you,

(b) (6)

Sent from my iPhone

On Jul 27, 2021, at 4:21 AM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Thanks (b) (6) for the update.

I am glad that you feel at least partially better compared to months ago.

It would be great if you can send me those results helping us completing the report.

Best Regards,

Farinaz

From: (b) (6)

Sent: Monday, July 26, 2021 10:53:17 PM

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

<(b) (6)>

Subject: Re: Myself

Hello Farinaz,

What a surprise to hear from you! No I am not well. I am not as sick as I was (b) (6) but continue with constant paresthesias in my face,

From: (b) (6)
Sent: Saturday, May 15, 2021
11:01:21 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)>
Subject: Re: Myself

I am very sorry. I was not asking for you to propose treatment. I just wanted to understand why (b) (6) would be helpful for me. Thank you for your help.

Sent from my iPhone

On May 15, 2021, at
7:45 PM, Safavi, Farinaz
(NIH/NINDS) [E]
<(b) (6)>
> wrote:

I really can not
propose any
treatment for a patient
that I have not seen
or worked up
appropriately.
I can discuss and
share what we know
with your neurologist if
you think it is helpful.

Farinaz

From: (b) (6)
Sent: Saturday, May 15,
2021 8:45:06 PM
To: Safavi, Farinaz
(NIH/NINDS) [E]
<(b) (6)>
>
Subject: Re: Myself

I was on (b) (6)
(b) (6)
thought switching to
(b) (6) would help with
the vibrations I feel. If I
had those findings in
(b) (6)

(b) (6)

Sent from my iPhone

On May
15, 2021,
at 4:35
PM,
Safavi,
Farinaz
(NIH/NIND
S) [E]

(b) (6)

wrote:

What is
the
reason
for (b) (6)

?

Immune
stimulation
is a
very
vague
term.
CSF IgG
index and
oligoclonal
band
are clues
for
neuroinflammation.
(b) (6)

Unfortunately do
not know
anyone
here
either.
Hope you
feel
better.

Farinaz

From:

(b) (6)

Sent:

Saturday,
May 15,
2021
7:30:54
PM

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

(b) (6)

Subject:

Re: Myself

Thank you
for
respondin
g. I have
an appt
with the
neurologis
t (b) (6)

on
Thursday
and will
ask him. I
don't feel
that I have
the
autonomi
c
symptoms
that
others are
having.

My (b) (6)

I
am alittle
nervous
about

(b) (6)

(b) (6)

What
would you
be looking
for? I
hope the

(b)
(6)

Is

there
someone
at the NIH
that
might be
able to
help me?
Or the
Mayo
Clinic?

Sent from
my iPhone

On May 15, 2021, at 4:21 PM, Safavi, Farinaz (NIH/NINDS) [E]

<(b) (6)> wrote:

Hi (b) (6)

How about (b) (6)?

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

From: (b) (6)

Sent: Saturday, May 15, 2021 6:28:35 PM

To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>

Subject: Myself

Hi Farinaz,

REL0000229219

I hope you are well. I am not sure if you will read my email by I will send it anyway. I continue to be very symptomatic with paresthesias throughout my body and internal vibration and twitches. I have seen many doctors who have never heard of these reactions. I had [REDACTED] (b) (6) I had

[REDACTED] (b) (6) . I
am on [REDACTED] (b) (6)

I have had [REDACTED] (b) (6)

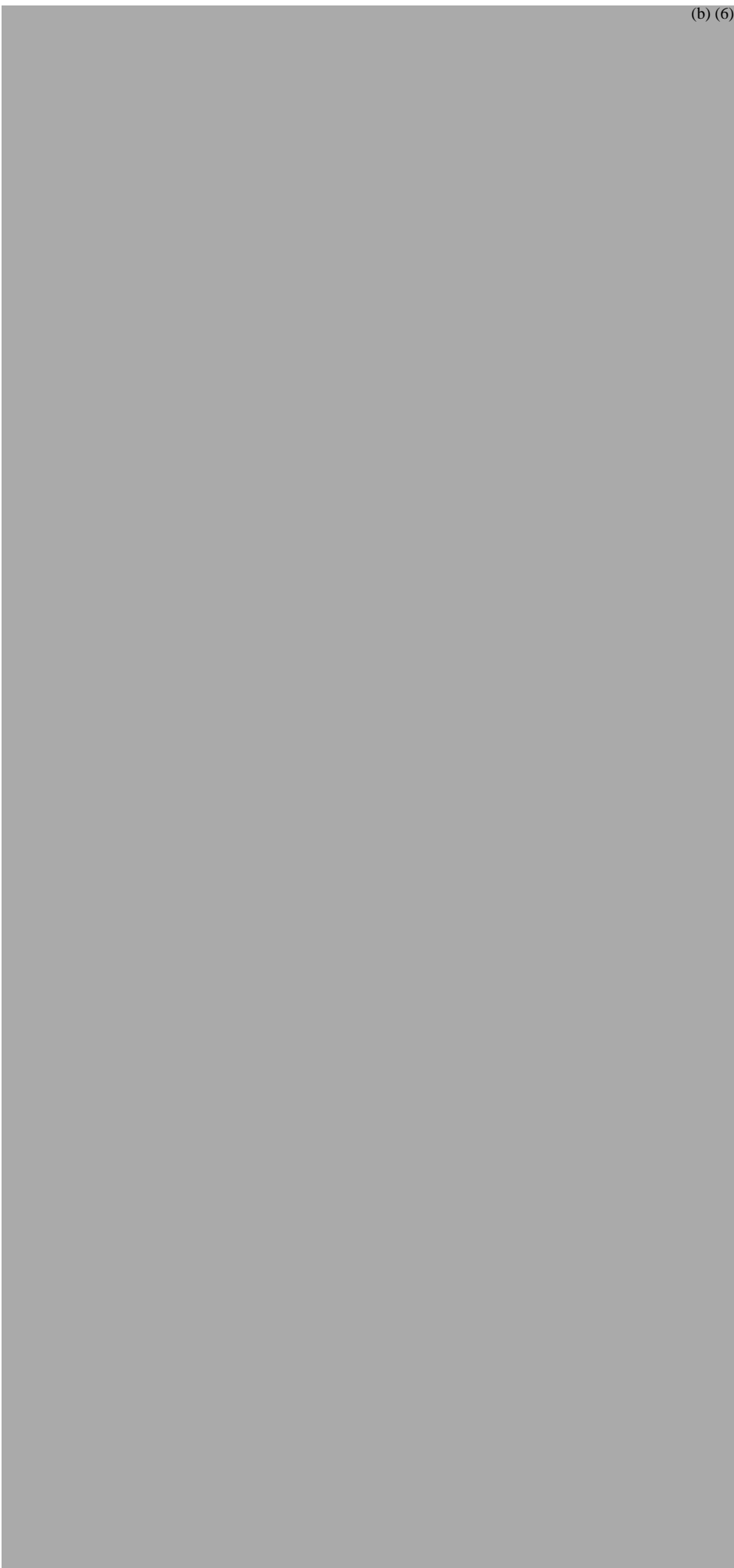
I tell you this as it may give you clues for other patients. I would like to get help and recover from this but am not optimistic as I have not found help so far. I have lost [REDACTED] (b) (6) of my life. Thank you for all your efforts in trying to help others.

Sincerely,
[REDACTED] (b) (6)

Sent from my iPhone

To: Gavin, Angelique (NIH/NINDS) [C] (b) (6)
From: (b) (6)
Sent: Fri 4/8/2022 6:15:21 PM (UTC-05:00)
Subject: Re: [EXTERNAL] Re: NIH 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.



This is a progress note from my doc too

Sent from my iPhone

On Apr 8, 2022, at 5:59 PM, (b) (6) wrote:

Sent from my iPhone

On Apr 8, 2022, at 5:32 PM, Gavin, Angelique (NIH/NINDS) [C] <(b) (6)> wrote:

Hi (b) (6)

Can you take a screenshot and then resend the test result? We need the date from your screenshot, not a date that you've typed yourself. Sorry for making this difficult.

Thank you,
Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

10 Center Drive

Building 10, Room 3B19, MSC 1251

Bethesda, MD 20814-9692

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

https://clinicaltrials.gov_study_number_000089_N

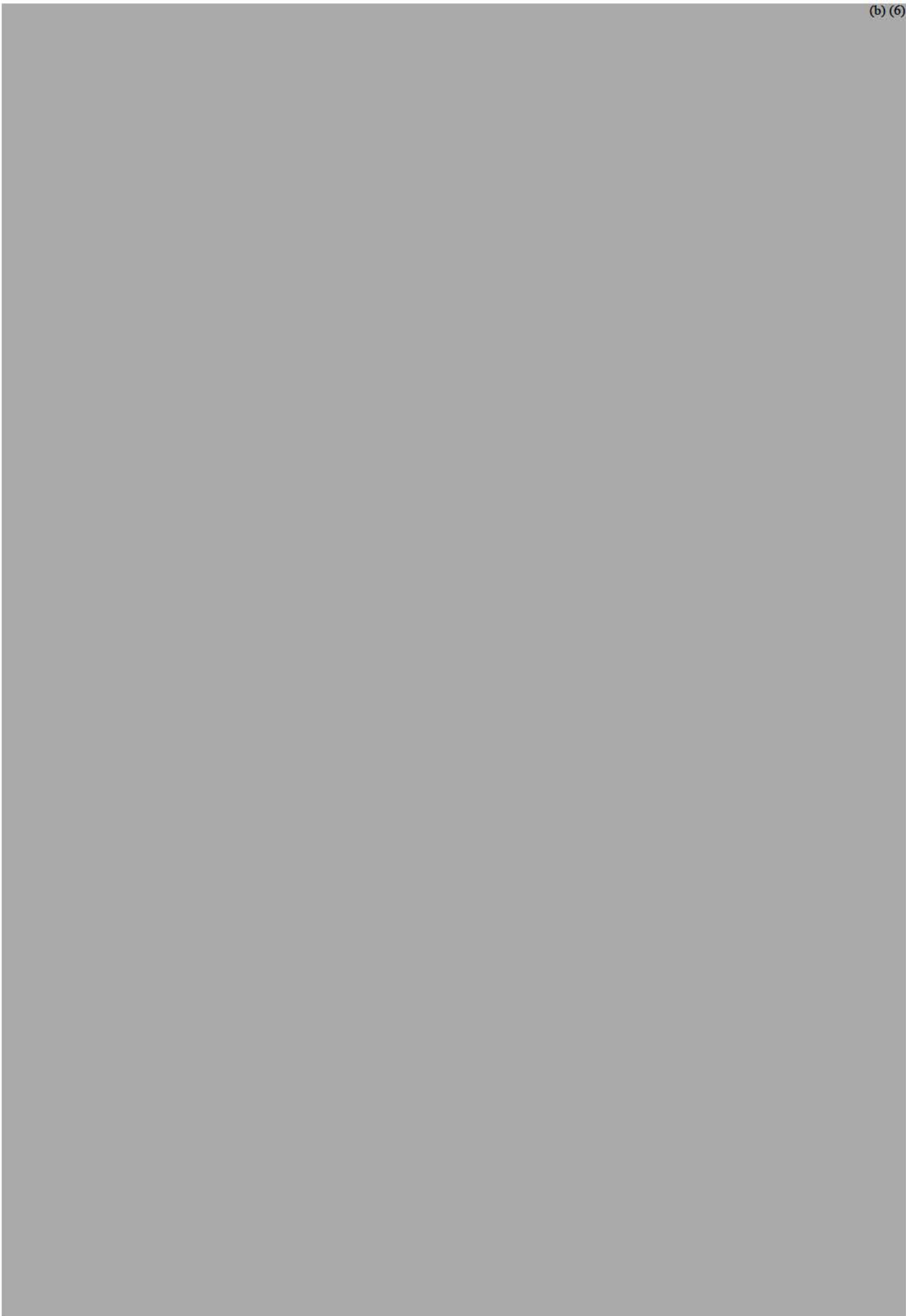
From: (b) (6)

Sent: Friday, April 8, 2022 5:06 PM

To: Gavin, Angelique (NIH/NINDS) [C] <(b) (6)>

Subject: Re: [EXTERNAL] Re: NIH 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.



On Apr 7, 2022, at 9:13 AM, Gavin, Angelique (NIH/NINDS) [C] <(b) (6)> wrote:

Thank you (b) (6) for your reply! Would Friday, April 8 at 4:30 pm CST work for you?

Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

10 Center Drive

Building 10, Room 3B19, MSC 1251

Bethesda, MD 20814-9692

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

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

-

From: (b) (6)

Sent: Wednesday, April 6, 2022 10:46 PM

To: Gavin, Angelique (NIH/NINDS) [C] <(b) (6)>

Subject: Re: [EXTERNAL] Re: NIH 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.

I'm free after 4 CST tomorrow or Friday. I'm also free all weekend.

Sent from my iPhone

On Apr 6, 2022, at 2:26 PM, Gavin, Angelique (NIH/NINDS) [C]

<(b) (6)> wrote:

Thank you (b) (6)! I'd like to arrange a short (15 minute) eligibility interview for our COVID-19 study. Let me know of some days and times (Eastern Standard Time) within the next two weeks and I'll get back to you with an option that is ideal for us both. I look forward to speaking with you soon.

Sincerely,
Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

10 Center Drive

Building 10, Room 3B19, MSC 1251

Bethesda, MD 20814-9692

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

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

From: (b) (6)

Sent: Wednesday, April 6, 2022 2:04 PM

To: Gavin, Angelique (NIH/NINDS) [C] <(b) (6)>

Subject: [EXTERNAL] Re: NIH 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.

Yes I'm interested in both studies. Let me know what you need from me.

Thanks

Sent from my iPhone

On Apr 6, 2022, at 12:53 PM, Gavin, Angelique (NIH/NINDS) [C]

<(b) (6)> wrote:

Dear (b) (6)

I hope this finds you doing well. I received your inquiry from Dr. Avindra Nath. Our vaccine study is not yet approved but should be soon. We will be doing telephone interviews and online questionnaires to gather information about what vaccine recipients are experiencing. Let me know if you would like to be placed on our wait list and we will contact you as soon as recruitment begins. In addition, our COVID-19 study is recruiting. It is a similar study with interviews and online questionnaires. It may provide you access to other studies taking place at the clinical center. Let me know if you are interested in either or both studies and we can make arrangements to speak further by phone.

Thank you,

Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

10 Center Drive

Building 10, Room 3B19, MSC 1251

Bethesda, MD 20814-9692

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

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

-

To: (b) (6)
From: Gavin, Angelique (NIH/NINDS) [C]/[O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=6E97392E947E4F7EBB17EEB8AC87C5D5-(b) (6)
Sent: Mon 8/8/2022 11:33:21 AM (UTC-05:00)
Subject: RE: [EXTERNAL] Re: NIH COVID-19 vaccine study

Hi (b) (6)! Thank you for checking in with us. We are starting out incrementally so that we can trouble shoot and ensure all is working as it should. We will be contacting you in the near future.

Sincerely,
Angelique

Angelique Gavin, MS (Contractor)

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

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

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

From: (b) (6)
Sent: Saturday, August 6, 2022 1:38 PM
To: Gavin, Angelique (NIH/NINDS) [C] <(b) (6)>
Subject: Re: [EXTERNAL] Re: NIH COVID-19 vaccine study

When will the vaccine reaction study start? I saw someone post they got something for it? I haven't gotten anything?

(b) (6)

Sent from my iPhone

On May 23, 2022, at 2:39 PM, Gavin, Angelique (NIH/NINDS) [C] <(b) (6)> wrote:

Hi (b) (6)! Unfortunately, the recover study is not affiliated with our study here at the NIH. You must go online <https://recovercovid.org>.

Best Wishes,
Angelique

Angelique Gavin, MS (Contractor)

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

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

From: (b) (6)
Sent: Monday, May 23, 2022 1:29 PM
To: Gavin, Angelique (NIH/NINDS) [C] <(b) (6)>
Subject: Re: [EXTERNAL] Re: NIH COVID-19 vaccine study

How do I get into the recover study?

(b) (6)

Sent from my iPhone

On Apr 11, 2022, at 10:26 AM, Gavin, Angelique (NIH/NINDS) [C] <(b) (6)> wrote:

Oh goodness yes! Tomorrow, April 12.

Thank you!

Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

10 Center Drive

Building 10, Room 3B19, MSC 1251

Bethesda, MD 20814-9692

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

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

From: (b) (6)
Sent: Monday, April 11, 2022 10:17 AM
To: Gavin, Angelique (NIH/NINDS) [C] <(b) (6)>
Subject: Re: [EXTERNAL] Re: NIH 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.

Do you mean April 12? Yes that would work 4/12/22 5:30 est

Sent from my iPhone

On Apr 11, 2022, at 9:01 AM, Gavin, Angelique (NIH/NINDS) [C]
<(b) (6)> wrote:

Thank you (b) (6) Would Tuesday, May 12 at 5:30 pm EST work for you? Have a good day today!

Angelique

Angelique Gavin, MS (Contractor)

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

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

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

From: (b) (6)

Sent: Saturday, April 9, 2022 4:50 PM

To: Gavin, Angelique (NIH/NINDS) [C] <(b) (6)>

Subject: Re: [EXTERNAL] Re: NIH 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.

Anytime after 4 cst this week

Sent from my iPhone

On Apr 9, 2022, at 2:35 PM, Gavin, Angelique (NIH/NINDS) [C]
<(b) (6)> wrote:

Thank you (b) (6) This is sufficient for your needs. I'd like to arrange our next interview which I anticipate will take approximately 45 minutes of your time. Please let me know of some days and times within the next two weeks. I look forward to speaking with you again soon.

Sincerely,
Angelique

Angelique Gavin, MS (Contractor)

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

(b) (6) (office)

(b) (6) (cell)
(301) 480-5368 (efax)
(b) (6)

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

-

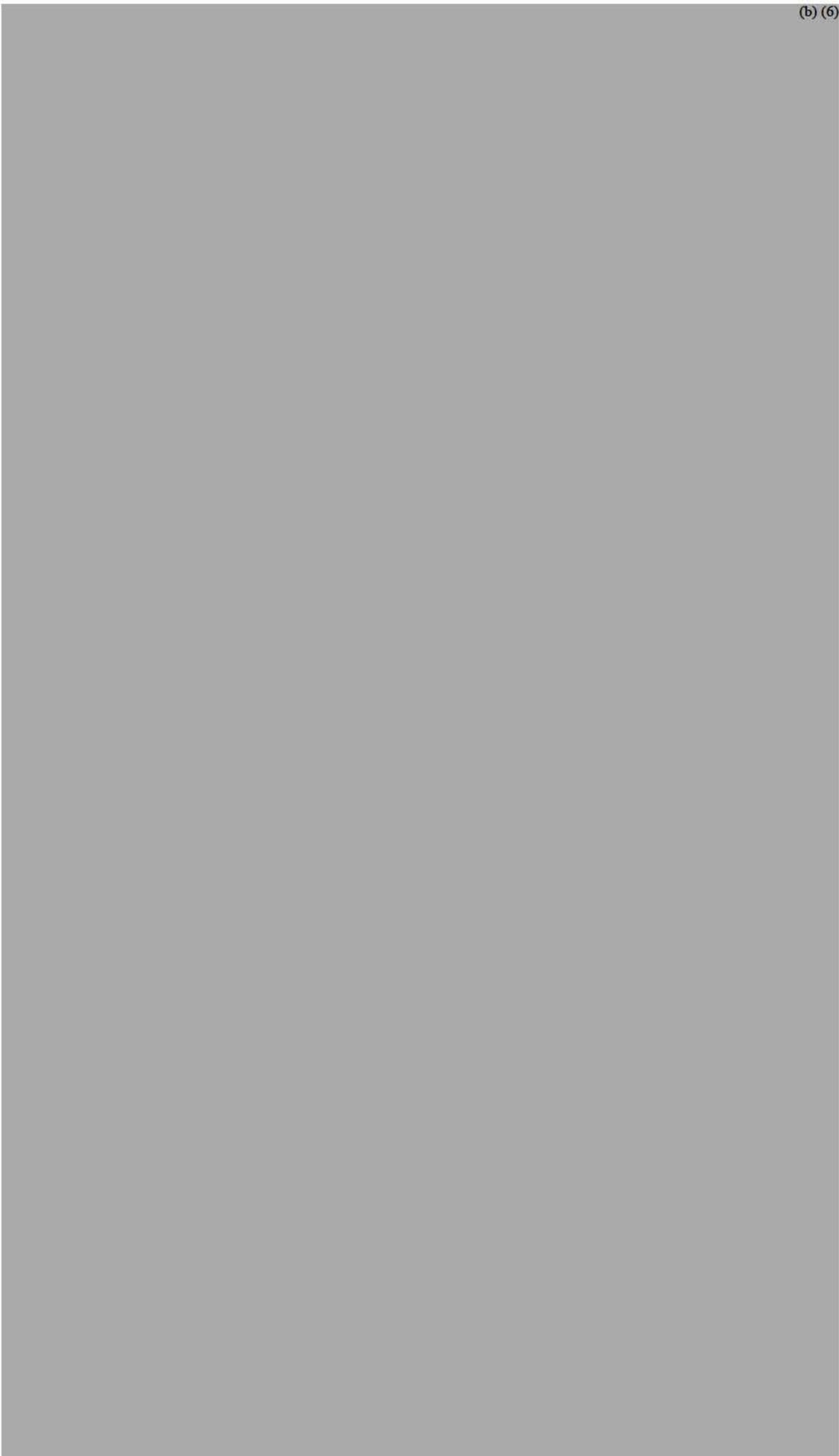
From: (b) (6)
Sent: Saturday, April 9, 2022 1:58 AM
To: Gavin, Angelique (NIH/NINDS) [C] <(b) (6)>
Subject: Re: [EXTERNAL] Re: NIH COVID-19 vaccine study

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.

Another issue that was new post covid was ulnar nerve pain/numbness while sleeping along with my 4th and 5th finger

Sent from my iPhone

On Apr 8, 2022, at 5:59 PM, (b) (6)
(b) (6) wrote:



On Apr 8, 2022, at 5:32 PM, Gavin, Angelique (NIH/NINDS) [C] <(b) (6)> wrote:

Hi (b) (6)

Can you take a screenshot and then resend the test result? We need the date from your screenshot, not a date that you've typed yourself. Sorry for making this difficult.

Thank you,
Angelique

Angelique Gavin, MS (Contractor)

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

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

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

-

From: (b) (6)

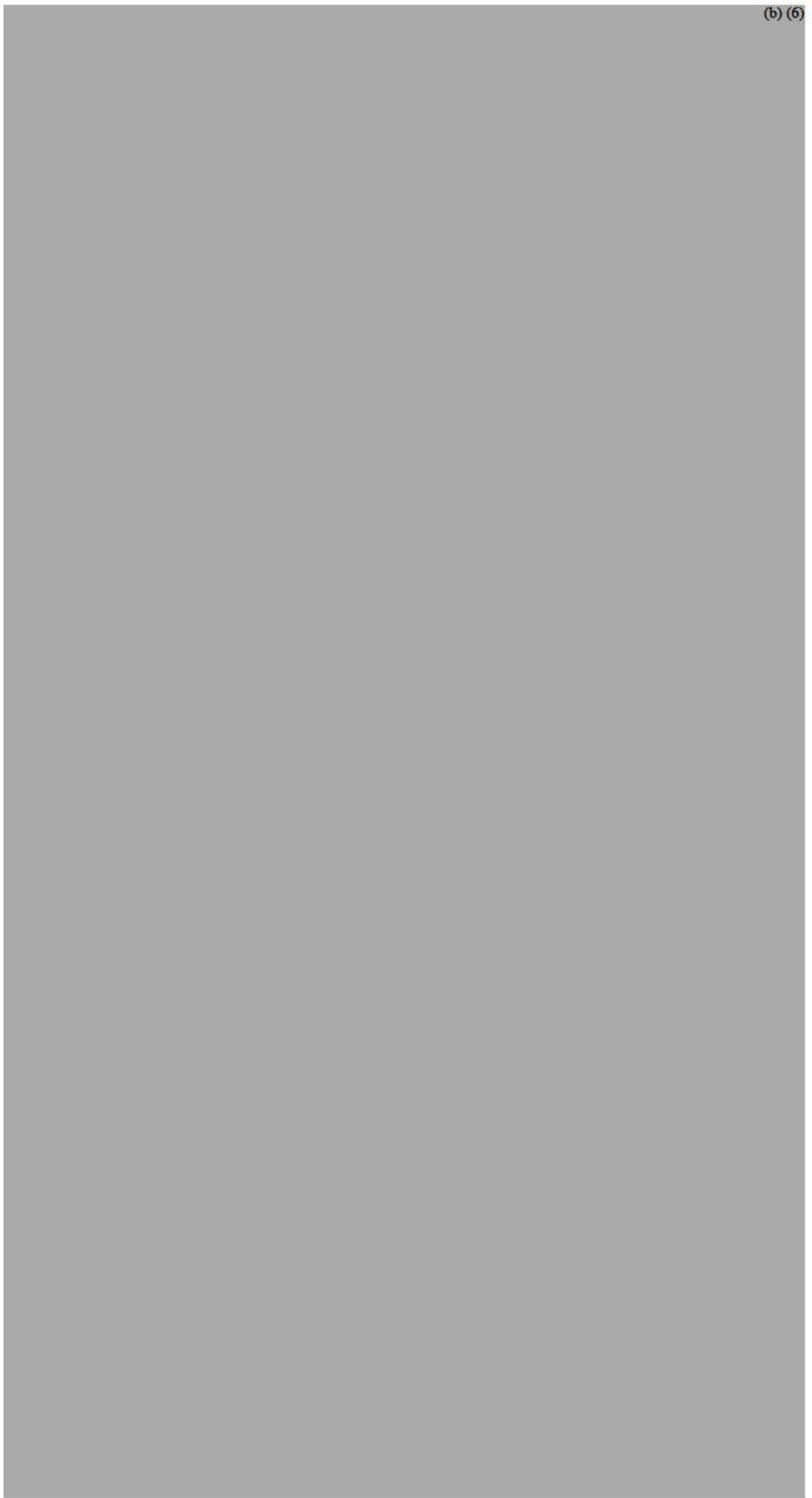
Sent: Friday, April 8, 2022 5:06 PM

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

<(b) (6)>

Subject: Re: [EXTERNAL] Re: NIH 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.



(b) (6)
Sent from my iPhone

On Apr 7, 2022, at 9:13 AM, Gavin,
Angelique (NIH/NINDS) [C]
<(b) (6)> wrote:

Thank you (b) (6) for your reply!
Would Friday, April 8 at 4:30 pm CST
work for you?

Angelique

Angelique Gavin, MS
(Contractor)
NIH/NINDS Clinical Operations
Manager
Contractor Preferred Solutions Group
National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692
(b) (6) (office)
(b) (6) (cell)
(301) 480-5368 (efax)
(b) (6)
[https://clinicaltrials.gov - study
number 000089-N](https://clinicaltrials.gov - study number 000089-N)

From: (b) (6)
Sent: Wednesday, April 6, 2022
10:46 PM
To: Gavin, Angelique (NIH/NINDS) [C]
<(b) (6)>
Subject: Re: [EXTERNAL] Re: NIH
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.

I'm free after 4 CST tomorrow or
Friday. I'm also free all weekend.

Sent from my iPhone

On Apr 6, 2022, at 2:26 PM, Gavin, Angelique (NIH/NINDS) [C]

<[REDACTED] (b) (6)>

ov> wrote:

Thank you [REDACTED] (b) (6) I'd like to arrange a short (15 minute) eligibility interview for our COVID-19 study. Let me know of some days and times (Eastern Standard Time) within the next two weeks and I'll get back to you with an option that is ideal for us both. I look forward to speaking with you soon.

Sincerely,
Angelique

Angelique Gavin,

MS (Contractor)

NIH/NINDS Clinical
Operations Manager
Contractor Preferred
Solutions Group
National Institutes of
Health

10 Center Drive
Building 10, Room
3B19, MSC 1251
Bethesda, MD 20814-
9692

[REDACTED] (b) (6) (office)

[REDACTED] (b) (6) (cell)

(301) 480-5368 (efax)

[REDACTED] (b) (6)

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

-

From: [REDACTED] (b) (6)

Sent: Wednesday, April 6, 2022 2:04 PM
To: Gavin, Angelique (NIH/NINDS) [C]

(b) (6)

Subject: [EXTERNAL]
Re: NIH 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.

Yes I'm interested in both studies. Let me know what you need from me. Thanks

Sent from my iPhone

On Apr 6, 2022, at 12:53 PM, Gavin, Angelique (NIH/NINDS) [C]

(b) (6)

wrote:

Dear (b) (6)

I hope this finds you doing well. I received your inquiry from Dr. Avindra

Nath. Our vaccine study is not yet approved but should be soon. We will be doing telephone interviews and online questionnaires to gather information about what vaccine recipients are experiencing. Let me know if you would like to be placed on our wait list and we will contact you as soon as recruitment begins. In addition, our COVID-19 study is recruiting. It is a similar study with interviews and online questionnaires. It may provide you access to other studies taking place at the clinical center. Let me

know if
you are
interested
in either
or both
studies
and we
can make
arrangem
ents to
speak
further by
phone.

Thank

you,

Angelique

Angeliqu

e Gavin,

MS

(Contrac
tor)

NIH/NIND

S Clinical

Operation

s Manager

Contracto

r

Preferred

Solutions

Group

National

Institutes

of Health

10 Center

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10, Room

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(efax)

(b) (6)

[https://cli
nicaltrials.](https://clinicaltrials.gov-study)

[gov -](https://clinicaltrials.gov-study)

[study](https://clinicaltrials.gov-study)

[number](#)
[000089-N](#)

-

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To: (b) (6)
From: Gavin, Angelique (NIH/NINDS) [C]/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=6E97392E947E4F7EBB17EEB8AC87C5D5 (b) (6)
Sent: Thur 4/7/2022 10:24:48 AM (UTC-05:00)
Subject: RE: [EXTERNAL] Re: NIH COVID-19 vaccine study

Thank you! I look forward to speaking with you tomorrow.

Sincerely,
Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

10 Center Drive

Building 10, Room 3B19, MSC 1251

Bethesda, MD 20814-9692

(b) (6) (office)

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(301) 480-5368 (efax)

(b) (6)

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

From: (b) (6)
Sent: Thursday, April 7, 2022 11:20 AM
To: Gavin, Angelique (NIH/NINDS) [C] <(b) (6)>
Subject: Re: [EXTERNAL] Re: NIH 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.

Yes (b) (6)

Sent from my iPhone

On Apr 7, 2022, at 9:13 AM, Gavin, Angelique (NIH/NINDS) [C] <(b) (6)> wrote:

Thank you (b) (6) for your reply! Would Friday, April 8 at 4:30 pm CST work for you?

Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

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(b) (6) (cell)

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(b) (6)

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

From: (b) (6)
Sent: Wednesday, April 6, 2022 10:46 PM
To: Gavin, Angelique (NIH/NINDS) [C] <(b) (6)>
Subject: Re: [EXTERNAL] Re: NIH COVID-19 vaccine study

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I'm free after 4 CST tomorrow or Friday. I'm also free all weekend.

Sent from my iPhone

On Apr 6, 2022, at 2:26 PM, Gavin, Angelique (NIH/NINDS) [C] <(b) (6)> wrote:

Thank you (b) (6) I'd like to arrange a short (15 minute) eligibility interview for our COVID-19 study. Let me know of some days and times (Eastern Standard Time) within the next two weeks and I'll get back to you with an option that is ideal for us both. I look forward to speaking with you soon.

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NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
National Institutes of Health
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Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692
(b) (6) (office)
(b) (6) (cell)
(301) 480-5368 (efax)
(b) (6)
<https://clinicaltrials.gov - study number 000089-N>

From: (b) (6)
Sent: Wednesday, April 6, 2022 2:04 PM
To: Gavin, Angelique (NIH/NINDS) [C] <(b) (6)>
Subject: [EXTERNAL] Re: NIH COVID-19 vaccine study

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Yes I'm interested in both studies. Let me know what you need from me. Thanks

Sent from my iPhone

On Apr 6, 2022, at 12:53 PM, Gavin, Angelique (NIH/NINDS) [C]

< (b) (6) wrote:

Dear (b) (6)

I hope this finds you doing well. I received your inquiry from Dr. Avindra Nath. Our vaccine study is not yet approved but should be soon. We will be doing telephone interviews and online questionnaires to gather information about what vaccine recipients are experiencing. Let me know if you would like to be placed on our wait list and we will contact you as soon as recruitment begins. In addition, our COVID-19 study is recruiting. It is a similar study with interviews and online questionnaires. It may provide you access to other studies taking place at the clinical center. Let me know if you are interested in either or both studies and we can make arrangements to speak further by phone.

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To: (b) (6)
From: Gavin, Angelique (NIH/NINDS) [C]/[O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=6E97392E947E4F7EBB17EEB8AC87C5D5-(b) (6)
Sent: Sat 4/9/2022 8:22:13 AM (UTC-05:00)
Subject: RE: [EXTERNAL] Re: NIH COVID-19 vaccine study

Thank you (b) (6) Much appreciated.

Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

National Institutes of Health

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Bethesda, MD 20814-9692

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(b) (6) (cell)

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(b) (6)

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

From: (b) (6)

Sent: Saturday, April 9, 2022 1:58 AM

To: Gavin, Angelique (NIH/NINDS) [C] <(b) (6)>

Subject: Re: [EXTERNAL] Re: NIH COVID-19 vaccine study

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Sent from my iPhone

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Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

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(b) (6)

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

-

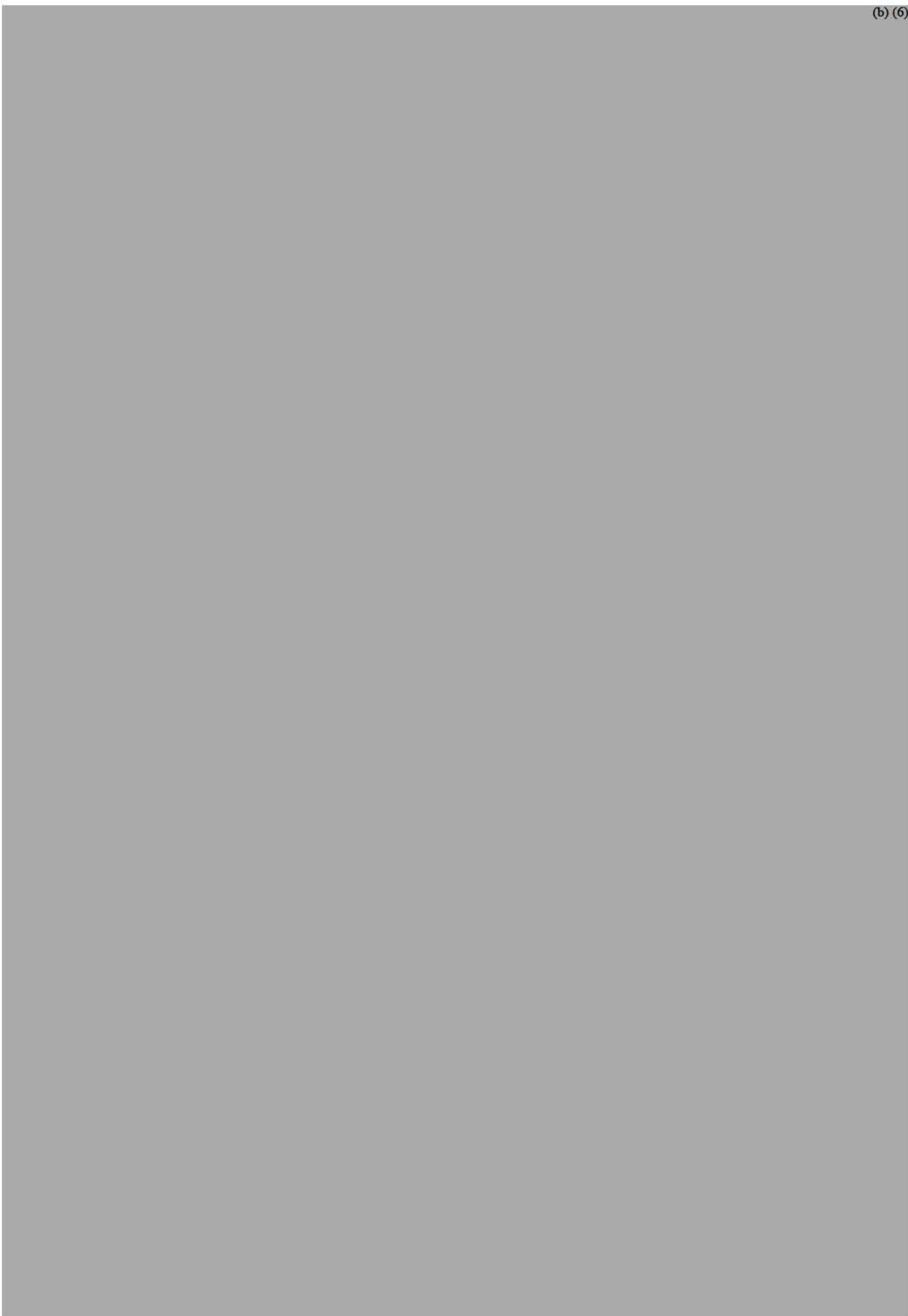
From: (b) (6)

Sent: Friday, April 8, 2022 5:06 PM

To: Gavin, Angelique (NIH/NINDS) [C] <(b) (6)>

Subject: Re: [EXTERNAL] Re: NIH COVID-19 vaccine study

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(b) (6)
Sent from my iPhone

On Apr 7, 2022, at 9:13 AM, Gavin, Angelique (NIH/NINDS) [C] <(b) (6)> wrote:

Thank you (b) (6) for your reply! Would Friday, April 8 at 4:30 pm CST work for you?

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Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

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(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

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

-

From: (b) (6)

Sent: Wednesday, April 6, 2022 10:46 PM

To: Gavin, Angelique (NIH/NINDS) [C] <(b) (6)>

Subject: Re: [EXTERNAL] Re: NIH COVID-19 vaccine study

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I'm free after 4 CST tomorrow or Friday. I'm also free all weekend.

Sent from my iPhone

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Thank you (b) (6) I'd like to arrange a short (15 minute) eligibility interview for our COVID-19 study. Let me know of some days and times (Eastern Standard Time) within the next two weeks and I'll get back to you with an option that is ideal for us both. I look forward to speaking with you soon.

Sincerely,
Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager

Contractor Preferred Solutions Group

REL0000229939

National Institutes of Health
10 Center Drive
Building 10, Room 3B19, MSC 1251
Bethesda, MD 20814-9692

(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

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

-

From: (b) (6)

Sent: Wednesday, April 6, 2022 2:04 PM

To: Gavin, Angelique (NIH/NINDS) [C] <(b) (6)>

Subject: [EXTERNAL] Re: NIH 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.

Yes I'm interested in both studies. Let me know what you need from me.
Thanks

Sent from my iPhone

On Apr 6, 2022, at 12:53 PM, Gavin, Angelique (NIH/NINDS) [C]
<(b) (6)> wrote:

Dear (b) (6)

I hope this finds you doing well. I received your inquiry from Dr. Avindra Nath. Our vaccine study is not yet approved but should be soon. We will be doing telephone interviews and online questionnaires to gather information about what vaccine recipients are experiencing. Let me know if you would like to be placed on our wait list and we will contact you as soon as recruitment begins. In addition, our COVID-19 study is recruiting. It is a similar study with interviews and online questionnaires. It may provide you access to other studies taking place at the clinical center. Let me know if you are interested in either or both studies and we can make arrangements to speak further by phone.

Thank you,
Angelique

Angelique Gavin, MS (Contractor)

NIH/NINDS Clinical Operations Manager
Contractor Preferred Solutions Group
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(b) (6) (office)

(b) (6) (cell)

(301) 480-5368 (efax)

(b) (6)

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

-

To: Safavi, Farinaz (NIH/NINDS) [E] (b) (6)
From: (b) (6)
Sent: Sat 5/15/2021 9:55:08 PM (UTC-05:00)
Subject: Re: Myself

Thank you

Sent from my iPhone

On May 15, 2021, at 7:45 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

I really can not propose any treatment for a patient that I have not seen or worked up appropriately. I can discuss and share what we know with your neurologist if you think it is helpful.

Farinaz

From: (b) (6)
Sent: Saturday, May 15, 2021 8:45:06 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Myself

I was on (b) (6) thought switching to (b) (6) would help with the vibrations I feel. If I had those findings in (b) (6)

Sent from my iPhone

On May 15, 2021, at 4:35 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

What is the reason for (b) (6)?
Immune stimulation is a very vague term.
CSF IgG index and oligoclonal band are clues for neuroinflammation. (b) (6)
(b) (6). Unfortunately do not know anyone here either.
Hope you feel better.

Farinaz

From: (b) (6)
Sent: Saturday, May 15, 2021 7:30:54 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Myself

Thank you for responding. I have an appt with the neurologist (b) (6) on Thursday and will ask him. I don't feel that I have the autonomic symptoms that others are having. My (b) (6)
(b) (6) I am alittle nervous about having (b) (6)
(b) (6) What would you be looking for? I hope the (b) (6)
(b) (6). Is there someone at the NIH that might be able to help me? Or the Mayo Clinic?

Sent from my iPhone

On May 15, 2021, at 4:21 PM, Safavi, Farinaz (NIH/NINDS) [E]

<(b) (6)> wrote:

Hi (b) (6)

How about (b) (6)

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

From: (b) (6)

Sent: Saturday, May 15, 2021 6:28:35 PM

To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>

Subject: Myself

Hi Farinaz,

I hope you are well. I am not sure if you will read my email by I will send it anyway. I continue to be very symptomatic with paresthesias throughout my body and internal vibration and twitches. I have seen many doctors who have never heard of these reactions. I had (b) (6). I had (b) (6)

(b) (6). I am on (b) (6)

I have had (b) (6)

(b) (6)

I tell you this as it may give you clues for other patients. I would like to get help and recover from this but am not optimistic as I have not found help so far. I have lost (b) (6) of my life.

Thank you for all your efforts in trying to help others.

Sincerely,

(b) (6)

Sent from my iPhone

To: Safavi, Farinaz (NIH/NINDS) [E] (b) (6)
From: (b) (6)
Sent: Thur 4/29/2021 11:36:24 PM (UTC-05:00)
Subject: Re: Testing

Thank you so much, and yes, I would appreciate receiving the list of tests you suggest. I will pass your contact information to (b) (6). And I will send my blood to you on Tuesday.
I am grateful for all your hard work!
(b) (6)

Sent from my iPhone

On Apr 29, 2021, at 8:19 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6),
Thank you very much for update. I completely agree with your neurologist and I believe you are in good hands. Unfortunately I can not bring non local patients easily due to COVID restriction but I can speak with (b) (6) and share our understanding about your symptoms with him. (b) (6) both are important diagnostic modality I have been using. I also can send you list of tests that I am sending for patients and your physician can check them.
If (b) (6) helps your symptoms I think you certainly should continue it.
Please let me know if I can be any help.
Best

Farinaz

From: (b) (6)
Sent: Thursday, April 29, 2021 11:09:56 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Testing

Hello Farinaz,
I saw my neurologist today (b) (6) and he reviewed past and current symptoms, in addition to all blood work and test results and scans. (b) (6)
(b) (6)

(b) (6) told me his concerns related to my symptoms are (b) (6) I told him your working hypothesis is (b) (6)
(b) (6) I am scheduled for these tests (b) (6). Is this the testing protocol you recommend? Also, I received my blood box today and will have a draw on Monday and ship back to you overnight. I started (b) (6)
(b) (6). I've noticed a reduction of symptoms, but it doesn't last so I may need to add (b) (6)
Is there a benefit to having these tests performed at NIH? I'm open to your input.

Thank you.
(b) (6)

Sent from my iPhone

To: (b) (6); Safavi, Farinaz (NIH/NINDS) [E] (b) (6)
From: Nahar, Kymani (NIH/NINDS) [C]//O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=4F432F899337490EA7CBDE0A4B52EFFB- (b) (6)
Sent: Mon 4/26/2021 7:23:28 AM (UTC-05:00)
Subject: Re: Post J&J Shot

Good Morning (b) (6)

I'm sorry to hear about your worsening symptoms. Can you please let me know when you are free next week to come in for (b) (6)? Thanks so much!

Best,
Kymani

From: (b) (6)
Date: Sunday, April 25, 2021 at 5:21 PM
To: "Safavi, Farinaz (NIH/NINDS) [E]" <(b) (6)>
Cc: KYMANI NAHAR <(b) (6)>
Subject: Re: Post J&J Shot

Thank you for your well wishes Farinaz. (b) (6)

(b) (6)
Then 3 weeks after the J&J vaccine, I started experiencing the current onset of symptoms— new, yet similar in ways to some of my early vaccine reactions — (b) (6)
Although I cannot prove the latest onset is part of a vaccine reaction, I'm suspicious that the vaccine is playing "Whac-A-Mole" in my body given the timing, similarities, and circumstances. I have a standing appointment with the physician who ordered (b) (6)

I'll contact Kymani about scheduling, and see if anything works between your time frame and some time for me to heal.

I appreciate you looking at the (b) (6) with your neuroradiologists, yet wish it was useful to you.

Best, (b) (6)

On Apr 24, 2021, at 8:30 AM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

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

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

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

I wish you rapid recovery.
Best Regards,

Farinaz Safavi MD, PhD

From: (b) (6)
Sent: Friday, April 23, 2021, 7:40 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Re: Post J&J Shot
Farinaz,

I recognized there may be a problem with meeting the terms of the protocol as I truly cannot lay on my back and typical treatment modalities, (b) (6) have spiraled me downward. These symptoms are so uncharacteristic for me, and likely further signs of inflammation. I just walked in the door from (b) (6) — to try to better understand why this has gone downhill rather rapidly. You're trying to get your research questions answered in a timely manner, and likewise, I'm trying to get answers about what is happening to me now.

I don't know how you define "very near future", so perhaps you can explain. And since you didn't tell me before, how long after (b) (6)? I was estimating 2 weeks after (b) (6)

Best, (b) (6)

On Apr 23, 2021, at 6:44 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

(b) (6),
I went over your (b) (6) with our neuroradiologists and (b) (6)

If you think you can not get the tests we need in very near future, unfortunately we can not keep you on the research protocol.

I hope your health conditions improve soon.
Best Regards,

Farinaz

From: (b) (6)
Sent: Friday, April 23, 2021 2:30:43 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Post J&J Shot

Farinaz,

Again, I apologize that it has taken so long to respond. It's been an unusual week and I've been avoiding time on the computer as it further aggravates my symptoms. Plus, I had to talk with some of my medical providers about expected recovery and one of those appointments was late yesterday afternoon.

Your clarification that (b) (6) isn't required for my research participation is much appreciated. I'm relieved. And thank you for copying the study coordinator to help quell contradictions.

I'd like to participate in this research effort but am not sure how to do so. I cannot tolerate lying on my back for a 75-minute test. Recovery and (b) (6) will interfere with (b) (6). It may be 5-6 weeks before I can realistically do (b) (6) at NIH. I don't wish to delay your research efforts. If another participant can take my spot in the study and

participate in-person, please do not let me stand in the way. Or, if I can switch to being remote going forward so you can fully accept (b) (6) and move forward with my participation in the study as such, perhaps that could be considered. I'd understand if you may need to make a change at this point as neither of us expected I'd have yet another medical curveball hurled at me, and neither of us needs more pressure, Or, maybe the time frame of when I can likely resume testing is okay with you.

Yes, it takes a lot of effort to schedule study participants for NIH tests. It's unfortunate I developed new symptoms (b) (6) and (b) (6) couldn't be done while I was at NIH April 12th. I've met every NIH request for scheduling, and its request for changes. To have (b) (6) at NIH, last week you asked me to cancel a scheduled (b) (6). I canceled it. On Monday April 12th Kymani asked if I could do (b) (6) at 8am Friday, April 16th. I replied I could. She contacted me a few days later to say she had underestimated the amount of time for (b) (6), and Friday was out –and inquired whether I could instead do the next Monday at 8am or Tuesday at 1:30pm. Although I had commitments both days at those times, I replied I could. I chose Monday thinking sooner was better. Kymani and I discussed when I should arrive for the appointment and it was doable for me. Then the Friday before I was told to arrive almost an hour earlier, (b) (6). Had (b) (6) been known, of course I'd have selected Tuesday at 1:30pm so I could drive to NIH safely. But I didn't cancel given that change. Although I was having a medical issue, I asked Kymani to please hold the Monday appointment as I hoped to get the test done. Unfortunately, I physically declined over the weekend. I've had (b) (6) and my questions about NIH's (b) (6) screening process were for my information. By nature, I tend to ask questions. And while I'd prefer that repeat testing be done if/when symptoms get worse, I understand your research protocol needs. My point is that I tried to make (b) (6) work on my end when NIH requested schedule changes and a (pleasant and helpful) new staff member wasn't familiar with some test requirements and their implications on scheduling. Scheduling is a challenge even under the best of circumstances. Still, I'm glad that you have (b) (6) scan for me that was completed during the week (b) (6).

As an investigator, I'd want to know if materials aren't reaching study participants. Since I was looking out for the study protocol and didn't receive it or much else pertinent to the study, I'm puzzled. To the best of my knowledge, all materials from Dr. Hallett I were received. I have no motives to tell you anything differently than what I experienced.

The decision about my participation is yours to decide as to what works for you. Please advise whether or not my circumstances still fit your timeline (or anything else), and if so, where I best fit among your participants, e.g. remote or in-person. And if not, to repeat, I understand research demands.

Best,

(b) (6)

On Apr 21, 2021, at 7:46 PM, (b) (6) wrote:

Farinaz,

Thank you for your quick response. I do not intend to appear rude and apologize I haven't been able to promptly reply to you. A medical issue that started late last week and caused my cancellation of (b) (6) at NIH, has continued to worsen. I hope to get back with you soon and appreciate your understanding.

Best, (b) (6)

On Apr 20, 2021, at 6:53 AM, Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)> wrote:

(b) (6)
I believe the study material was sent to you three times. As we discussed in your visit, participating in our study is completely voluntary.

Following your visit, Dr. Nath and I discussed your case and because of your history of (b) (6)

Basically as explained to you we included many procedures in our consent form but it does not mean we perform all those tests on everyone. Additionally, even for required tests in the protocol, we can decide not to perform some of them if we feel the risks outweigh the benefits.

There have been a lot of efforts to bring patients to NIH and schedule tests. If you are not interested to proceed please let me know and we will proceed accordingly.

Best Regards,

Farinaz

From: (b) (6)
Sent: Monday, April 19, 2021 11:59:01 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Post J&J Shot

Dear Dr. Safavi,

I was a researcher my entire career, both at prestigious academic settings and the NIH. After having read 1000's of NIH and other study protocols over the years, developed many of my own, and consented several participants, it's disturbing as to what has happened to me in your research. I was not properly consented to a study presented during the appointment with you and Dr. Nath last Tuesday, April 13th. Dr. Nath verbally highlighted some of elements in the consent document, but I didn't have the opportunity to read the protocol, much less understand

the document consented to required testing. I'd requested the protocol on previous occasions. For example, when Kymami called me March 24th to set up an appointment with you and Dr. Nash, I asked her how I could get a copy of the protocol. She deferred to you and you kindly called back that that same day to say the study protocol was being worked on.

During our meeting last Tuesday, Dr. Nath described some of the study components, but none were identified by him as either required or optional. I didn't expect him to delineate requisite testing as in your March 29th email to me, you said absolutely "nothing was mandatory in our research protocol." When he mentioned (b) (6) and asked if I had problems with (b) (6) again, with the assumption this was not required testing and he seemed short on time for a discussion. He noted on the form about (b) (6). He cited a few other tests, again, without categorizing any as requisite, and seemed rushed as he said he still had to exam me. No mention of side effects of any test. Then he stood up and crossed the room to sign the consent, not hand it to me to read. I walked over to the table, too, and signed so he could get on with his day.

Since I did not have the opportunity to read the form during the in-person appointment, or prior, the following day (April 14th) I called Amanda and asked her about (b) (6). She replied it was a study requirement and was only waived when contraindicated. This was stunning news to me. I expressed that I hadn't heard of any study participants being required to do (b) (6). She said there are 2 study arms on covid-vaccine effects, but it seems none of the few dozens of people I know who are aware of NINDS' study have any idea about 2 study arms, including me. During this same conversation with Amanda, I asked her to send me a copy of the protocol in an unencrypted email. Hours later I still hadn't received it and emailed her. At 5:53pm Wednesday, a copy of the study protocol was sent to me. I read it and was floored. Had I known of the requirements, I wouldn't have consented to the protocol described. Past (b) (6)

It baffles me that I wasn't sent a letter or note about the study, a study protocol, -- anything about consent. On March 22nd, I only received a one-line email -- no greeting, no explanation -- just a single sentence to say a medical records request form was attached. I'll forward you that email. March 22nd also was the same day I met with Dr. Hallett via his protocol, which, by the way, I was able to read in advance. The single sentence email made no mention of which study. The afternoon before my in-person appointment last Tuesday, Amanda called me to do a Covid screen, and I told her I never received a copy of the protocol. She then sent me a copy in an encrypted email message, and I explained while I was on the phone that I couldn't open the encrypted message and didn't have time to work with the NIH Helpdesk. It's unknown why it couldn't have been resent in an unencrypted message as it was an unsigned form. I resolved to quit worrying about it and assumed the protocol consent reflected what several covid vaccine effect study participants describe as their experiences on social media -- e.g. tele visits with you, available

medical test results are forwarded to NIH, no invasive mandatory tests, you speak with participants' neurologists, etc. I assumed I was enrolling in the same covid vaccine study protocol since you advised me on March 22nd to find a general neurologist for you to communicate with.

Learning, after the fact, about details of the study has created angst and confusion. You emailed me that there was absolutely nothing mandatory in the study. Yet, the consent I signed states otherwise, and Amanda verified the requisite testing when I inquired about (b) (6). I wouldn't have consented to a study with this requirement. No study personnel made an effort to help assure I was informed to about this fact. A potential participant shouldn't have to initiate requests for fundamental study materials to help guide their decision about participation. It's difficult to withdraw from something I didn't properly consent to in the first place, so will state I cannot go forward with the study I signed, under false pretenses, about requirements. It cannot be emphasized enough that a consent to participate in research needs to be transparent.

Sincerely,

(b) (6)

(b) (6)

On Apr 14, 2021, at 4:32 PM, (b) (6) wrote:

Thanks for your quick reply Dr. Safavi. Yes, since I'm unable to address them with him tomorrow, his staff are looking for a future date when he and I can discuss the findings.

Best, (b) (6)

On Apr 14, 2021, at 4:22 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

Your (b) (6)

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

From: (b) (6)

Sent: Wednesday, April 14, 2021 4:16 PM

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

Subject: Re: Post J&J Shot

Hi Dr Safavi,

Please find attached a copy of (b) (6)

This (b) (6)

(b) (6) He was supposed to give me the written report tomorrow at the outpatient surgery center during (b) (6) but per your request, I canceled the appointment. My neck has been more symptomatic during the past 24 hours.

Best, (b) (6)

<6443F73B1CD64281B83F049E0CB8E24E.jpg>

On Apr 10, 2021, at 4:01 PM, (b) (6)

wrote:

Thanks for letting me know... I'll bring the CD.

Best, (b) (6)

On Apr 10, 2021, at 3:49 PM, Safavi, Farinaz (NIH/NINDS) [E]

< (b) (6)

> wrote:

Dear (b) (6)
No worries about (b) (6). It would be great if you can bring the CD with you on Tuesday.

Best

Farinaz

<B14CC6B39C964AD48549ED4676681A5E.png

>
From: (b) (6)
>
Sent: Saturday, April
10, 2021 1:23:39 PM
To: Safavi, Farinaz
(NIH/NINDS) [E]
< (b) (6) >
Subject: Re: Post J&J
Shot

Hi Dr. Safavi,

It was so kind of you
to respond late on a
Friday night.

Thank you for your
helpful explanation
that cranial
neuropathies require a
differential diagnosis
before attributing it to
a vaccine.

I appreciate your
explanation about NIH
(b) (6). I'll
email Kymani and see
if she can check on the
availability of a future
appointment. The
facility where I had the
(b) (6) scheduled for
next week had a
cancellation, and
subsequently, I had
(b) (6)

Although I believe it'd
be useful for you to see
(b) (6) before
my meeting with you
on Tuesday morning,
I'm unfamiliar with
this
neurologist's office. If
you think NIH might
have sway to get the
report before Tuesday,
please advise how I
can help. Or, we can

wait.

Hope you're having a nice weekend and not immersed in work emails :)

Best, (b) (6)

On Apr 9,
2021, at
11:16 PM,
Safavi,
Farinaz
(NIH/NIND
S) [E]

(b) (6)

wrote:

Dear

(b) (6)

When
someone
develops
specific
symptom
s like

(b) (6)

that
points
toward
involvement of
intracranial parts
of
nervous
system,we
e as
neurologists have
to make
sure all
the
possible
differential
diagnosis
excluded
before
attributing it to
vaccine
or
anything

else. Cranial neuropathies are a little bit different from other entities like fasciculations and paresthesia in limbs.

Regarding

a (b) (6)

would like to get

(b) (6)

at NIH because our machines are much more sensitive than many outside (b) (6) and

we use (b) (6)

(b) (6)

I leave the decision to you if you want to get

(b) (6)

and even in that case I highly suggest to repeat

(b) (6)

at NIH since

they are
much
more
accurate
and our
neuroradi
ologists
are very
experts
to read

(b)
(6)

See you
on
Tuesday
Best
Regards,

Farinaz

<C8B3F44
2584B459
7AF58F23
CD73CEB8
2.png>

From: (b)
(6)

Sent: Wed
nesday,
April 7,
2021
10:12:53
PM

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

(b) (6)

Subject: R
e: Post J&J
Shot

Hi Dr.
Safavi,

Thank
you for
your
quick
reply and
reassuran

ce that
NIH can
help treat
me if I'm
enrolled
and
there's
not other
diseases
mimickin
g the
same
symptom
s. As
you've
heard, my
skull
paranesth
esia
started 2
hours
post-
injection
and soon
thereafter
(~2 days),
a right
eye
"twitch"
began. I
don't
recall
mentionin
g the
right eye
to you,
likely
because it
wasn't in
spasms at
the
moment.
However,
I
identified
it to other
providers,
and my
impressio
n was that
they
considere
d it
innocuou
s. After

discussin
g it with
the
ophthalm
ologist
who just
examined
me, I now
recognize
it was a
stronger
muscle
pull. But
I'd never
previousl
y
experienc
ed a
twitch in
my right
eye, so
only
knew to
describe it
as a
"twitch."
We'll talk
about it
more on
Tuesday
and will
just say
herein
that my
eye
symptom
s are not a
coinciden
ce after (b)
(6)

Yes, it
could be a
disease,
but if so,
it existed
sub
clinically
prior to
the
vaccine.

For
example,
in the last
(b) (6)
I had 3

appointm
ents

(b) (6)

with 2

rheumato
logists

who took

detailed

medical

histories

and were

inquisitiv

e. No

autoimm

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disorders

were

evident or

suspected

. What if

the

vaccine in

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that

would ha

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otherwise

been

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dormant t

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someone'

s life?

My

immediat

e feet and

leg

vaccine

reactions:

I

don't thin

k any of

my

current

and past

practition

ers would

see those

reactions

as a

disease.

I waited
to
respond
to you
today to
collapse
emails
you'd
receive. I
appreciat
e you
asking
Kyamani
to check
the
availabilit
y of (b)
(6)
appointm
ents next
Tuesday,
when I'll
be at
NIH. No
openings
that day,
but she
called me
today and
we
discussed
other
openings
at the
Clinical
Center.
I'll
probably
keep my
April
14th appoin
tment at
(b) (6)
as it will
be a bit
earlier.
Nonethel
ess,
thanks for
offering
me the
possibilit
y to be
tested at
NIH.

Again,
I'm
grateful
for your
responsiv
eness and
willingne
ss to help
if
possible.

The (b)
(6)
)

the
physician
assistant
prescribe
d me, the
one she
said she
standardl
y gives
her
patients,
has given
me the
worst
headache
I've had
in ages.
This feels
in the
wrong
direction;
I hope it
isn't. I
look
forward
to seeing
you
Tuesday.

Best,
(b) (6)

On Apr 6, 2021, at 7:11 AM, Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)> wrote:

Dear (b) (6)

Thank you very much to reach out. I am really sorry to hear
about your new symptoms. I am glad we can see at NIH on
Tuesday.

Cranial neuropathy is something that we really need to

examine you and investigate further. You certainly need (b) (6)

Let me check with our team and hopefully we can schedule you for (b) (6) on the same day of visit when you come to NIH.

If you get enrolled in our protocol we can treat you with appropriate treatment but first we need to make sure we are not missing any other diseases that mimic the same symptoms.

I will be in touch.
Best Regards,

Farinaz

Farinaz

<CF4CECCDD1646C38A43DF139B57C959.png>

From: (b) (6)

Sent: Tuesday, April 6, 2021 12:56:27 AM

To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>

Subject: Re: Post J&J Shot

Hi Dr. Safavi,

I've developed (b) (6). No previous history. Examined by a seasoned ophthalmologist yesterday.

He says (b) (6)

I've not had headaches since the 2nd day after the Pfizer shot; only persistent parentheses. Now have intermittent aches above eyebrows. Cranium has an increasing sensation of tightening; had previously felt stable.

The general neurologist I saw last Monday (b) (6)

(b) (6) negated I had a vaccine reaction and brusquely asked if I was there for meds or tests, even prior to taking my history. I mentioned to you previously that I had to convince her to assess the strength of my foot and leg. With her lack of interest, I made an appointment last week with a new general neurologist's practice ((b) (6)), but have no appointments scheduled yet to meet him as he's booked. Only met with his young physician assistant (PA). The PA concluded that I needed (b) (6)

I requested (b) (6)

She (b) (6) insisted their office only prescribes (b) (6)

At least with

That's scheduled for next

Wednesday, which seems to be the earliest I can get an appointment at a facility with a reputable diagnostic radiologist.

You, Dr. Nath, and I are scheduled to meet next Tuesday at NIH. Is it only after I've signed the study protocol that you are able to speak with a neurologist on my behalf? It's been difficult to persuade a neurologist of what may be helpful, say, based on working with others with post-vaccine neuro reactions, e.g. steroid dosing. If I understand correctly, J&J continues to build antibodies for a month – much like first shots of mRNA vaccines. My immune system might be in overdrive for the next number of weeks.

Thanks, (b) (6)

On Mar 29, 2021, at 10:13 PM, (b) (6)
(b) (6) wrote:

I appreciate your quick response! Thank you for clarifying that the test isn't mandatory. With that, I'll defer the (b) (6) as I don't think I could tolerate it. And as such, it wouldn't be a good use of the physician's time who's administering the test to have to stop the test prematurely because the test is unbearable. Sort of a "Catch-22" for those of us who cannot bear the pain of the test to get treatment for the pain.

A side story... in my effort to find a general neurologist in (b) (6), today I had an appointment with one as a new patient. She started by asking why I was there and I replied that I had a vaccine reaction and explained the neuro symptoms that started 2 hours after the Pfizer vaccine injection. She said she doubted it could've been the vaccine and added that perhaps I was dehydrated (I drink 64+ oz of water a day). She asked me to stand on my toes. My left foot could barely do so – much less even lift my left toes. Obvious weakness. I had to ask her to assess the strength of my left leg and foot as she had no intent of touching my lower extremities otherwise. There were visible spasms in both legs, but I doubt they were noted as she never looked at or touched them. She acted like I was wasting her time, and concluded (b) (6)

(b) (6). It was the most unproductive medical appointment I've experienced. Will need to keep shopping for a general neurologist.

Best, (b) (6)

On Mar 29, 2021, at 7:46 PM, Safavi, Farinaz
(NIH/NINDS) [E] <(b) (6)> wrote:

Dear (b) (6),
Thank you for reaching out and clarification
about your symptoms.

I completely understand your concerns. I also
would like to emphasize that there is nothing
mandatory in our research protocol. If you do not
want to have (b) (6) we will not do it.

(b) (6) basically helps us to determine the cause
of your new symptoms and worsening of your
previous neuropathy whether there is an
ongoing inflammatory process or not. If so we
may be able to offer you treatment to improve
your pain and paresthesia symptoms.
However, if you are not interested we defer it
and bring you here just for a visit and blood
draw.

Please let us know and we can plan
accordingly.

Best Regards,
Farinaz

<AABC2F3577F04EBBB17B1F1BC91CC517.png>

From: (b) (6)

Sent: Monday, March 29, 2021 7:13:32 PM

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

<(b) (6)>

Subject: Post J&J Shot

Hello Dr. Safavi,

It's was a pleasure to meet you last Monday
during my NIH visit (March 22nd), and receive
your call last Wednesday (March 24th).

During our phone chat, I told you I'd received the
J&J vaccination (b) (6). It's
been interesting to compare my neuro reactions
from Pfizer vs. J&J. But to be brief herein... I had
no neuro symptoms (actually, any symptoms)
from J&J until the day after the injection, when I
experienced severe L4-5 pain in my left foot and
leg. The pain was more severe than the original
neuropathy following (b) (6)
(b) (6), and any time thereafter. There's
been reduction in intensity since then, yet it
remains highly sensitive and I'm currently less

mobile than when you saw me. I wouldn't bother you with my 2nd shot reaction, except Kymani contacted me today to schedule appointments for an upcoming NIH visit, which would include (b) (6). I've had (b) (6)

(b) (6) Physicians used to remark about my high pain tolerance. That's no longer the case. After the aggravation from Pfizer and J&J (b) (6) -- I wouldn't be able to tolerate (b) (6) in the foreseeable future, maybe ever. I wanted to bring this to your attention as you may not want to include me in your study without (b) (6), and if so, Kymania and I won't go forward with scheduling the visit.

In closure, I don't wish to leave you with bad impressions of J&J. There are other Pfizer-induced neuro symptoms that are better, thus far, since the J&J injection. And some are about the same, after both shots. It's just the 2nd vaccination didn't show any mercy to a vulnerable nerve, one that had a history of neuropathy. And interestingly, my worst reactions after Pfizer followed the first post-injection week. Seems I still have a few more weeks to see how J&J will play out.

Best regards,

(b) (6)

(b) (6)

(b) (6)

To: Safavi, Farinaz (NIH/NINDS) [E] (b) (6)
From: (b) (6)
Sent: Thur 3/25/2021 9:35:15 AM (UTC-05:00)
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Hi Farinaz,

The doctor in the ER mentioned both to the neurologist she spoke to on the phone. I have still not seen a neurologist in person, or had (b) (6), but there are urgent (b) (6). "Urgent" unfortunately means very little in the area where I live. I'm hoping to get (b) (6) within the next week. My sister, (b) (6), has written to several members of our provincial ministry of health regarding concerns about lack of transparency around adverse vaccine reactions, lack of access to reporting resources, and lack of access to medical care post reaction. One would think they want to be very proactive about gathering this data and treating those affected. I hope some positive actions comes out of this. Thank you again for your concern and assistance.

(b) (6)

Sent from my iPhone

On Mar 24, 2021, at 12:39, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

I am so glad you finally able to see someone. Did you talk to them about possibility of (b) (6) or (b) (6)?

Farinaz

From: (b) (6)
Sent: Wednesday, March 24, 2021 3:27:23 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Hi Farinaz,

After writing the email to you yesterday, I decided to go into the ER for assessment. I have an urgent (b) (6) pending and the ER doctor did a phone consult with a neurologist from (b) (6). Thank you for your response

(b) (6)

Sent from my iPhone

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Hi (b) (6)

I think the best approach in your case would be seeing a neurologist. I would be happy to get in touch with any physician to provide any further information.

Farinaz

From: (b) (6)
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Regards,
(b) (6)

<3515F8BDB8C746D5BAB57CCE680D4F60.jpg>
<3BC2BA49122A4D63A6A110812D81FE8A.jpg>

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On Mar 23, 2021, at 07:43, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

hi, give me a few minutes and i will send it again

Farinaz

<7868991B08644CCCB2945A2D1384D9B8.png>

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Subject: Re: Neurological symptoms post Pfizer COVID vaccine

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(b) (6)

Sent from my iPhone

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Thank you. Maybe you ask or GP to check for spike and capsid Abs. They can

distinguish previous or vaccine related COVID.
Our nurse will contact you as soon as she can for paperwork. Thanks for your fast response.

Farinaz

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Sent: Monday, March 22, 2021 4:37 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Hello Farinaz,
I did have some symptoms last March that started two weeks after returning from Mexico that I wasn't tested for. I had an odd burning sensation in my chest and an infrequent dry cough that persisted intermittently for about 2 days. I was afebrile and had no other symptoms. Our daily cab driver in Mexico had taken a day off because of a "bad flu". I have no past history of medical conditions, besides (b) (6)

(b) (6) The only medication I do take is (b) (6). The only autoimmune disease I'm aware of in my family is (b) (6)

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Sent from my iPhone

On Mar 22, 2021, at 12:41, Safavi, Farinaz (NIH/NINDS) [E]
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Hi (b) (6)

I have two questions for you.
Do you think you ever had COVID in the course of last year?
Do you have any family member with autoimmune or inflammatory diseases?
Any Past medical Hx or medication?
Thank you

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

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Hi Farinaz,
I'm so sorry. I'm having an issue with my wifi this morning and

am unable to log into the Teams meeting. I'm attempting to connect using my phone's data plan, but that also isn't working. I'm attempting to resolve this issue and hopefully will be able to quickly.

(b) (6)

Sent from my iPhone

On Mar 18, 2021, at 16:38, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

I am sorry to hear about your illness. I would be happy to speak with you through televisit and discuss your issues. Does Monday 11am or 12noon ET work for you?

Best
Farinaz

Farinaz

<94EBE1012C554021AC219AAFF0FC888F.png>

From: (b) (6)

Sent: Thursday, March 18, 2021 3:48:26 AM

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

<(b) (6)>

Subject: Neurological symptoms post Pfizer COVID vaccine

Hello Farinaz,

I was referred to you by (b) (6) who I have been in correspondence with since yesterday.

The following is my story:

I am a (b) (6) from (b) (6). I am a healthy, very active (b) (6)

I received my first dose of the Pfizer COVID vaccine, administered to the left deltoid, (b) (6). Early (b) (6) morning I woke with numbness to my left shin and right hand. When I woke later that morning, these symptoms remained. Throughout the day I developed paresthesia to all four extremities and the right side of my face, along the trigeminal nerve pathway. Along with this paresthesia, which was intermittently worse in one

limb vs another, I developed traveling intermittent sensations of coldness, as if someone was suddenly splashing me with cold water. I also experienced intermittent, traveling prickly electrical sensations. The next day the paresthesia persisted, but with less intensity and seemed to be affecting mainly the right side of my face and right arm and hand. That day, I had intermittent sensations of burning heat, most prominent to the right side of my face. Today, (b) (6) I'm experiencing slight paresthesia to my left shin and a feeling of heaviness/numbness to my right arm and hand with cramping of my right hand, which requires increased effort to use as I normally would. The paresthesia to the right side of my face remains, but the sensation seems to be changing to a neuropathy instead. I feel as if I've been punched incredibly hard in my cheek. I also have intermittent sharp pains to the sides of my fingers, my hand, along the radial and ulnar nerves, and to my upper arm. Fortunately, I am still mostly functional and able to carry on with my normal activities without issues, beside the hand cramping. My fear is what this may progress to in the future. Being Canadian, I have incredibly limited access to any specialized care, and will never be able to be assessed by a neurologist. I've had a phone appointment with a GP, another with my own, and was seen by my own GP in person today. My neurological exam was (b) (6) I've been told that if my symptoms become largely focal then I need to be seen urgently to have (b) (6) booked. I've also been advised to closely self monitor my symptoms. The first

doctor told me my symptoms were not due to the COVID vaccine, even though I was perfectly healthy before the vaccine with no pre-existing conditions or history of neurological symptoms. My own GP is reluctant to say the vaccine is the cause, but has filed an adverse reaction report, as have I.

Thank you for taking the time to review my story. Please let me know if I can assist your study in any way.

Regards,

(b) (6)

To: Safavi, Farinaz (NIH/NINDS) [E] (b) (6)
From: (b) (6)
Sent: Tue 4/13/2021 12:40:55 PM (UTC-05:00)
Subject: Re: Neurological symptoms post Pfizer COVID vaccine
(b) (6)

Good morning Dr Safavi,

I finally have a copy of the transcribed report of my (b) (6) to share with you. I'm comfortable sharing it here, so will attach it.

I presented to the ER again two days ago with increasing numbness to my right foot and right leg, and was finally seen in person by a neurologist. He has decided (b) (6)

(b) (6) He reviewed (b) (6). He has ordered (b) (6). I will update you once I know more. Overall, I feel my concerns continue to be brushed off and it's incredibly frustrating.

Regards,
(b) (6)

Sent from my iPhone

On Apr 5, 2021, at 11:04, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

(b) (6)

The reason that I wanted to speak with you was that if there is an objective evidence for (b) (6)

Of course I leave the decision to you.

Best

Farinaz

From: (b) (6)
Sent: Monday, April 5, 2021 1:55:15 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Hi,

I'll be traveling tomorrow so unfortunately will not be available for a meeting tomorrow. I will be back home Thursday afternoon, so the soonest I will be available is Friday morning.

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Sent from my iPhone

On Apr 5, 2021, at 08:50, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Sure,

It takes us 14 days to get the records so that if you can get it from your family doctor that would be

much faster. It would be great if you can try tomorrow and let me know.
We may be able to meet around 4pm ET tomorrow? Does it work for you?

Farinaz Safavi MD, PhD
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I would love to send it to you, but I don't have access to it. I may be able to request a copy from my family doctor, but her office does not reopen until tomorrow. In the consents that I signed and sent to Amanda, I did give permission to access results of my diagnostic tests, if that is helpful.

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Hi (b) (6)
Thank you for your email and information. I agree with that diagnosis.
Can you send me your (b) (6) by any chance?

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I haven't noticed any paresthesias or neurological issues to any other areas of my body (those seem to have resolved) besides to my right foot where I sometimes notice numbness (considerable at times) and pins and needles feelings, especially when laying still. It occasionally feels as if I have the same odd cramping sensation to my foot and toes that I have to my hands.

I am still awaiting an appointment with a neurologist, as I still have not seen one in person, and am still awaiting (b) (6). I've been told that I may need be treated with (b) (6). The radiologist who approved (b) (6)

Overall, I'm incredibly frustrated and disheartened with the lack of care and attention my condition has received from the medical professionals in my area. I'm so very appreciative that I was able to connect with you and you took the time to speak with me and assess me. Without you, I would have had no idea what was going on in my body.

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On Apr 5, 2021, at 06:33, Safavi, Farinaz (NIH/NINDS) [E]
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Hi (b) (6)
Hope your symptoms have improved.
Can you please update me with your symptoms and test results you have done so far?

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< (b) (6) >
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Best
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Farinaz

<94EBE10

12C55402
1AC219AA
FF0FC888
F.png>

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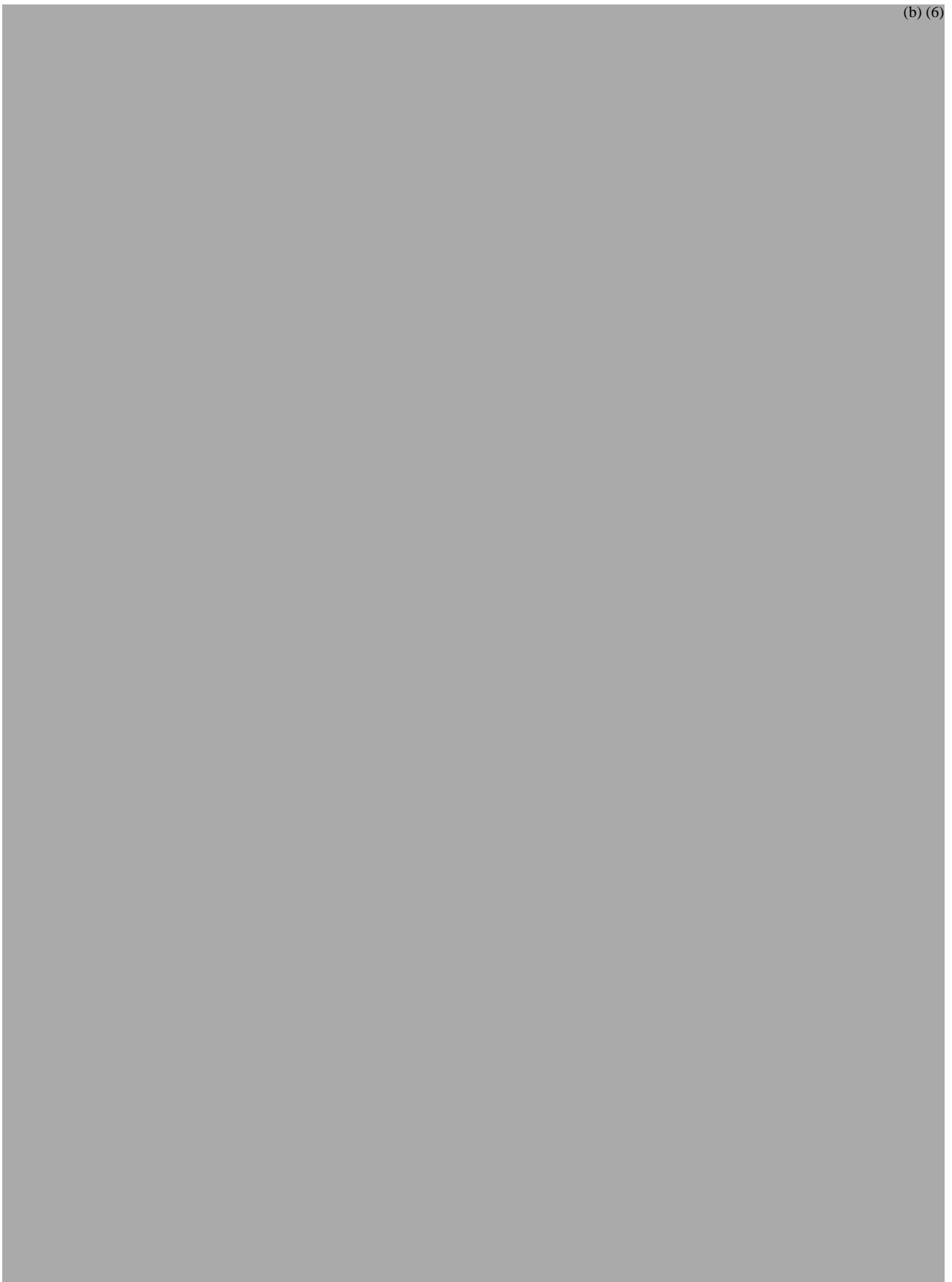
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Hi Dr Safavi,

Yes, I definitely understand that and am incredibly frustrated that there has been so many delays in my treatment, and there continues to be.

(b) (6)

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Can you please update me with your symptoms and test results you have done so far?

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

From: (b) (6)
Sent: Wednesday, March 24, 2021 3:27 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Hi Farinaz,
After writing the email to you yesterday, I decided to go into the ER for assessment. I have (b) (6) pending and the ER doctor did a phone consult with a neurologist from (b) (6). Thank you for your response

(b) (6)

Sent from my iPhone

On Mar 24, 2021, at 10:04, Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)> wrote:

Hi (b) (6)
I think the best approach in your case would be seeing a neurologist. I would be happy to get in touch with any physician to provide any further information.

Farinaz

From: (b) (6)
Sent: Tuesday, March 23, 2021 3:30 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Hello Farinaz,
I just wanted to thank you again for taking the time to speak with me and offer some suggestions as to what the source of my symptoms may be. My husband is also very grateful. It's been very reassuring to speak to you and it has put my mind much at ease. I have noticed a new symptom today and am wondering if you might be able to offer some clarity as to what this may mean. Please see the attached photos. I believe I may be exhibiting what is known as Wartenberg's Sign in the fifth finger of my right hand. I am able to adduct the fifth finger towards the fourth, although it does require some effort. The position in the photo is where my fifth finger automatically goes to if my hand is relaxed. I have included a photo of my left hand for comparison. I very much appreciate any information you can provide. Also, I should have some downtime this afternoon to be able to complete and submit the consent forms to Amanda.

Regards,
(b) (6)

<3515F8BDB8C746D5BAB57CCE680D4F60.jpg>
<3BC2BA49122A4D63A6A110812D81FE8A.jpg>

Sent from my iPhone

On Mar 23, 2021, at 07:43, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

hi,give me a few minutes and i will send it again

Farinaz

<7868991B08644CCCB2945A2D1384D9B8.png>
From: (b) (6)
Sent: Tuesday, March 23, 2021 10:25:23 AM
To: Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)>
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Good morning Farinaz,
I have not received an invitation to our Teams meetings this morning. I'm not sure if maybe it got misplaced in the mail somewhere?

Thanks,

(b) (6)

Sent from my iPhone

On Mar 22, 2021, at 13:39, Safavi, Farinaz (NIH/NINDS) [E]

<(b) (6)> wrote:

Thank you. Maybe you ask or GP to check for spike and capsid Abs. They can distinguish previous or vaccine related COVID.

Our nurse will contact you as soon as she can for paperwork. Thanks for your fast response.

Farinaz

From: (b) (6)

Sent: Monday, March 22, 2021 4:37 PM

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

Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Hello Farinaz,
I did have some symptoms last March that started two weeks after returning from Mexico that I wasn't tested for. I had an odd burning sensation in my chest and an infrequent dry cough that persisted intermittently for about 2 days. I was afebrile and had no other symptoms. Our daily cab driver in Mexico had taken a day off because of a "bad flu". I have no past history of medical conditions, besides (b) (6)

(b) (6). The only medication I do take is (b) (6)

(b) (6) The only autoimmune disease I'm aware of in my family is (b) (6)

REL0000230306

Sent from my iPhone

On Mar 22, 2021, at
12:41, Safavi, Farinaz
(NIH/NINDS) [E]

<[REDACTED] (b) (6)>
> wrote:

Hi [REDACTED] (b) (6)

I have two questions for
you.

Do you think you ever
had COVID in the
course of last year?

Do you have any family
member with
autoimmune or
inflammatory diseases?

Any Past medical Hx or
medication?

Thank you

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

From: [REDACTED] (b) (6)

Sent: Monday, March
22, 2021 12:05 PM

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

Subject: Re:
Neurological symptoms
post Pfizer COVID
vaccine

Hi Farinaz,
I'm so sorry. I'm having
an issue with my wifi
this morning and am
unable to log into the
Teams meeting. I'm
attempting to connect
using my phone's data
plan, but that also isn't
working. I'm attempting
to resolve this issue and
hopefully will be able to

quickly.

(b) (6)

Sent from my iPhone

On Mar
18, 2021,
at 16:38,
Safavi,
Farinaz
(NIH/NIND
S) [E]

(b) (6)

wrote:

Hi

(b) (6)

I am
sorry to
hear
about
your
illness. I
would be
happy to
speak
with you
through
televisit
and
discuss
your
issues. Does
Monday
11am or
12noon
ET work
for you?
Best
Farinaz

Farinaz

<94EBE10
12C55402
1AC219AA
FF0FC888
F.png>

From:

(b) (6)

Sent:
Thursday,
March 18,
2021
3:48:26
AM
To: Safavi,
Farinaz
(NIH/NIND
S) [E]
(b) (6)
Subject:
Neurologi
cal
symptoms
post Pfizer
COVID
vaccine

Hello Farinaz,

I was referred to you by (b) (6) who I have been in correspondence with since yesterday.

The following is my story:

I am a (b) (6) from (b) (6). I am a healthy, very active (b) (6)

(b) (6). I received my first dose of the Pfizer COVID vaccine, administered to the left deltoid, (b) (6). Early (b) (6) morning I woke with numbness to my left shin and right hand. When I woke later that morning, these symptoms remained. Throughout the day I developed paresthesia to all four extremities and the right side of my face, along the trigeminal nerve pathway. Along with this paresthesia, which was intermittently worse in one limb vs another, I developed traveling intermittent sensations of coldness, as if someone was suddenly splashing me with cold water. I also experienced intermittent, traveling prickly electrical sensations. The next day the paresthesia persisted, but with less intensity and seemed to be affecting mainly the right side of my face and right arm and hand. That day, I had intermittent sensations of burning heat, most prominent to the right side of my face.

Today, (b) (6) I'm experiencing slight paresthesia to my left shin and a feeling of heaviness/numbness to my right arm and hand with cramping of my right hand, which requires increased effort to use as I normally would. The paresthesia to the right side of my face remains, but the sensation seems to be changing to a neuropathy instead. I feel as if I've been punched incredibly hard in my cheek. I also have intermittent sharp pains to the sides of my fingers, my hand, along the radial and ulnar nerves, and to my upper arm. Fortunately, I am still mostly functional and able to carry on with my normal activities without issues, beside the hand cramping. My fear is what this may progress to in the future. Being Canadian, I have incredibly limited access to any specialized care, and will never be able to be assessed by a neurologist. I've had a phone appointment with a GP, another with my own, and was seen

by my own GP in person today. My neurological exam was (b) (6). I've been told that if my symptoms become largely focal then I need to be seen urgently to have (b) (6) booked. I've also been advised to closely self monitor my symptoms. The first doctor told me my symptoms were not due to the COVID vaccine, even though I was perfectly healthy before the vaccine with no pre-existing conditions or history of neurological symptoms. My own GP is reluctant to say the vaccine is the cause, but has filed an adverse reaction report, as have I.

Thank you for taking the time to review my story. Please let me know if I can assist your study in any way.

Regards,
(b) (6)

To: Safavi, Farinaz (NIH/NINDS) [E] (b) (6)
From: (b) (6)
Sent: Tue 4/13/2021 3:49:12 PM (UTC-05:00)
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Unfortunately, I don't think there's any way I can have access to those. It was very difficult to even access this transcription. I will try to get in touch with my Dr's office to see, but I don't really think I will be able to.

Sent from my iPhone

On Apr 13, 2021, at 12:59, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

Thank you for the update. Is there any possibility you send us the original imagings?

I cc Amanda to guide us through this possibility.

Best

Farinaz

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

From: (b) (6)
Sent: Tuesday, April 13, 2021 1:42 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Good morning Dr Safavi,

I finally have a copy of the transcribed report of (b) (6) to share with you. I'm comfortable sharing it here, so will attach it.

I presented to the ER again two days ago with increasing numbness to my right foot and right leg, and was finally seen in person by a neurologist. He has decided (b) (6)

(b) (6). He reviewed (b) (6). He has ordered (b) (6). I will update you once I know more. Overall, I feel my concerns continue to be brushed off and it's incredibly frustrating.

Regards,
(b) (6)

Sent from my iPhone

On Apr 5, 2021, at 11:04, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

(b) (6)
The reason that I wanted to speak with you was that if there is an objective evidence for (b) (6)
(b) (6)
Of course I leave the decision to you.

Best

Farinaz

<AB7521D3C6A14A92AEE9E41803DDB9ED.png>

From: (b) (6)
Sent: Monday, April 5, 2021 1:55:15 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Hi,
I'll be traveling tomorrow so unfortunately will not be available for a meeting tomorrow. I will be back home Thursday afternoon, so the soonest I will be available is Friday morning.

(b) (6)

Sent from my iPhone

On Apr 5, 2021, at 08:50, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Sure,
It takes us 14 days to get the records so that If you can get it from your family doctor that would be much faster. It would be great if you can try tomorrow and let me know.
We may be able to meet around 4pm ET tomorrow? Does it work for you?

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

From: (b) (6)
Sent: Monday, April 5, 2021 11:46 AM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Hi Dr Safavi,
I would love to send it to you, but I don't have access to it. I may be able to request a copy from my family doctor, but her office does not reopen until tomorrow. In the consents that I signed and sent to Amanda, I did give permission to access results of my diagnostic tests, if that is helpful.

(b) (6)

Sent from my iPhone

On Apr 5, 2021, at 08:42, Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)> wrote:

Hi (b) (6)
(b) (6) for your email and information. I agree with that diagnosis.

REL0000230314

Can you send me your (b) (6) by any chance?

Thanks

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: (b) (6)

Sent: Monday, April 5, 2021 11:35 AM

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

Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Good morning Dr Safavi,

The episodes of numbness to my right hand, fingers, and arm are becoming more infrequent, but are still occurring. I still have difficulty using my right hand and fingers, to increasing degrees, because of the feeling of it taking increased effort to use my fingers and the feeling of heaviness and cramping in my fingers I described before. It's difficult to write or type for more than a couple of minutes at a time because of it. I've also had some issues with fine motor function of my fingers, such as screwing the backs on my earrings. I finally did have the (b) (6). I'm so incredibly thankful that I was able to speak to you and you suggested that diagnosis, because I know I never would have been able to have it diagnosed if it wasn't for you.

I haven't noticed any paresthesias or neurological issues to any other areas of my body (those seem to have resolved) besides to my right foot where I sometimes notice numbness (considerable at times) and pins and needles feelings, especially when laying still. It occasionally feels as if I have the same odd cramping sensation to my foot and toes that I have to my hands.

I am still awaiting an appointment with a neurologist, as I still have not seen one in person, and am still awaiting (b) (6). I've been told that I may need be treated with (b) (6). The radiologist who approved (b) (6)

Overall, I'm incredibly frustrated and disheartened with the lack of care and attention my condition has received from the medical professionals in my area. I'm so very appreciative that I was able to connect with you and you took the time to speak with me and assess me. Without you, I would have had no idea what was going on in my body.

(b) (6)

On Apr 5, 2021, at 06:33, Safavi, Farinaz (NIH/NINDS) [E]

<(b) (6)> wrote:

Hi (b) (6)

Hope your symptoms have improved.

Can you please update me with your symptoms and test results you have done so far?

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: (b) (6)

Sent: Wednesday, March 24, 2021 3:27 PM

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Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Hi Farinaz,

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10:25:23 AM

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Subject: Re: Neurological symptoms
post Pfizer COVID vaccine

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Sent from my iPhone

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> wrote:

Thank you. Maybe you
ask or GP to check for
spike and capsid
Abs. They can
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Our nurse will contact
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for paperwork. Thanks
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Farinaz

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Sent: Monday, March
22, 2021 4:37 PM
To: [Safavi, Farinaz](#)
[\(NIH/NINDS\) \[E\]](#)
Subject: Re:
Neurological symptoms
post Pfizer COVID
vaccine

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The
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take is (b) (6)

The
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disease I'm aware of in
my family is (b) (6)

(b) (6)

(b) (6)

Sent from my iPhone

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I have two
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Do you
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Do you
have any
family
member
with
autoimmu
ne or
inflammat
ory
diseases?
Any Past

medical
Hx or
medication?
Thank you

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

From:

(b) (6)

Sent:

Monday,
March 22,
2021

12:05 PM

To: [Safavi,](#)

[Farinaz](#)

[\(NIH/NINDS\)](#)

[\[E\]](#)

Subject:

Re:
Neurological
symptoms
post Pfizer
COVID
vaccine

Hi
Farinaz,
I'm so
sorry. I'm
having an
issue with
my wifi
this
morning
and am
unable to
log into
the Teams
meeting.

I'm
attemptin
g to
connect
using my
phone's
data plan,
but that
also isn't
working.
I'm
attemptin
g to
resolve
this issue
and
hopefully
will be
able to
quickly.

(b) (6)

Sent from
my iPhone

On Mar 18, 2021, at 16:38, Safavi, Farinaz (NIH/NINDS) [E]

<(b) (6)> wrote:

Hi (b) (6)

I am sorry to hear about your illness. I would be happy to
speak with you through televisit and discuss your
issues. Does Monday 11am or 12noon ET work for you?

Best

Farinaz

Farinaz

<94EBE1012C554021AC219AAFF0FC888F.png>

From: (b) (6)

Sent: Thursday, March 18, 2021 3:48:26 AM

To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>

Subject: Neurological symptoms post Pfizer COVID vaccine

Hello Farinaz,

I was referred to you by (b) (6), who I have
been in correspondence with since yesterday.

The following is my story:

I am a (b) (6) from (b) (6). I
am a healthy, very active (b) (6).

I received my first dose of the
Pfizer COVID vaccine, administered to the left deltoid,
(b) (6). Early (b) (6) morning I woke with
numbness to my left shin and right hand. When I woke
later that morning, these symptoms remained.

Throughout the day I developed paresthesia to all four
extremities and the right side of my face, along the

trigeminal nerve pathway. Along with this paresthesia, which was intermittently worse in one limb vs another, I developed traveling intermittent sensations of coldness, as if someone was suddenly splashing me with cold water. I also experienced intermittent, traveling prickly electrical sensations. The next day the paresthesia persisted, but with less intensity and seemed to be affecting mainly the right side of my face and right arm and hand. That day, I had intermittent sensations of burning heat, most prominent to the right side of my face. Today, (b) (6) I'm experiencing slight paresthesia to my left shin and a feeling of heaviness/numbness to my right arm and hand with cramping of my right hand, which requires increased effort to use as I normally would. The paresthesia to the right side of my face remains, but the sensation seems to be changing to a neuropathy instead. I feel as if I've been punched incredibly hard in my cheek. I also have intermittent sharp pains to the sides of my fingers, my hand, along the radial and ulnar nerves, and to my upper arm. Fortunately, I am still mostly functional and able to carry on with my normal activities without issues, beside the hand cramping. My fear is what this may progress to in the future. Being Canadian, I have incredibly limited access to any specialized care, and will never be able to be assessed by a neurologist. I've had a phone appointment with a GP, another with my own, and was seen by my own GP in person today. My neurological exam was (b) (6). I've been told that if my symptoms become largely focal then I need to be seen urgently to have (b) (6) booked. I've also been advised to closely self monitor my symptoms. The first doctor told me my symptoms were not due to the COVID vaccine, even though I was perfectly healthy before the vaccine with no pre-existing conditions or history of neurological symptoms. My own GP is reluctant to say the vaccine is the cause, but has filed an adverse reaction report, as have I.

Thank you for taking the time to review my story.
Please let me know if I can assist your study in any way.

Regards,
(b) (6)

To: Safavi, Farinaz (NIH/NINDS) [E] (b) (6)
From: (b) (6)
Sent: Thur 3/18/2021 11:14:57 PM (UTC-05:00)
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Hi Farinaz,
That would be excellent. 1200 EST would work best for me.

Regards,
(b) (6)

Sent from my iPhone

On Mar 18, 2021, at 16:38, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)
I am sorry to hear about your illness. I would be happy to speak with you through televisit and discuss your issues. Does Monday 11am or 12noon ET work for you?
Best
Farinaz

Farinaz

From: (b) (6)
Sent: Thursday, March 18, 2021 3:48:26 AM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Neurological symptoms post Pfizer COVID vaccine

Hello Farinaz,
I was referred to you by (b) (6), who I have been in correspondence with since yesterday.
The following is my story:
I am a (b) (6) from (b) (6). I am a healthy, very active (b) (6).
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(b) (6) I'm experiencing slight paresthesia to my left shin and a feeling of heaviness/numbness to my right arm and hand with cramping of my right hand, which requires increased effort to use as I normally would. The paresthesia to the right side of my face remains, but the sensation seems to be changing to a neuropathy instead. I feel as if I've been punched incredibly hard in my cheek. I also have intermittent sharp pains to the sides of my fingers, my hand, along the radial and ulnar nerves, and to my upper arm. Fortunately, I am still mostly functional and able to carry on with my normal activities without issues, beside the hand cramping. My fear is what this may progress to in the future. Being Canadian, I have incredibly limited access to any specialized care, and will never be able to be assessed by a neurologist. I've had a phone appointment with a GP, another with my own, and was seen by my own GP in person today. My neurological exam was (b) (6). I've been told that if my symptoms become largely focal then I need to be seen urgently to have (b) (6) booked. I've also been advised to closely self monitor my symptoms. The first doctor told me my symptoms were not due to the COVID vaccine, even though I was perfectly healthy before the vaccine with no pre-existing conditions or history of neurological symptoms. My own GP is reluctant to say the vaccine is the cause, but has filed an adverse reaction report, as have I.

Thank you for taking the time to review my story. Please let me know if I can assist your study in any way.

Regards,

(b) (6)

To: Safavi, Farinaz (NIH/NINDS) [E] (b) (6)
From: (b) (6)
Sent: Tue 3/23/2021 12:28:52 PM (UTC-05:00)
Subject: Re: Potential SPAM:Re: Referral from (b) (6) neurological vaccine reaction

Here is my phone number (b) (6)
I am actually on the meeting link now!!

Oh please!!

Sent from my iPhone

On Mar 23, 2021, at 10:26 AM, (b) (6) wrote:

I am trying now, please can we still do it? You said 1 and I thought that meant 1 my time
Sent from my iPhone

On Mar 23, 2021, at 10:12 AM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hello (b) (6)

I and my NP joined to meet with you through MS teams at 1pm and unfortunately you did not join. Did the link work for you? If not we can reschedule.

Thanks

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

From: (b) (6)

Sent: Sunday, March 21, 2021 10:02 PM

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

Subject: Potential SPAM:Re: Referral from (b) (6) neurological vaccine reaction

Yes ma'am. Let me know how we proceed!!! Thank you!!!

Sent from my iPhone

On Mar 21, 2021, at 6:32 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

I am sorry to hear about your illness. We definitely can discuss your issues through televisit. I have availability on Tuesday. Does 1pm work for you?

Please let me know

Farinaz Safavi MD, PhD
Division of Neuroimmunology and Neurovirology

From: (b) (6)
Sent: Sunday, March 21, 2021 3:08 AM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#); [Wiebold, Amanda \(NIH/NINDS\) \[E\]](#)
Subject: Referral from (b) (6) neurological vaccine reaction

Hello! I was told to reach out to you and see if you could help me. My story is below. I currently live in (b) (6). My phone number is (b) (6). Thanks for your time!

My story:

I am a (b) (6). I am a (b) (6). I was healthy and fit before getting vaccinated. In 2020 I did (b) (6).

On (b) (6) I got my first and only Moderna shot in my left arm..No symptoms besides a sore arm for 2-3 days. On the 8th day I noticed some lymphadenopathy while I was at work. And then my neck started to feel hot. After that anytime I would eat my entire body felt a hot/burning sensation and accompanied by a rash that would migrate. This came and went for about a week. And then on the 14th day, I noticed my feet felt tingly. I had just taken my kids to (b) (6) to play in the snow that morning and thought it had something to do with that. On the 15th day, (b) (6) the tingling had gotten worse. It was now in both feet and ankles. It felt like icicles in my veins. I went to my primary and she insisted it couldn't be from the vaccine and prescribe me (b) (6) for the full body flushing. And gave me a referral to an allergist to give me a peace of mind that I could do the 2nd dose of vaccine. About an hour later it was worse so I went back the Dr but she said just to sent her pics via email. I told her my knees looked purple and the tingling was getting worse and traveling to my knees. She said if I was that concerned to go to the ER. I finished my day at the office and tried to go workout but it was persistent. I decided to go to (b) (6). They ran (b) (6). The Dr. said he thought (b) (6).

. They gave me (b) (6). That seemed to help with the full body flushing. The tingling in my feet persisted and also began in my hands. I went and saw the allergist and he had no idea. He gave me a prescription for (b) (6). He ordered (b) (6). He then referred me to (b) (6) for a 2nd opinion and also a neuro referral. I saw (b) (6) he said not to get the 2nd shot same thing the first allergist said. He order (b) (6).

The following Monday (b) (6) I went back to the ER my blood

pressure I took after work was (b) (6) and then (b) (6). I got to the ER and it had come down to (b) (6) or something like that. They did (b) (6). They ran some more labs. My (b) (6). The ER doctor had no idea, but said I should see a neurologist. He knew I was scared and he said I could help jump start the process and he ordered (b) (6).

I got in with the nurse practitioner at the primary. She ordered more labs and told me to (b) (6).

I remained tingly and my muscles aches, random twitching and electrical impulses in my right quad and my upper right shoulder/back area was randomly numb/tingly. I was exhausted and I lost 13 pounds in 2 weeks, hard to do when you are relatively healthy. My BP started to go down and stay around (b) (6). Now the low blood pressure was a new thing. I became very vascular and complained of my veins hurting. I went to neuro. He ordered (b) (6).

Finally I made a follow up appointment with him to discuss (b) (6).

Grrr. I have not lost my strength in all of this nor my balance. I did lose a little strength in the beginning because of the rapid weight loss but I have since regained that back. I am still down 8 or 9 lbs but maintaining that very well with a good diet, staying as low histamine as I can, most of the time. I went back to see my nurse practitioner on Friday (b) (6) because my veins in my wrists were hurting, almost like they were going to explode. The moment I would raise my hand the blood would rapidly disappear and my veins would sink in. I have videos of it happening. She denied me a vascular referral and prescribe me (b) (6). I filled the prescription and never took any. I did see a rheumatologist and she ordered a gamet of testing. She took me serious because she she also had numbness in her arm for an hour or two after her shot. (b) (6).

She said to follow up in 4 weeks in the meantime she was going to contact some colleagues at (b) (6) and see if they had heard of anything and she was going to check in with the NIH. She seems genuinely concerned. She wanted me to get a 2nd opinion from another neurologist. She thinks (b) (6).

She said that way we can rule things out. And so I just got approved for that on Friday and I am waiting for them to call me back to schedule.

My current symptoms are random burning sensations in my neck, hands, feet, and face. My tingling has subsided. But I notice if my shoes or socks are too tight it will start again. My hands and knuckles will get red and feel like they are hot. I had bad headaches, pulsing around my ears but those have subsided. My feet feel like they don't get good circulation and the color of

them changes. My veins change all the time, Super vascular and then barely there and then will bring on different sensory feelings. My hands/fingers fall asleep at night when I am sleeping and the tingling/ will also start in my feet when I lay down. My heels of my feet feel like they are burning as I type this! My energy is better and I think my BP has stabled more, or I am just not taking it as much at this point. If I am texting on my phone my fingers will tingle as if they are falling asleep. I used to get this cold feeling (icicles in my veins) in my forehead but that subsided and that feeling is now just randomly on the front side of my ankles. I don't seem to respond well to the cold.

I think that is all. I am sure I have left something out . But it has been a very busy (b) (6) since I had my first ER visit and the tests and bloodwork started! It has been (b) (6) since my shot. I would say things have improved since the beginning, especially when it comes to the intensity.

Interested on hearing your thoughts!

Thanks

(b) (6)

To: Safavi, Farinaz (NIH/NINDS) [E] (b) (6)
From: (b) (6)
Sent: Tue 3/23/2021 12:32:52 PM (UTC-05:00)
Subject: Re: Potential SPAM:Re: Referral from (b) (6) neurological vaccine reaction

Can we still do it?!

Sent from my iPhone

On Mar 23, 2021, at 10:26 AM, (b) (6) wrote:

I am trying now, please can we still do it? You said 1 and I thought that meant 1 my time
Sent from my iPhone

On Mar 23, 2021, at 10:12 AM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hello (b) (6).

I and my NP joined to meet with you through MS teams at 1pm and unfortunately you did not join. Did the link work for you? If not we can reschedule.

Thanks

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

From: (b) (6)
Sent: Sunday, March 21, 2021 10:02 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Potential SPAM:Re: Referral from (b) (6) neurological vaccine reaction

Yes ma'am. Let me know how we proceed!!! Thank you!!!

Sent from my iPhone

On Mar 21, 2021, at 6:32 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

I am sorry to hear about your illness. We definitely can discuss your issues through televisit. I have availability on Tuesday. Does 1pm work for you?
Please let me know

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

From: (b) (6)
Sent: Sunday, March 21, 2021 3:08 AM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#); [Wiebold, Amanda \(NIH/NINDS\) \[E\]](#)
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when I lay down. My heels of my feet feel like they are burning as I type this! My energy is better and I think my BP has stabled more, or I am just not taking it as much at this point. If I am texting on my phone my fingers will tingle as if they are falling asleep. I used to get this cold feeling (icicles in my veins) in my forehead but that subsided and that feeling is now just randomly on the front side of my ankles. I don't seem to respond well to the cold.

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Interested on hearing your thoughts!

Thanks

(b) (6)

To: Safavi, Farinaz (NIH/NINDS) [E] (b) (6)
From: (b) (6)
Sent: Thur 7/1/2021 7:38:45 PM (UTC-05:00)
Subject: Re: update

My symptoms with the elevated HR started while I was driving (b) (6). I almost passed out at the wheel. I saw a cardiologist the following day who did (b) (6) however, I continued to be symptomatic and he started me on (b) (6). My major post covid vaccine symptoms started after the second shot which was on (b) (6). My symptoms started 16 hours post 2nd vaccine. (b) (6) I have no cardiac history prior to this.
(b) (6)

Sent from my iPhone

On Jul 1, 2021, at 8:32 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

How long after vaccine your symptoms started?
I will discuss it with them team and see how we can coordinate it.

Farinaz

From: (b) (6)
Sent: Thursday, July 1, 2021 8:30:33 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: update

Yes, I think I would be interested since we do not know the reason song behind my elevated HR. I would just need to know a little bit more information.
(b) (6)

Sent from my iPhone

On Jul 1, 2021, at 8:19 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Autonomic testing includes tilt table test,qsweat and a couple of other noninvasive tests.

Farinaz

From: (b) (6)
Sent: Thursday, July 1, 2021 8:18:21 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: update

Hi,
What type of testing do you have in mind?
Thanks
(b) (6)

Sent from my iPhone

On Jul 1, 2021, at 7:26 PM, Safavi, Farinaz (NIH/NINDS) [E]

<[REDACTED] (b) (6)> wrote:

Hi [REDACTED] (b) (6)

Thank you very much for updating me. Actually we have been seeing some autonomic symptoms in patients post vaccine but the timeline in your case is very different since these symptoms usually starts in the course of a few weeks from vaccination.

If you are interested we can bring you back to NIH and perform formal autonomic testing and discuss other possibilities.

please let me know.

Farinaz

From: [REDACTED] (b) (6)

Sent: Tuesday, June 29, 2021 12:21:24 PM

To: Safavi, Farinaz (NIH/NINDS) [E] <[REDACTED] (b) (6)>

Subject: Re: update

Hi,

I hope you're doing well. In the last 4-5 weeks, I have been getting very dizzy, lightheaded and panicky out of nowhere for no reason. I also almost passed out at the wheel, several weeks ago. I went to see a cardiologist and did [REDACTED] (b) (6)

I still continued to be symptomatic so he started me on [REDACTED] (b) (6) [REDACTED] has actually helped. Not eliminated, but better. Do you think this had anything to do with the covid vaccine? I'd like to know your thoughts on this. I never had any issues with [REDACTED] (b) (6) before.

Thank you.

[REDACTED] (b) (6)

On Mon, May 17, 2021 at 7:44 PM Safavi, Farinaz (NIH/NINDS) [E]

<[REDACTED] (b) (6)> wrote:

Hi [REDACTED] (b) (6)

[REDACTED] (b) (6) My apologies for delay respond. It has been a very busy a few weeks.

Please update me with your symptoms. I am hoping you feel much better by now.

Thanks

Farinaz

From: [REDACTED] (b) (6)

Sent: Friday, April 30, 2021 12:07:01 AM

To: Safavi, Farinaz (NIH/NINDS) [E] <[REDACTED] (b) (6)>

Subject: Re: update

Hi,

Sorry for the delayed response. [REDACTED] (b) (6)

[REDACTED] My right arm is 95% better. My left arm is unchanged. I

still have the pressure in my left upper arm and my left arm still feels very heavy. I have noticed a burning sensation to my right forearm. It feels like a sunburn, but it's not a sunburn. It's not red, no rash, no skin lesion, it just burns occasionally. It burns for a 5 minutes or so and then goes away. Probably occurs 1-2 times a day. Let me know if you have any questions.

Thanks!!

(b) (6)

Sent from my iPhone

On Apr 27, 2021, at 8:26 PM, Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)> wrote:

Hi (b) (6)

How are you doing?

please let me know how are your symptoms.

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: (b) (6)
Sent: Saturday, April 10, 2021 5:09 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: update

Okay, thank you!

(b) (6)

Sent from my iPhone

On Apr 10, 2021, at 4:05 PM, Safavi, Farinaz
(NIH/NINDS) [E] <(b) (6)> wrote:

Dear (b) (6)

Hope all is well.I went through your (b) (6)

I will follow up about (b) (6) and let you know.

Best

Farinaz

To: Safavi, Farinaz (NIH/NINDS) [E] (b) (6)
From: (b) (6)
Sent: Tue 3/23/2021 2:30:31 PM (UTC-05:00)
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Hello Farinaz,

I just wanted to thank you again for taking the time to speak with me and offer some suggestions as to what the source of my symptoms may be. My husband is also very grateful. It's been very reassuring to speak to you and it has put my mind much at ease. I have noticed a new symptom today and am wondering if you might be able to offer some clarity as to what this may mean. Please see the attached photos. I believe I may be exhibiting what is known as Wartenberg's Sign in the fifth finger of my right hand. I am able to adduct the fifth finger towards the fourth, although it does require some effort. The position in the photo is where my fifth finger automatically goes to if my hand is relaxed. I have included a photo of my left hand for comparison. I very much appreciate any information you can provide. Also, I should have some downtime this afternoon to be able to complete and submit the consent forms to Amanda.

Regards,
(b) (6)

(b) (6)

Sent from my iPhone

On Mar 23, 2021, at 07:43, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

hi,give me afew minutes and i will send it again

Farinaz

From: (b) (6)
Sent: Tuesday, March 23, 2021 10:25:23 AM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Good morning Farinaz,
I have not received an invitation to our Teams meetings this morning. I'm not sure if maybe it got misplaced in the mail somewhere?

Thanks,

(b) (6)

Sent from my iPhone

On Mar 22, 2021, at 13:39, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Thank you. Maybe you ask or GP to check for spike and capsid Abs. They can distinguish previous or vaccine related COVID.

Our nurse will contact you as soon as she can for paperwork. Thanks for your fast response.

Farinaz

From: (b) (6)

Sent: Monday, March 22, 2021 4:37 PM

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

Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Hello Farinaz,

I did have some symptoms last March that started two weeks after returning from Mexico that I wasn't tested for. I had an odd burning sensation in my chest and an infrequent dry cough that persisted intermittently for about 2 days. I was afebrile and had no other symptoms. Our daily cab driver in Mexico had taken a day off because of a "bad flu". I have no past history of medical conditions, besides

(b) (6). The only medication I do take is (b) (6). The only autoimmune disease I'm aware of in my family is (b) (6)

(b) (6)

Sent from my iPhone

On Mar 22, 2021, at 12:41, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

I have two questions for you.

Do you think you ever had COVID in the course of last year?

Do you have any family member with autoimmune or inflammatory diseases?

Any Past medical Hx or medication?

Thank you

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: (b) (6)

Sent: Monday, March 22, 2021 12:05 PM

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

REL0000230415

Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Hi Farinaz,

I'm so sorry. I'm having an issue with my wifi this morning and am unable to log into the Teams meeting. I'm attempting to connect using my phone's data plan, but that also isn't working. I'm attempting to resolve this issue and hopefully will be able to quickly.

(b) (6)

Sent from my iPhone

On Mar 18, 2021, at 16:38, Safavi, Farinaz (NIH/NINDS) [E]

<(b) (6)> wrote:

Hi (b) (6)

I am sorry to hear about your illness. I would be happy to speak with you through televisit and discuss your issues. Does Monday 11am or 12noon ET work for you?

Best

Farinaz

Farinaz

<94EBE1012C554021AC219AAFF0FC888F.png>

From: (b) (6)

Sent: Thursday, March 18, 2021 3:48:26 AM

To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>

Subject: Neurological symptoms post Pfizer COVID vaccine

Hello Farinaz,

I was referred to you by (b) (6) who I have been in correspondence with since yesterday.

The following is my story:

I am a (b) (6) from (b) (6). I am a healthy, very active (b) (6)

I received my first dose of the Pfizer COVID vaccine, administered to the left deltoid, (b) (6)

Early (b) (6) morning I woke with numbness to my left shin and right hand. When I woke later that morning, these symptoms remained. Throughout the day I developed paresthesia to all four extremities and the right side of my face, along the trigeminal nerve pathway. Along with this paresthesia, which was intermittently worse in one limb vs another, I developed traveling intermittent sensations of coldness, as if someone was suddenly splashing me with cold water. I also experienced intermittent, traveling prickly electrical sensations. The next day the paresthesia persisted, but with less intensity and seemed to be affecting mainly the right side of my face and right arm and hand. That day, I had intermittent sensations of burning heat, most prominent to the right side of my face. Today, (b) (6) I'm experiencing slight paresthesia to my left shin and a feeling of heaviness/numbness to my right arm and hand with cramping of my right hand, which requires increased

REL0000230415

effort to use as I normally would. The paresthesia to the right side of my face remains, but the sensation seems to be changing to a neuropathy instead. I feel as if I've been punched incredibly hard in my cheek. I also have intermittent sharp pains to the sides of my fingers, my hand, along the radial and ulnar nerves, and to my upper arm. Fortunately, I am still mostly functional and able to carry on with my normal activities without issues, beside the hand cramping. My fear is what this may progress to in the future. Being Canadian, I have incredibly limited access to any specialized care, and will never be able to be assessed by a neurologist. I've had a phone appointment with a GP, another with my own, and was seen by my own GP in person today. My neurological exam was (b) (6) I've been told that if my symptoms become largely focal then I need to be seen urgently to have (b) (6) booked. I've also been advised to closely self monitor my symptoms. The first doctor told me my symptoms were not due to the COVID vaccine, even though I was perfectly healthy before the vaccine with no pre-existing conditions or history of neurological symptoms. My own GP is reluctant to say the vaccine is the cause, but has filed an adverse reaction report, as have I.

Thank you for taking the time to review my story. Please let me know if I can assist your study in any way.

Regards,

(b) (6)

To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
From: (b) (6)
Sent: Thur 7/8/2021 6:12:44 AM (UTC-05:00)
Subject: Re: update

Yes of course. I got the news last night at 93 pm and will call to schedule (b) (6) when they open at 9am. It won't be today that they fit me in.
Sent from my iPhone

On Jul 8, 2021, at 5:58 AM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

I am sorry to hear that. You definitely need to follow up with your cardiologist for further evaluation. Let me discuss it with our team because I have not heard about it before.

Hope you feel better.

Best

Farinaz

Farinaz

From: (b) (6)
Sent: Wednesday, July 7, 2021 11:51:04 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: update

Hi,

My cardiologist called me tonight to tell me that (b) (6)

(b) (6) will call tomorrow am. This makes me extremely nervous and scared. (b) (6)

(b) (6) Please let me know your thoughts. I'm definitely on edge.

Sent from my iPhone

On Jul 1, 2021, at 8:32 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

How long after vaccine your symptoms started?

I will discuss it with them team and see how we can coordinate it.

Farinaz

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Sent from my iPhone

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Thank you.
(b) (6)

On Mon, May 17, 2021 at 7:44 PM Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)> wrote:

Hi (b) (6)
(b) (6) My apologies for delay respond. It has
been a very busy a few weeks.
Please update me with your symptoms. I am hoping you feel much
better by now.
Thanks

Farinaz

From: (b) (6)
Sent: Friday, April 30, 2021 12:07:01 AM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: update

Hi,
Sorry for the delayed response. (b) (6)
(b) (6) My right arm is 95% better. My left
arm is unchanged. I still have the pressure in my left upper arm and my
left arm still feels very heavy. I have noticed a burning sensation to my
right forearm. It feels like a sunburn, but it's not a sunburn. It's not
red, no rash, no skin lesion, it just burns occasionally. It burns for a 5
minutes or so and then goes away. Probably occurs 1-2 times a day.
Let me know if you have any questions.
Thanks!!
(b) (6)

Sent from my iPhone

On Apr 27, 2021, at 8:26 PM, Safavi, Farinaz
(NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

How are you doing?

please let me know how are your symptoms.

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: (b) (6)
Sent: Saturday, April 10, 2021 5:09 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: update

Okay, thank you!

(b) (6)

Sent from my iPhone

On Apr 10, 2021, at 4:05 PM, Safavi, Farinaz
(NIH/NINDS) [E] <(b) (6)>
wrote:

Dear (b) (6)

Hope all is well. I went through your (b) (6)

I will follow up about (b) (6) and let you know.

Best

Farinaz

To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
From: (b) (6)
Sent: Mon 7/12/2021 8:39:18 PM (UTC-05:00)
Subject: Re: update

Thank you!

Sent from my iPhone

On Jul 12, 2021, at 9:34 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

I will ask Dr.Nath but I am not aware of anyone working on this issue here.
Will let you know

Farinaz

From: (b) (6)
Sent: Monday, July 12, 2021 7:37:30 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: update

Can you refer me to someone at the NIH who would be interested in my situation.
Thanks
(b) (6)

Sent from my iPhone

On Jul 12, 2021, at 1:01 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)
I discussed your case in our meeting and actually the team thinks that you have to follow up with your cardiologist since (b) (6) go under cardiology expertise and are not neurologic in nature. I am so glad you have a cardiologist and getting an appropriate work up about this issue.
I hope you feel better soon.
Best
Farinaz

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

From: (b) (6)
Sent: Thursday, July 8, 2021 10:52 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: update

I have (b) (6) appt July 14 and (b) (6) July 20.

Sent from my iPhone

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Let me discuss it with our team because I have not heard about it before.

Hope you feel better.

Best

Farinaz

Farinaz

3CD55E0C994442D9A9B7491F2565EE4D.png

From: (b) (6)

Sent: Wednesday, July 7, 2021 11:51:04 PM

To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>

Subject: Re: update

Hi,

My cardiologist called me tonight to tell me that (b) (6)

(b) (6) I will call tomorrow am. This makes me extremely nervous and scared. (b) (6) Please let me know your thoughts. I'm definitely on edge.

(b) (6)

Sent from my iPhone

On Jul 1, 2021, at 8:32 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

How long after vaccine your symptoms started?

I will discuss it with them team and see how we can coordinate it.

Farinaz

<46FBF03B3E5C49E780AFB24ABB826FF0.png>

From: (b) (6)

Sent: Thursday, July 1, 2021 8:30:33 PM

To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>

Subject: Re: update

Yes, I think I would be interested since we do not know the reason song behind my elevated HR. I would just need to know a little bit more information.

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Sent from my iPhone

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Autonomic testing includes tilt table test,qsweat and a couple of other noninvasive tests.

Farinaz

<F898216A7F634243A80DC195C8CB5C11.png>

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Sent: Thursday, July 1, 2021 8:18:21 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: update

Hi,
What type of testing do you have in mind?
Thanks
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Sent from my iPhone

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Hi (b) (6)
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Farinaz

<672C26873C5445689FA43CFC2E6C22E8.png>

From: (b) (6)
Sent: Tuesday, June 29, 2021 12:21:24 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)>
Subject: Re: update

Hi,
I hope you're doing well. In the last 4-5 weeks, I

REL0000230435

have been getting very dizzy, lightheaded and panicky out of nowhere for no reason. I also almost passed out at the wheel, several weeks ago. I went to see a cardiologist and (b) (6) I still continued to be symptomatic so he started me on (b) (6) has actually helped. Not eliminated, but better. Do you think this had anything to do with the covid vaccine? I'd like to know your thoughts on this. I never had any issues with (b) (6) before. Thank you. (b) (6)

On Mon, May 17, 2021 at 7:44 PM Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)
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My apologies for delay respond. It has been a very busy few weeks. Please update me with your symptoms. I am hoping you feel much better by now. Thanks

Farinaz

<A7560659551D4CD29BD95276F07595DF.png>

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Hi,
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delayed
response. (b) (6)

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My right
arm is 95%
better. My left
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Let me know if
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Farinaz Safavi MD, PhD

Division of Neuroimmunology
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NINDS, NIH, Bethesda, MD

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Hope all is well. I
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I will follow up
about (b) (6) and
let you know.

Best

Farinaz

To: Safavi, Farinaz (NIH/NINDS) [E] (b) (6)
From: (b) (6)
Sent: Mon 7/12/2021 6:34:16 PM (UTC-05:00)
Subject: Re: update

Yup. I'm following up with (b) (6) this Wednesday and (b) (6) on July 20th

Sent from my iPhone

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NINDS, NIH, Bethesda, MD

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To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>

Subject: Re: update

Hi,

What type of testing do you have in mind?

Thanks

(b) (6)

Sent from my iPhone

REL0000230440

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Thank you.

(b) (6)

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Thanks

Farinaz

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12:07:01 AM

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

< (b) (6) >

Subject: Re: update

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My left arm is unchanged. I
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sunburn, but it's not a
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no skin lesion, it just burns
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minutes or so and then goes
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times a day.

Let me know if you have any
questions.

Thanks!!

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Sent from my iPhone

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Farinaz Safavi MD, PhD

Division of Neuroimmunology and
Neurovirology

NINDS, NIH, Bethesda, MD

From: (b) (6)
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Okay, thank you!

(b) (6)

Sent from my iPhone

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<(b) (6)> wrote:

Dear (b) (6)

Hope all is well. I went through
(b) (6)

I will follow up about (b) (6)
and let you know.

Best

Farinaz

To: Safavi, Farinaz (NIH/NINDS) [E] (b) (6)
From: (b) (6)
Sent: Fri 8/13/2021 7:08:24 PM (UTC-05:00)
Subject: WHO Scale
[WHO scale post-COVID.docx](#)
[WHO scale post-COVID.docx](#)

Hi Farinaz,
I am attaching The Who Scale

Begin forwarded message:

From: "Safavi, Farinaz (NIH/NINDS) [E]" <(b) (6)>
Subject: RE: Testing
Date: August 4, 2021 at 7:44:41 AM PDT
To: (b) (6)

Thanks (b) (6)

If you can get those records and email it to us that might be faster approach.
For WHO scale, you just need to fill out the form I sent you. That gives us an idea your baseline scale.
Thank you

Farinaz

From: (b) (6)
Sent: Wednesday, August 4, 2021 10:42 AM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Good morning! I hand delivered the signed release to my neurologist office last week. I will call this morning to request a quick send-off to you.

Still waiting for insurance approval of (b) (6) IN the meantime, I had (b) (6)
(b) (6) I imagine it couldn't hurt.

I hope you are well in the midst of so much going on around us.

(b) (6)

Sent from my iPhone

On Aug 4, 2021, at 7:31 AM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)
Hope all is ok!
I have not received result of your (b) (6) and WHO scaling yet.
Can you please update me?
Thank you

From: (b) (6)
Sent: Wednesday, July 28, 2021 12:18 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Absolutely, I'll fill out paperwork. I requested my medical records be sent to you. Thank you for your willingness to confirm my treatment protocol. I know you work crazy long hours and I'm not sure how often you get a pat on the back for a job well-done, but I appreciate you and the hours you spend researching for answers to COVID vaccine injury.

Warmly,
(b) (6)

Sent from my iPhone

On Jul 28, 2021, at 8:58 AM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)
(b) (6) emailed me and I completely agree with him regarding (b) (6). You are in good hands.
Can you please fill out attached file weekly before and after treatment to give us some idea how you are doing?
Thank you
Farinaz

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

From: (b) (6)
Sent: Monday, July 26, 2021 8:04 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

What is your Fax number (required) for records? Although, I'm going to ask they be sent electronically.

Sent from my iPhone

On Jul 26, 2021, at 4:53 PM, (b) (6) wrote:

I just wrote him and gave him your email address.

Thank you for trying to help me.

(b) (6)

Sent from my iPhone

On Jul 26, 2021, at 4:50 PM, Safavi, Farinaz (NIH/NINDS) [E]

< (b) (6) > wrote:

I am not sure I left my cell phone number though. It would be great you give him my email address.

Thank you

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: (b) (6)

Sent: Monday, July 26, 2021 7:42 PM

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

Subject: Re: Testing

Absolutely, I will ask for the tests results to be emailed to you.

It is strange to me that (b) (6) has not returned your call as he was highly interested in gaining your opinion on (b) (6)

(b) (6) I will email him and provide him with your email.

Thank you,

(b) (6)

On Jul 26, 2021, at 4:34 PM, Safavi, Farinaz

(NIH/NINDS) [E] < (b) (6) > wrote:

Hi

I have not spoke or got email from him yet.

Can you do me a favor and send me (b) (6)

(b) (6)
We need to save it in our file.

Thank you

Farinaz

From: (b) (6)

Sent: Friday, July 23, 2021 2:31 PM

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

Subject: Re: Testing

Hello!! So, (b) (6) did not return your call?
Thank you for advocating for me and helping
educate my community doctor.

Warmly,

(b) (6)

Sent from my iPhone

On Jul 23, 2021, at 6:45 AM, Safavi,
Farinaz (NIH/NINDS) [E]

<(b) (6)> wrote:

Thank you for the update. I will be
happy to discuss with him. Let see
how things go with your insurance
process.
Farinaz

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

From: (b) (6)

Sent: Tuesday, July 20, 2021 2:52 PM

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

Subject: Re: Testing

Hello.

I saw (b) (6) this morning and
clarified my worsening symptoms. He
has agree (b) (6)

(b) (6) I told him you had called
and left a message and that you were
willing to discuss treatment to help
me. He would like to talk with you
and welcomes your input and
recommendations on dosage etc. I
feel hopeful for the first time in (b) (6)
(b) (6) I hope you and (b) (6) are
able to connect. I also hope my
insurance approves.

(b) (6)

Sent from my iPhone

On Jul 19, 2021, at 5:11 PM, (b) (6)

wrote:

(b) (6)

Thank you for trying to reach him! I will send him your email contact through the patient portal and when I see him tomorrow morning I will tell him you tried to contact him this afternoon.

Thank you!

(b) (6)

Sent from my iPhone

On Jul 19,
2021, at
2:33 PM,
Safavi,
Farinaz
(NIH/NIND
S) [E]

(b) (6)

wrote:

Thank
you.
I tried to
call him

REL0000230491

but his
MA did
not
respond
the
phone. Please
let
him know
and I will
definitely
speak
with him.
Just
remind
me about
one thing,

(b) (6)

[REDACTED]

Thank you

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

From: (b) (6)

[REDACTED]

Sent: Monday,
July 19, 2021
5:26 PM

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

Subject: Re: Testing

Farinaz,
I am

seeing my
neurologis
t again
tomorrow
morning
to update
him on my
symptoms
. His name
is (b) (6)
(b) (6) and
his
number is
(b) (6)
(b) (6) I
will share
your email
with him
and you
have a
signed ROI
with my
permissio
n to
discuss my
case.

THANK
YOU!!
(b) (6)

Sent from
my iPhone

On Jul 19, 2021, at 9:09 AM, Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)> wrote:

(b) (6)
I would like to speak with your neurologist to see how we can
help you. Can you send me his contact and share with him my
email.
Thank you!
Best

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

From: (b) (6)
Sent: Monday, July 19, 2021 3:49 AM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Thank you for responding. I feel like I'm running out of time and options at this (b) (6) mark post-vaccine. I think my neurologist would be willing to explore (b) (6) with a bit of encouragement. I am certain he would speak to you.

I know early treatment is essential. In your (off the record) opinion... do you think I'm too far out from my initial reaction or do you think I may benefit from (b) (6)? I trust your opinion and your judgement.

(b) (6)

Sent from my iPhone

On Jul 18, 2021, at 7:56 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6),
Thanks for the update. Research work takes time and I don't have any result from your samples yet.
What's your neurologist opinion about (b) (6)? I can speak with him if you think that may help.
Please let me know.
Farinaz

Farinaz

<425E7D44381946D6827F2FA0F2E232CA.png>

From: (b) (6)
Sent: Friday, July 16, 2021 8:22:25 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)>
Subject: Re: Testing

Hello Farinaz,

To date, here is a list of my worsening symptoms: increased nerve pain in scalp, left thigh, left forearm, left hand. Internal tremor occurs more days than not. I feel this shakiness in my limbs, hands, and head. Increased muscle weakness and I

fatigue easily. I am no longer able to walk more than a 1/2 mile which is a significant decline from the 3-5 miles I was able to walk shortly up to about (b) (6) post vaccine. Muscle twitching in both calves 24/7. L/R foot neuropathy. Left hand neuropathy and burning right hand fingertips. I continue to be severely constipated and am unable to have a bowel movement with the use of glycerin suppositories. This has remained the same since (b) (6). Continued and constant facial paresthesia and burning lips. I am unable to withstand normal life stressors without my hands shaking and experiencing worsening brain fog. Intermittent bladder pain. Continued heat/cold intolerance. I am not able to ride my mountain bike or fly fish. I am not able to babysit my grandchildren alone due to lack of stamina. My daily life has been severely impacted by my physical limitations.

(b) (6)

In your opinion, would I benefit from (b) (6)? My symptoms seem to be worsening. I am really scared by the downward turn. Was there any indication of abnormalities in the blood I sent to NIH months ago?

My best to you,
(b) (6)

On Jun 14, 2021, at 8:14 PM, Safavi, Farinaz
(NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)
Thank you very much for the update. I am out of office currently and will be back next week. Can you please send me the result of (b) (6)

Please update me with your symptoms? If your symptoms are still severe I can speak with (b) (6) and share our understanding about this process.
Best

Farinaz

<6355AF710D834536860FCA4D001DACAC.png>

From: (b) (6)

Sent: Tuesday, June 15, 2021 2:49:23 AM

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

< (b) (6) >

Subject: Re: Testing

Hello Farinaz,

I haven't wanted to bother you, but I wanted to follow-up on my blood work results to learn if there was an indication of abnormality or an area that needs further follow-up. In an earlier email, You also mentioned other tests you were suggesting. (b) (6)

I hope you are doing well.

Warmly,
(b) (6)

Sent from my iPhone

On Apr 29, 2021, at 8:19 PM, Safavi, Farinaz (NIH/NINDS) [E] < (b) (6) > wrote:

Hi (b) (6)

Thank you very much for update. I completely agree with your neurologist and I believe you are in good hands. Unfortunately I can not bring non local patients easily due to COVID restriction but I can speak with (b) (6) and share our understanding about your symptoms with him. (b) (6)

(b) (6) I also can send you list of tests that I am sending for patients and your physician can check them.

If (b) (6) helps your symptoms I think you certainly should continue it. Please let me know if I can be any help. Best

Farinaz

<086E01E723E44FE794462A76AEC331F6.png

>

From: (b) (6)

Sent: Thursday, April 29, 2021 11:09:56 PM

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

<(b) (6)>

Subject: Testing

Hello Farinaz,

I saw my neurologist today (b) (6) and he reviewed past and current symptoms, in addition to all blood work and test results and scans. (b) (6)

(b) (6)

(b) (6) told me his concerns related to my symptoms are (b) (6)

(b) (6)

Is this the testing protocol you recommend? Also, I received my blood box today and will have a draw on Monday and ship back to you overnight. I started (b) (6). I've noticed a reduction of symptoms, but it doesn't last so I may need to (b) (6). Is there a benefit to having these tests performed at NIH? I'm open to your input.

Thank you,

(b) (6)

Sent from my iPhone

<WHO scale post-COVID.docx>

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

Score:

0 No Difficulty

1 Mild Difficulty

2 Moderate Difficulty

3 Severe Difficulty

4 Extreme Difficulty or Cannot do

To: Safavi, Farinaz (NIH/NINDS) [E] (b) (6)
From: (b) (6)
Sent: Sun 8/15/2021 3:04:38 PM (UTC-05:00)
Subject: Re: WHO Scale

Yes, I will fill it out weekly.
Hope you are doing well,
(b) (6)

Sent from my iPhone

On Aug 15, 2021, at 10:22 AM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

We received your medical records. Thank you for WHO scale. You just need to fill it out weekly. It would be great if you keep filling them out specially when you (b) (6) giving us the assess your improvement.
Best

Farinaz

From: (b) (6)
Sent: Friday, August 13, 2021 8:08 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: WHO Scale

Hi Farinaz,

I am attaching The Who Scale

Begin forwarded message:

From: "Safavi, Farinaz (NIH/NINDS) [E]" <(b) (6)>
Subject: RE: Testing
Date: August 4, 2021 at 7:44:41 AM PDT
To: (b) (6)

Thanks (b) (6)

If you can get those records and email it to us that might be faster approach.
For WHO scale, you just need to fill out the form I sent you. That gives us an idea your baseline scale.
Thank you

Farinaz

From: (b) (6)
Sent: Wednesday, August 4, 2021 10:42 AM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)

Subject: Re: Testing

Good morning! I hand delivered the signed release to my neurologist office last week. I will call this morning to request a quick send-off to you.

Still waiting for insurance approval of (b) (6) IN the meantime , I had (b) (6)
(b) (6) I imagine it couldn't hurt.

I hope you are well in the midst of so much going on around us.

(b) (6)

Sent from my iPhone

On Aug 4, 2021, at 7:31 AM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
wrote:

Hi (b) (6)

Hope all is ok!

I have not received result of (b) (6) and WHO scaling yet.

Can you please update me?

Thank you

Farinaz

From: (b) (6)

Sent: Wednesday, July 28, 2021 12:18 PM

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

Subject: Re: Testing

Absolutely, I'll fill out paperwork. I requested my medical records be sent to you. Thank you for your willingness to confirm my treatment protocol. I know you work crazy long hours and I'm not sure how often you get a pat on the back for a job well-done, but I appreciate you and the hours you spend researching for answers to COVID vaccine injury.

Warmly,

(b) (6)

Sent from my iPhone

On Jul 28, 2021, at 8:58 AM, Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)> wrote:

Hi (b) (6)

(b) (6) emailed me and I completely agree with him regarding (b) (6)
.You are in good hands.

REL0000230492

Can you please fill out attached file weekly before and after treatment to give us some idea how you are doing?

Thank you

Farinaz

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: (b) (6)
Sent: Monday, July 26, 2021 8:04 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

What is your Fax number (required) for records? Although, I'm going to ask they be sent electronically.

Sent from my iPhone

On Jul 26, 2021, at 4:53 PM, (b) (6)
(b) (6) wrote:

I just wrote him and gave him your email address.
Thank you for trying to help me.

(b) (6)

Sent from my iPhone

On Jul 26, 2021, at 4:50 PM, Safavi, Farinaz
(NIH/NINDS) [E] <(b) (6)> wrote:

I am not sure I left my cell phone number
though. It would be great you give him my email
address.
Thank you

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

From: (b) (6)
Sent: Monday, July 26, 2021 7:42 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Absolutely, I will ask for the tests results to be emailed to you. It is strange to me that (b) (6) has not returned your call as he was highly interested in gaining your opinion on (b) (6). I will email him and provide him with your email.

Thank you,
(b) (6)

On Jul 26, 2021, at 4:34 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi
I have not spoke or got email from him yet.
Can you do me a favor and send me your (b) (6).
We need to save it in our file.
Thank you

Farinaz

From: (b) (6)
Sent: Friday, July 23, 2021 2:31 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Hello!! So, (b) (6) did not return your call?
Thank you for advocating for me and helping educate my community doctor.

Warmly,

(b) (6)

Sent from my iPhone

On Jul 23, 2021, at 6:45 AM, Safavi, Farinaz (NIH/NINDS) [E]

< [REDACTED] (b) (6)
> wrote:

Thank you for the
update. I will be happy
to discuss with him. Let
see how things go with
your insurance process.
Farinaz

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

From: [REDACTED] (b) (6)
Sent: Tuesday, July 20,
2021 2:52 PM
To: [Safavi, Farinaz](#)
[\(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Hello.
I saw [REDACTED] (b) (6) this
morning and clarified
my worsening
symptoms. He has
agreed [REDACTED] (b) (6)
[REDACTED]
I told him you had
called and left a
message and that you
were willing to discuss
treatment to help me.
He would like to talk
with you and welcomes
your input and
recommendations on
dosage etc. I feel
hopeful for the first
time in [REDACTED] (b) (6). I
hope you and [REDACTED] (b) (6)
are able to connect. I
also hope my insurance
approves.

[REDACTED] (b) (6)

Sent from my iPhone

On Jul 19,
2021, at
5:11 PM,
(b) (6)

wrote:

(b) (6)

Thank you
for trying
to reach
him! I will
send him
your email
contact
through
the
patient
portal and
when I see
him
tomorrow
morning I
will tell
him you
tried to
contact
him this
afternoon.

Thank
you!

(b) (6)

Sent from
my iPhone

On Jul 19, 2021, at 2:33 PM, Safavi, Farinaz (NIH/NINDS) [E]

<(b) (6)> wrote:

Thank you.

I tried to call him but his MA did not respond the phone. Please let him know and I will definitely speak with him.

Just remind me about one thing, (b) (6)

(b) (6)

Thank you

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: (b) (6)

Sent: Monday, July 19, 2021 5:26 PM

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

Subject: Re: Testing

Farinaz,

I am seeing my neurologist again tomorrow morning to update him on my symptoms. His name is (b) (6) and his number is (b) (6). I will share your email with him and you have a signed ROI with my permission to discuss my case.

THANK YOU!!

(b) (6)

Sent from my iPhone

On Jul 19, 2021, at 9:09 AM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

(b) (6)

I would like to speak with your neurologist to see how we can help you. Can you send me his contact and share with him my email.

Thank you!

Best

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: (b) (6)

Sent: Monday, July 19, 2021 3:49 AM

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

Subject: Re: Testing

Thank you for responding. I feel like I'm running out of time and options at this (b) (6) mark post-vaccine. I think my neurologist would be willing to explore (b) (6) with a bit of encouragement. I am certain he would speak to you.

I know early treatment is essential. In your (off the record) opinion... do you think I'm too far out from my initial reaction or do you think I may benefit from (b) (6)? I trust your opinion and your judgement.

(b) (6)

Sent from my iPhone

On Jul 18, 2021, at 7:56 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

Thanks for the update. Research work takes time and I don't have any result from your samples yet.

What's your neurologist opinion about (b) (6)? I can speak with him if you think that may help. please let me know.

Farinaz

Farinaz

<425E7D44381946D6827F2FA0F2E232CA.png>

From: (b) (6)

Sent: Friday, July 16, 2021 8:22:25 PM

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

<(b) (6)>

Subject: Re: Testing

Hello Farinaz,

To date, here is a list of my worsening symptoms: increased nerve pain in scalp, left thigh, left forearm, left hand. Internal tremor occurs more days than not. I feel this shakiness in my limbs, hands, and head. Increased muscle weakness and I fatigue easily. I am no longer able to walk more than a 1/2 mile

which is a significant decline from the 3-5 miles I was able to walk shortly up to about (b) (6) post vaccine. Muscle twitching in both calves 24/7. L/R foot neuropathy. Left hand neuropathy and burning right hand fingertips. I continue to be severely constipated and am unable to have a bowel movement with the use of glycerin suppositories. This has remained the same since (b) (6). Continued and constant facial paresthesia and burning lips. I am unable to withstand normal life stressors without my hands shaking and experiencing worsening brain fog. Intermittent bladder pain. Continued heat/cold intolerance. I am not able to ride my mountain bike or fly fish. I am not able to babysit my grandchildren alone due to lack of stamina. My daily life has been severely impacted by my physical limitations.

(b) (6)

In your opinion, would I benefit from (b) (6)? My symptoms seem to be worsening. I am really scared by the downward turn. Was there any indication of abnormalities in the blood I sent to NIH months ago?

My best to you,

(b) (6)

On Jun 14, 2021, at 8:14 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

Thank you very much for the update. I am out of office currently and will be back next week.

Can you please send me the result of (b) (6)?

Please update me with your symptoms? If your symptoms are still severe I can dprak with (b) (6) and share our understanding about this process.

Best

Farinaz

<6355AF710D834536860FCA4D001DACAC.p

ng>

From: (b) (6)

Sent: Tuesday, June 15, 2021 2:49:23 AM

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

<(b) (6)>

Subject: Re: Testing

Hello Farinaz,

I haven't wanted to bother you, but I wanted to follow-up on my blood work results to learn if there was an indication of abnormality or an area that needs further follow-up. In an earlier email, You also mentioned other tests you were suggesting.

(b) (6)

I hope you are doing well.

Warmly,

(b) (6)

Sent from my iPhone

On Apr 29, 2021, at 8:19 PM, Safavi, Farinaz (NIH/NINDS) [E]

<(b) (6)> wrote:

Hi (b) (6)

Thank you very much for update. I completely agree with your neurologist and I believe you are in good hands. Unfortunately I can not bring non local patients easily due to COVID restriction but I can speak with (b) (6) and share our understanding about your symptoms with him. (b) (6)

(b) (6) I also can send you list of tests that I am sending for patients and your physician can check them.

If (b) (6) helps your symptoms I think you certainly should continue

it.
Please let me know if I can be any
help.
Best

Farinaz

<086E01E723E44FE794462A76AEC331

F6.png>

From: (b) (6)

Sent: Thursday, April 29, 2021

11:09:56 PM

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

<(b) (6)>

Subject: Testing

Hello Farinaz,

I saw my neurologist today (b) (6)
(b) (6) and he reviewed past and
current symptoms, in addition to all
blood work and test results and scans.

(b) (6)

(b) (6) told me his concerns related
to my symptoms are (b) (6)

(b) (6)

Is
this the testing protocol you
recommend? Also, I received my
blood box today and will have a draw
on Monday and ship back to you
overnight. I started (b) (6)

(b) (6) I've noticed a
reduction of symptoms, but it doesn't
last so I may need to (b) (6)

(b) (6) Is there a benefit to having these
tests performed at NIH? I'm open to
your input.

Thank you,
(b) (6)

Sent from my iPhone

To: Safavi, Farinaz (NIH/NINDS) [E] (b) (6)
From: (b) (6)
Sent: Mon 6/14/2021 11:57:56 PM (UTC-05:00)
Subject: Re: Testing

Absolutely, I will update you with results and current symptoms when test results vine back.
Thank you so much!
(b) (6)

Sent from my iPhone

On Jun 14, 2021, at 8:14 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

Thank you very much for the update. I am out of office currently and will be back next week.

Can you please send me the result of (b) (6)?

Please update me with your symptoms? If your symptoms aee still severe I can dprak with (b) (6) and share our understanding about this process.

Best

Farinaz

From: (b) (6)
Sent: Tuesday, June 15, 2021 2:49:23 AM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Testing

Hello Farinaz,

I haven't wanted to bother you, but I wanted to follow-up on my blood work results to learn if there was an indication of abnormality or an area that needs further follow-up. In an earlier email, You also mentioned other tests you were suggesting. (b) (6)

I hope you are doing well.

Warmly,

(b) (6)

Sent from my iPhone

On Apr 29, 2021, at 8:19 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

Thank you very much for update. I completely agree with your neurologist and I believe you are in good hands. Unfortunately I can not bring non local patients easily due to COVID restriction but I can speak with (b) (6) and share our ubderstanding about your symptoms with him. (b) (6)

(b) (6) I also can send you list of tests that I am sending for patients and your physician can check them.

If (b) (6) helps your symptoms I think you certainly should continue it.

Please let me know if I can be any help.

Best

From: (b) (6)
Sent: Thursday, April 29, 2021 11:09:56 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Testing

Hello Farinaz,

I saw my neurologist today (b) (6) and he reviewed past and current symptoms, in addition to all blood work and test results and scans. (b) (6)

(b) (6) told me his concerns related to my symptoms are (b) (6)
Is this the testing protocol you recommend? Also, I received my blood box today and will have a draw on Monday and ship back to you overnight. I started (b) (6) I've noticed a reduction of symptoms, but it doesn't last so I may need to (b) (6) Is there a benefit to having these tests performed at NIH? I'm open to your input.

Thank you,
(b) (6)

Sent from my iPhone

To: (b) (6)
From: Safavi, Farinaz (NIH/NINDS) [E]/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246- (b) (6)
Sent: Mon 4/5/2021 5:54:41 PM (UTC-05:00)
Subject: Re: Referral from (b) (6) neurological vaccine reaction

Sorry it is a medical word. It means your symptoms are not somatoform disorder. They have organic causes and now getting better.

Farinaz

From: (b) (6)
Sent: Monday, April 5, 2021 6:53:04 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Referral from (b) (6) neurological vaccine reaction

Amanda is out of town this week and she said she will send it out next week when she gets back. You don't think my symptoms are functional? What do you mean by that? I am learning to stay busy and it helps keep my mind off of things. Even tried sound healing yoga to chill out my nervous system!! Heck I will do anything at this point! Thanks for reaching out. Shows how compassionate you are.

Thanks

(b) (6)

Sent from my iPhone

On Apr 5, 2021, at 3:28 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

I am so glad your symptoms have improved. It is a great news. I think however it may take time to recover completely, decrease in frequency of symptoms is a good sign.
I really do not think your symptoms are functional.
I forgot to ask you, have you received sample collection kit from us?

Farinaz

From: (b) (6)
Sent: Monday, April 5, 2021 5:08:43 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Referral from (b) (6) neurological vaccine reaction

My symptoms have improved since Friday! I am not having the tingling in my feet like I was. My flushing has improved. It feels like it's right underneath the skin but doesn't come to fruition! I am taking a (b) (6)
I am having tingling in my right palm as I type this, but not like before. My fingers did fall asleep last night again, usually the ring and pinky finger.
I don't want to jinx my improvements because it's devastating when they come back. I wonder if it could be hormone related?!

(b) (6)

I have another neurologist appointment tomorrow morning. My first neuro guy didn't know what it was and that (b) (6). Grrrrrr!

It's just weird how these symptoms seem to improve and then they reappear! Hopefully they will continue to improve!!!

Thanks

(b) (6)

Sent from my iPhone

On Apr 5, 2021, at 6:37 AM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

How are you doing? Can you update me with your current symptoms?

I also wanted to know have you had (b) (6)

Best

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

From: (b) (6)

Sent: Tuesday, March 30, 2021 7:39 PM

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

Subject: Re: Referral from (b) (6) neurological vaccine reaction

I tried reaching Amanda and it came back as an undeliverable address. Can you have her contact me?

Thanks

Sent from my iPhone

On Mar 30, 2021, at 1:09 PM, (b) (6) wrote:

I was waiting to hear from you guys. I just sent her an email and would love to get you a sample. My symptoms remain the same. Still feel like an overall burning sensation and my feet and fingertips still bug me. It seems so vascular.

Lots of praying on my side for some answers.

Thanks

(b) (6)

Sent from my iPhone

<[REDACTED] (b) (6)> wrote:

Hi [REDACTED] (b) (6)

How is everything? Hope your symptoms have improved.

Our research nurse did not receive any call from you for consent. Can you please contact her and schedule the consent which helps us to complete our paperwork. (her email address is [REDACTED] (b) (6))

I also think at this moment bringing you to NIH is not easily possible but if you give us the consent we can send you a kit and information to send us your serum sample.

Please let me know if you have any questions/concerns

Thank you

Farinaz

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: [REDACTED] (b) (6)

Sent: Tuesday, March 23, 2021 11:28 PM

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

Subject: Re: Potential SPAM:Re: Referral from [REDACTED] (b) (6) neurological vaccine reaction

I started [REDACTED] (b) (6)

My [REDACTED] (b) (6)

My [REDACTED] (b) (6)

[REDACTED] (b) (6)

I was exposed to people with covid. I was tested 4 or 5 times when I was and I always came back negative.

[REDACTED] (b) (6)

Do you have an email address or somewhere where I can send my records?!

Thanks again for talking to me today. I am hoping and praying that I will recover and get back to my old ways!!

[REDACTED] (b) (6)

Just so there isn't any confusion down the road!

Thanks again

[REDACTED] (b) (6)

On Mar 23, 2021, at 6:05 PM, Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)> wrote:

(b) (6)

I have a few questions for you.

Can you tell me the exact dates you (b) (6)

two more questions

have you had or guess you may have COVID in last year?

do you have any family members with autoimmune diseases?

Thank you

Farinaz

<C76A02588DDD431EAF8BF19485CEA4EE.png>

From: (b) (6)

Sent: Tuesday, March 23, 2021 1:52:06 PM

To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>

Subject: Re: Potential SPAM:Re: Referral from (b) (6)
neurological vaccine reaction

Hello

I want to apologize about the confusion with the time zones. I had it at 1pm pacific standard time. I got on the meeting at 10:20 but it was too late. I have the day off from work and my kids arranged to do this meeting. Can we still do it? I am available anytime today and would love to talk to you. My phone number is (b) (6) and I will be refreshing my emails also.

Thanks

(b) (6)

Sent from my iPhone

On Mar 23, 2021, at 10:26 AM, (b) (6)
<(b) (6)> wrote:

I am trying now, please can we still do it? You said 1 and I thought that meant 1 my time

Sent from my iPhone

On Mar 23, 2021, at 10:12 AM,
Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)> wrote:

Hello (b) (6)
I and my NP joined to meet with you
through MS teams at 1pm and
unfortunately you did not join. Did
the link work for you? If not we can
reschedule.
Thanks

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

From: (b) (6)
Sent: Sunday, March 21, 2021 10:02
PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Potential SPAM:Re: Referral
from (b) (6) neurological
vaccine reaction

Yes ma'am. Let me know how we
proceed!!! Thank you!!!

Sent from my iPhone

On Mar 21, 2021, at
6:32 PM, Safavi, Farinaz
(NIH/NINDS) [E]
<(b) (6)>
> wrote:

Hi (b) (6)
I am sorry to hear
about your illness. We
definitely can discuss
your issues through
televisit. I have
availability on Tuesday.
Does 1pm work for
you?
Please let me know

Farinaz Safavi MD, PhD
Division of

Neuroimmunology and
Neurovirology
NINDS, NIH, Bethesda,
MD

From: (b) (6)
Sent: Sunday, March
21, 2021 3:08 AM
To: [Safavi, Farinaz](#)
[\(NIH/NINDS\) \[E\]](#);
[Wiebold, Amanda](#)
[\(NIH/NINDS\) \[E\]](#)
Subject: Referral from
(b) (6)
neurological vaccine
reaction

Hello! I
was told
to reach
out to you
and see if
you could
help me.

My story
is below. I
currently
live in

(b) (6)

My phone
number
is (b) (6)

Thanks
for your
time!

My story:

I am a (b) (6)

(b) (6)

I am
a (b) (6)

(b) (6)
[REDACTED]
I
was
healthy
and fit
before
getting
vaccinated
. In 2020 I
did

(b) (6)
[REDACTED]

On (b) (6)
[REDACTED] I got
my first
first and
only
Moderna
shot in my
left
arm..No
symptoms
besides a
sore arm
for 2-3
days. On
the 8th
day I
noticed
some
lymphade
nopathy
while I
was at
work.
And then
my neck
started to
feel hot.
After that
anytime I
would eat
my entire
body felt a
hot/burni
ng

sensation
and
accompan
ied by a
rash that
would
migrate.

This came
and went
for about
a week.

And then
on the
14th day, I
noticed
my feet
felt tingly.

I had just
taken my
kids to

(b) (6)
to play in
the snow
that
morning
and
thought it
had

something
to do with
that. On
the 15th
day, (b) (6)

(b) (6) the
tingling
had
gotten
worse. It
was now
in both
feet and
ankles. It
felt like
icicles in
my veins.

I went to
my
primary
and she
insisted it
couldn't
be from
the
vaccine
and
prescribe
me

(b) (6)

(b) (6) for the
full body
flushing.

And gave
me a
referral to
an
allergist to
give me a
peace of
mind that
I could do
the 2nd
dose of
vaccine.

About an
hour later
it was
worse so I
went back
the Dr but
she said
just to
sent her
pics via
email. I
told her
my knees
looked
purple
and the
tingling
was
getting
worse and
traveling
to my
knees. She
said if I
was that
concerned
to go to
the ER. I
finished
my day at
the office
and tried
to go
workout
but it was
persistent.
I decided
to go to

(b) (6)

They
ran (b) (6)
(b) (6)

(b) (6)

The Dr.
said he
thought (

b

)

(

6

)

They gave
me

(b) (6)

That
seemed to
help with
the full
body
flushing.

The
tingling in
my feet
persisted
and also
began in
my hands.

I went
and saw
the
allergist
and he
had no
idea. He
gave me a
prescripti
on for

(b) (6)

(b) (6)

He
ordered a
(b) (6)

(b) (6)

He
then
referred
me to (b) (6)

(b) (6)
for a

2nd
opinion
and also a
neuro
referral. I
saw (b) (6)
he
said not to
get the
2nd shot
same
thing the
first
allergist
said. He
order
(b) (6)

(b) (6)

(b) (6)

The
following
Monday

(b) (6)

I
went back
to the ER
my blood
pressure I
took after
work was

(b) (6)

and then

(b) (6)

I got to
the ER
and it had

(b) (6)

They did

(b) (6)

They ran
some
more labs.

My

(b) (6)

The ER

doctor
had no
idea, but
said I
should see
a
neurologis
t. He
knew I
was
scared
and he

said I
could help
jump start
the
process
and he
ordered

(b) (6)

I got in
with the
nurse
practioner
at the
primary.
She
ordered

(b) (6)

I
remained

tingly and
my
muscles
aches,
random
twitching
and
electrical
impulses
in my
right quad
and my
upper
right
should/ba
ck area
was
randomly
numb/ting
ly. I was
exhausted
and I lost
13

pounds [in](#)
[2 weeks](#),
hard to do
when you
are
relatively
healthy.

My BP
started to
go down
and stay
around (b)
(6)

ow
the low
blood
pressure
was a new
thing. I
became
very
vascular
and
complaine
d of my
veins
hurting. I
went to
neuro. He
ordered

(b) (6)
E

(b) (6)

Finally I
made a
follow up
appointm
ent with
him to
discuss

(b)
(6)

(b) (6)

Grrr. I have not lost my strength in all of this nor my balance. I did lose a little strength in the beginning because of the rapid weight loss but I have since regained that back. I am still down 8 or

9 lbs but
maintainin
g that very
well with
a good
diet,
staying as
low
histamine
as I can,
most of
the time.

I went
back to
see my
nurse
practioner
on Friday

(b) (6)

because
my veins
in my
wrists
were
hurting,
almost
like they
were
going to
explode.

The
moment I
would
raise my
hand the
blood
wood
rapidly
disappear
and my
veins
would sink
in. I have
videos of
it
happening
. She
denied me
a vascular
referral
and
prescribe
me

(b) (6)

I filled
the
prescripti
on and

never
took any.
I did see
a
rheumatol
ogist and
she
ordered a
gamet of
testing.
She took
me
serious
because
she she
also had
numbness
in her arm
for an
hour or
two after
her shot.

(b) (6)



(b)
(6)

She
said to
follow up
in 4 weeks
in the
meantime
she was
going to
contact
some
colleagues
at (b) (6)
and see if
they had
heard of
anything
and she
was going
to check
in with
the NIH.

She
seems
genuinely
concerned
. She
wanted
me to get
a 2nd
opinion
from
another
neurologis
t. She
thinks I
need to
(b) (6)

She said that way we can rule things out. And so I just got approved for that on Friday and I am waiting for them to call me back to schedule. My current symptoms are random burning sensations in my neck, hands, feet, and face. My tingling has subsided. But I notice if my shoes or socks are too tight it will start again. My hands and knuckles will get red and feel like they are hot. I had bad headaches , pulsing around my ears but those have subsided. My feet feel like

they don't
get good
circulation
and the
color of
them
changes.

My veins
change all
the time,
Super
vascular
and then
barely
there and
then will
bring on
different
sensory
feelings.

My
hands/fingers
fall
asleep at
night
when I am
sleeping
and the
tingling/
will also
start in my
feet when
I lay
down. My
heels of
my feet
feel like
they are
burning as
I type this!

My
energy is
better and
I think my
BP has
stabled
more, or I
am just
not taking
it as much
at this
point. If I
am texting
on my
phone my
fingers
will tingle
as if they

are falling
asleep. I
used to
get this
cold
feeling
(icicles in
my veins)
in my
forehead
but that
subsided
and that
feeling is
now just
randomly
on the
front side
of my
ankles. I
don't
seem to
respond
well to the
cold.

I think
that is all.
I am sure
I have left
something
out . But it
has been
a very
busy (b
since I had
my first ER
visit and
the tests
and
bloodwork
started!
It has
been (b
since my
shot. I
would say
things
have
improved
since the
beginning,
especially
when it
comes to
the

intensity.

Interested
on hearing
your
thoughts!

Thanks

(b) (6)

To: (b) (6)
From: Safavi, Farinaz (NIH/NINDS) [E]/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246-(b) (6)
Sent: Tue 4/13/2021 6:41:08 PM (UTC-05:00)
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

(b) (6)

Thank you for sharing this with me.

I would like to emphasize on one point. Many neurological diseases can happen with specific incidence in population even without any known predisposition factor.

In scientific approach to these issues we need to compare the incidence of one disease for example (b) (6) before and after vaccination to say vaccine increases the chance of (b) (6).

I really do not believe so far we have that information or conclusion. Actually we see side effects but it doesn't mean it is much more than expected. So far it has not been.

Hope it helps

Farinaz

From: (b) (6)
Sent: Tuesday, April 13, 2021 5:06:25 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Hello again Dr Safavi,

This is a long video, but I believe it will be of interest to you if you have time to watch it. I'm attempting to connect with this Dr who practices in a small community in my province. He has seen severe, debilitating neurological reactions in some of his patients after having had the Moderna vaccine and likely has some valuable information to provide for your study. His name is Dr Charles Hoffe and he practices in Lytton, BC.

<https://m.youtube.com/watch?v=752EZogqueg&fbclid=IwAR06va4I-pTHFASrjwVyFOslApnHEH0wE5MuZFSmfWFbgLcyVpPaAiyktio>

(b) (6)

Sent from my iPhone

On Apr 13, 2021, at 12:59, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

Thank you for the update. Is there any possibility you send us the original images?

I cc Amanda to guide us through this possibility.

Best

Farinaz

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

From: (b) (6)
Sent: Tuesday, April 13, 2021 1:42 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)

REL0000230722

Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Good morning Dr Safavi,

I finally have a copy of the transcribed report of (b) (6) to share with you. I'm comfortable sharing it here, so will attach it.

I presented to the ER again two days ago with increasing numbness to my right foot and right leg, and was finally seen in person by a neurologist. He has decided (b) (6)

(b) (6). He reviewed (b) (6). He has ordered (b) (6). I will update you once I know more. Overall, I feel my concerns continue to be brushed off and it's incredibly frustrating.

Regards,

(b) (6)

Sent from my iPhone

On Apr 5, 2021, at 11:04, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

(b) (6)

The reason that I wanted to speak with you was that if there is an objective evidence for

(b) (6)

Of course I leave the decision to you.

Best

Farinaz

<AB7521D3C6A14A92AEE9E41803DDB9ED.png>

From: (b) (6)

Sent: Monday, April 5, 2021 1:55:15 PM

To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>

Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Hi,

I'll be traveling tomorrow so unfortunately will not be available for a meeting tomorrow. I will be back home Thursday afternoon, so the soonest I will be available is Friday morning.

(b) (6)

Sent from my iPhone

On Apr 5, 2021, at 08:50, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Sure,

It takes us 14 days to get the records so that If you can get it from your family doctor that would be much faster. It would be great if you can try tomorrow and let me know.

We may be able to meet around 4pm ET tomorrow? Does it work for you?

Farinaz Safavi MD, PhD

REL0000230722

From: (b) (6)
Sent: Monday, April 5, 2021 11:46 AM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Hi Dr Safavi,
I would love to send it to you, but I don't have access to it. I may be able to request a copy from my family doctor, but her office does not reopen until tomorrow. In the consents that I signed and sent to Amanda, I did give permission to access results of my diagnostic tests, if that is helpful.

(b) (6)

Sent from my iPhone

On Apr 5, 2021, at 08:42, Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)> wrote:

Hi (b) (6)
Thank you for your email and information. I agree with that diagnosis.
Can you send me your (b) (6) by any chance?

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

From: (b) (6)
Sent: Monday, April 5, 2021 11:35 AM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Good morning Dr Safavi,

The episodes of numbness to my right hand, fingers, and arm are becoming more infrequent, but are still occurring. I still have difficulty using my right hand and fingers, to increasing degrees, because of the feeling of it taking increased effort to use my fingers and the feeling of heaviness and cramping in my fingers I described before. It's difficult to write or type for more than a couple of minutes at a time because of it. I've also had some issues with fine motor function of my fingers, such as screwing the backs on my earrings. I finally did have the (b) (6). I'm so incredibly thankful that I was able to speak to you and you suggested that diagnosis, because I know I never would have been able to have it diagnosed if it wasn't for you.

I haven't noticed any paresthesias or neurological issues to any other areas of

my body (those seem to have resolved) besides to my right foot where I sometimes notice numbness (considerable at times) and pins and needles feelings, especially when laying still. It occasionally feels as if I have the same odd cramping sensation to my foot and toes that I have to my hands.

I am still awaiting an appointment with a neurologist, as I still have not seen one in person, and am still awaiting (b) (6). I've been told that I may need be treated with (b) (6). The radiologist who approved (b) (6).

Overall, I'm incredibly frustrated and disheartened with the lack of care and attention my condition has received from the medical professionals in my area. I'm so very appreciative that I was able to connect with you and you took the time to speak with me and assess me. Without you, I would have had no idea what was going on in my body.

(b) (6)

On Apr 5, 2021, at 06:33, Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)> wrote:

Hi (b) (6)

Hope your symptoms have improved.

Can you please update me with your symptoms and test results you have done so far?

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

From: (b) (6)
Sent: Wednesday, March 24, 2021 3:27 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Hi Farinaz,
After writing the email to you yesterday, I decided to go into the ER for assessment. I have (b) (6) pending and the ER doctor did a phone consult with a neurologist from (b) (6).
Thank you for your response

(b) (6)

Sent from my iPhone

On Mar 24, 2021, at 10:04, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

I think the best approach in your case would be seeing a neurologist. I would be happy to get in touch with any physician to provide any further information.

Farinaz

From: (b) (6)
Sent: Tuesday, March 23, 2021 3:30 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Neurological symptoms post Pfizer COVID vaccine

Hello Farinaz,

I just wanted to thank you again for taking the time to speak with me and offer some suggestions as to what the source of my symptoms may be. My husband is also very grateful. It's been very reassuring to speak to you and it has put my mind much at ease. I have noticed a new symptom today and am wondering if you might be able to offer some clarity as to what this may mean. Please see the attached photos. I believe I may be exhibiting what is known as Wartenberg's Sign in the fifth finger of my right hand. I am able to adduct the fifth finger towards the fourth, although it does require some effort. The position in the photo is where my fifth finger automatically goes to if my hand is relaxed. I have included a photo of my left hand for comparison. I very much appreciate any information you can provide. Also, I should have some downtime this afternoon to be able to complete and submit the consent forms to Amanda.

Regards,
(b) (6)

<3515F8BDB8C746D5BAB57CCE680D4F60.jpg>
<3BC2BA49122A4D63A6A110812D81FE8A.jpg>

Sent from my iPhone

On Mar 23, 2021, at 07:43, Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)> wrote:

hi,give me afew minutes and i will
send it again

Farinaz

<7868991B08644CCCB2945A2D1384
D9B8.png>

From: (b) (6)

Sent: Tuesday, March 23, 2021
10:25:23 AM

To: Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)>

Subject: Re: Neurological symptoms
post Pfizer COVID vaccine

Good morning Farinaz,
I have not received an invitation to
our Teams meetings this morning.
I'm not sure if maybe it got
misplaced in the mail somewhere?

Thanks,
(b) (6)

Sent from my iPhone

On Mar 22, 2021, at
13:39, Safavi, Farinaz
(NIH/NINDS) [E]
<(b) (6)>
> wrote:

Thank you.Maybe you
ask or GP to check for
spike and capsid
Abs.They can
distinguish previous or
vaccine related COVID.
Our nurse will contact
you as soon as she can
for paperwork.Thanks
for your fast response.

Farinaz

From: (b) (6)
Sent: Monday, March
22, 2021 4:37 PM

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

Subject: Re:
Neurological symptoms
post Pfizer COVID
vaccine

Hello Farinaz,
I did have some
symptoms last March
that started two weeks
after returning from
Mexico that I wasn't
tested for. I had an odd
burning sensation in my
chest and an infrequent
dry cough that
persisted intermittently
for about 2 days. I was
afebrile and had no
other symptoms. Our
daily cab driver in
Mexico had taken a day
off because of a "bad
flu". I have no past
history of medical
conditions, besides (b) (6)

(b) (6)
(b) (6)
. The
only medication I do
take is (b) (6)
(b) (6)
. The
only autoimmune
disease I'm aware of in
my family is (b) (6)
(b) (6)

(b) (6)

Sent from my iPhone

On Mar
22, 2021,
at 12:41,
Safavi,
Farinaz
(NIH/NIND
S) [E]

REL0000230722

(b) (6)
wrote:

Hi (b) (6)
I have two
questions
for you.
Do you
think you
ever had
COVID in
the course
of last
year?
Do you
have any
family
member
with
autoimmu
ne or
inflammat
ory
diseases?
Any Past
medical
Hx or
medicatio
n?
Thank you

Farinaz
Safavi MD,
PhD
Division of
Neuroim
munology
and
Neurovirol
ogy
NINDS,
NIH,
Bethesda,
MD

From:

(b) (6)

Sent:

Monday,
March 22,
2021

12:05 PM

To: [Safavi,](#)

[Farinaz](#)

[\(NIH/NIND](#)

[S\) \[E\]](#)

Subject:

Re:

Neurologi

cal

symptoms

post Pfizer

COVID

vaccine

Hi

Farinaz,

I'm so

sorry. I'm

having an

issue with

my wifi

this

morning

and am

unable to

log into

the Teams

meeting.

I'm

attemptin

g to

connect

using my

phone's

data plan,

but that

also isn't

working.

I'm

attemptin

g to

resolve

this issue

and

hopefully

will be

able to

quickly.

(b) (6)

Sent from

my iPhone

On Mar 18, 2021, at 16:38, Safavi, Farinaz (NIH/NINDS) [E]

<(b) (6)> wrote:

REL0000230722

Hi (b) (6)

I am sorry to hear about your illness. I would be happy to speak with you through televisit and discuss your issues. Does Monday 11am or 12noon ET work for you?

Best

Farinaz

Farinaz

<94EBE1012C554021AC219AAFF0FC888F.png>

From: (b) (6)

Sent: Thursday, March 18, 2021 3:48:26 AM

To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>

Subject: Neurological symptoms post Pfizer COVID vaccine

Hello Farinaz,

I was referred to you by (b) (6) who I have been in correspondence with since yesterday.

The following is my story:

I am a (b) (6) from (b) (6). I am a healthy, very active (b) (6).

I received my first dose of the Pfizer COVID vaccine, administered to the left deltoid, (b) (6). Early (b) (6) morning I woke with numbness to my left shin and right hand. When I woke later that morning, these symptoms remained.

Throughout the day I developed paresthesia to all four extremities and the right side of my face, along the trigeminal nerve pathway. Along with this paresthesia, which was intermittently worse in one limb vs another, I developed traveling intermittent sensations of coldness, as if someone was suddenly splashing me with cold water. I also experienced intermittent, traveling prickly electrical sensations. The next day the paresthesia persisted, but with less intensity and seemed to be affecting mainly the right side of my face and right arm and hand. That day, I had intermittent sensations of burning heat, most prominent to the right side of my face. Today, (b) (6) I'm experiencing slight paresthesia to my left shin and a feeling of heaviness/numbness to my right arm and hand with cramping of my right hand, which requires increased effort to use as I normally would. The paresthesia to the right side of my face remains, but the sensation seems to be changing to a neuropathy instead. I feel as if I've been punched incredibly hard in my cheek. I also have intermittent sharp pains to the sides of my fingers, my hand, along the radial and ulnar nerves, and to my upper arm. Fortunately, I am still mostly functional and able to carry on with my normal activities without issues, beside the hand cramping. My fear is what this may progress to in the future. Being Canadian, I have incredibly limited access to any specialized care, and will never be able to be assessed by a neurologist. I've had a phone appointment with a GP, another with my own, and was seen by my own GP in person today. My neurological exam was normal besides the ongoing

paresthesia. I've been told that if my symptoms become largely focal then I need to be seen urgently to have [REDACTED] (b) (6) I've also been advised to closely self monitor my symptoms. The first doctor told me my symptoms were not due to the COVID vaccine, even though I was perfectly healthy before the vaccine with no pre-existing conditions or history of neurological symptoms. My own GP is reluctant to say the vaccine is the cause, but has filed an adverse reaction report, as have I.

Thank you for taking the time to review my story.
Please let me know if I can assist your study in any way.

Regards,
[REDACTED] (b) (6)

To: (b) (6)
From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246- (b) (6)
Sent: Tue 3/23/2021 1:20:24 PM (UTC-05:00)
Subject: Re: Potential SPAM:Re: Referral from (b) (6) neurological vaccine reaction

Hi (b) (6)

How about we meet at 2:40pm ET?

Farinaz

From: (b) (6)
Sent: Tuesday, March 23, 2021 1:52:06 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Potential SPAM:Re: Referral from (b) (6) neurological vaccine reaction

Hello

I want to apologize about the confusion with the time zones. I had it at 1pm pacific standard time. I got on the meeting at 10:20 but it was too late. I have the day off from work and my kids arranged to do this meeting. Can we still do it? I am available anytime today and would love to talk to you. My phone number is (b) (6) and I will be refreshing my emails also.

Thanks

(b) (6)

Sent from my iPhone

On Mar 23, 2021, at 10:26 AM, (b) (6) wrote:

I am trying now, please can we still do it? You said 1 and I thought that meant 1 my time
Sent from my iPhone

On Mar 23, 2021, at 10:12 AM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hello (b) (6)

I and my NP joined to meet with you through MS teams at 1pm and unfortunately you did not join. Did the link work for you? If not we can reschedule.

Thanks

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

From: (b) (6)
Sent: Sunday, March 21, 2021 10:02 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)

Subject: Potential SPAM:Re: Referral from (b) (6) neurological vaccine reaction

Yes ma'am. Let me know how we proceed!!! Thank you!!!

Sent from my iPhone

On Mar 21, 2021, at 6:32 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

I am sorry to hear about your illness. We definitely can discuss your issues through televisit. I have availability on Tuesday. Does 1pm work for you?
Please let me know

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

From: (b) (6)
Sent: Sunday, March 21, 2021 3:08 AM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#); [Wiebold, Amanda \(NIH/NINDS\) \[E\]](#)
Subject: Referral from (b) (6) neurological vaccine reaction

Hello! I was told to reach out to you and see if you could help me. My story is below. I currently live in (b) (6). My phone number is (b) (6). Thanks for your time!

My story:

I am a (b) (6) I am a (b) (6). I was healthy and fit before getting vaccinated. In 2020 I did (b) (6)

On (b) (6) I got my first first and only Moderna shot in my left arm..No symptoms besides a sore arm for 2-3 days. On the 8th day I noticed some lymphadenopathy while I was at work. And then my neck started to feel hot. After that anytime I would eat my entire body felt a hot/burning sensation and accompanied by a rash that would migrate. This came and went for about a week. And then on the 14th day, I noticed my feet felt tingly. I had just taken my kids to (b) (6) to play in the snow that morning and thought it had something to do with that. On the 15th day, (b) (6) the tingling had gotten worse. It was now in both feet and ankles. It felt like icicles in my veins. I went to my primary and she insisted it couldn't be from the vaccine and prescribe me (b) (6) for the full body flushing. And gave me a referral to an allergist to give me a peace of mind that I could do the 2nd dose of vaccine. About an hour later it was worse so I went back the Dr but she said just to sent her pics via email. I told her my knees looked purple and the tingling was getting worse and traveling to my knees. She said if I was

that concerned to go to the ER. I finished my day at the office and tried to go workout but it was persistent. I decided to go to (b) (6). They ran (b) (6). The Dr. said he thought it was (b) (6).

. They gave me (b) (6).

. That seemed to help with the full body flushing. The tingling in my feet persisted and also began in my hands. I went and saw the allergist and he had no idea. He gave me a prescription for (b) (6). He ordered (b) (6).

. He then referred me to (b) (6) for a 2nd opinion and also a neuro referral. I saw (b) (6) he said not to get the 2nd shot same thing the first allergist said. He order (b) (6).

The following Monday (b) (6) I went back to the ER my blood pressure I took after work was (b) (6) and then (b) (6). I got to the ER and it had come down to (b) (6) or something like that. They did (b) (6). My (b) (6). The ER doctor had no idea, but said I should see a neurologist. He knew I was scared and he said I could help jump start the process and he ordered (b) (6).

I got in with the nurse practioner at the primary. She ordered (b) (6).

I remained tingly and my muscles aches, random twitching and electrical impulses in my right quad and my upper right should/back area was randomly numb/tingly. I was exhausted and I lost 13 pounds in 2 weeks, hard to do when you are relatively healthy. My BP started to go down and stay around (b) (6). Now the low blood pressure was a new thing. I became very vascular and complained of my veins hurting. I went to neuro. He ordered (b) (6).

Finally I made a follow up appointment with him to discuss (b) (6).

Grrr. I have not lost my strength in all of this nor my balance. I did lose a little strength in the beginning because of the rapid weight loss but I have since regained that back. I am still down 8 or 9 lbs but maintaining that very well with a good diet, staying as low histamine as I can, most of the time. I went back to see my nurse practioner on Friday (b) (6) because my veins in my wrists were hurting, almost like they were going to explode. The moment I would raise my hand the blood wood rapidly disappear and my veins would sink in. I have videos of it happening. She denied me a vascular referral and prescribe me (b) (6). I filled the prescription and never took any. I did see a rheumatologist and she ordered a gamet of testing. She took me serious because she she also had numbness in her arm for an hour or two after her shot. (b) (6).

[REDACTED] . She said to follow up in 4 weeks in the meantime she was going to contact some colleagues at (b) (6) and see if they had heard of anything and she was going to check in with the NIH. She seems genuinely concerned. She wanted me to get a 2nd opinion from another neurologist. She thinks I need to (b) (6)

[REDACTED] . She said that way we can rule things out. And so I just got approved for that on Friday and I am waiting for them to call me back to schedule.

My current symptoms are random burning sensations in my neck, hands, feet, and face. My tingling has subsided. But I notice if my shoes or socks are too tight it will start again. My hands and knuckles will get red and feel like they are hot. I had bad headaches, pulsing around my ears but those have subsided. My feet feel like they don't get good circulation and the color of them changes. My veins change all the time, Super vascular and then barely there and then will bring on different sensory feelings. My hands/fingers fall asleep at night when I am sleeping and the tingling/ will also start in my feet when I lay down. My heels of my feet feel like they are burning as I type this! My energy is better and I think my BP has stabled more, or I am just not taking it as much at this point. If I am texting on my phone my fingers will tingle as if they are falling asleep. I used to get this cold feeling (icicles in my veins) in my forehead but that subsided and that feeling is now just randomly on the front side of my ankles. I don't seem to respond well to the cold.

I think that is all. I am sure I have left something out . But it has been a very busy (b) (6) since I had my first ER visit and the tests and bloodwork started! It has been (b) (6) since my shot. I would say things have improved since the beginning, especially when it comes to the intensity.

Interested on hearing your thoughts!

Thanks

(b) (6)

To: (b) (6)
Cc: Wiebold, Amanda (NIH/NINDS) [E] (b) (6)
From: Safavi, Farinaz (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246- (b) (6)
Sent: Wed 3/24/2021 6:48:05 AM (UTC-05:00)
Subject: Re: Potential SPAM:Re: Referral from (b) (6) neurological vaccine reaction

Thank you very much (b) (6)

I cc our research nurse(Amanda) to send you the medical record release form and the link.

I will keep you in the loop as soon as I know how we want to proceed.

Best

Farinaz

From: (b) (6)
Sent: Tuesday, March 23, 2021 11:27:57 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Potential SPAM:Re: Referral from (b) (6) neurological vaccine reaction

I started (b) (6)

My (b) (6)

Mv (b) (6)

(b) (6)

I was exposed to people with covid. I was tested 4 or 5 times when I was and (b) (6)

(b) (6)

Do you have an email address or somewhere where I can send my records?!

Thanks again for talking to me today. I am hoping and praying that I will recover and get back to my old ways!!

Oh by the way (b) (6)

Just so there isn't any confusion down the road!

Thanks again

(b) (6)

On Mar 23, 2021, at 6:05 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

(b) (6)

I have a few questions for you.

Can you tell me the exact dates (b) (6)

two more questions

have you had or guess you may have COVID in last year?

do you have any family members with autoimmune diseases?

Thank you

Farinaz

From: (b) (6)
Sent: Tuesday, March 23, 2021 1:52:06 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Potential SPAM:Re: Referral from (b) (6) neurological vaccine reaction

Hello

I want to apologize about the confusion with the time zones. I had it at 1pm pacific standard time. I got on the meeting at 10:20 but it was too late. I have the day off from work and my kids arranged to do this meeting. Can we still do it? I am available anytime today and would love to talk to you. My phone number is (b) (6) and I will be refreshing my emails also.

Thanks

(b) (6)

Sent from my iPhone

On Mar 23, 2021, at 10:26 AM, (b) (6) wrote:

I am trying now, please can we still do it? You said 1 and I thought that meant 1 my time
Sent from my iPhone

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Division of Neuroimmunology and Neurovirology
NINDS, NIH, Bethesda, MD

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REL0000230790

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I went back to see my nurse practitioner on Friday (b) (6) because my veins in my wrists were hurting, almost like they were going to explode. The moment I would raise my hand the blood would rapidly disappear and my veins would sink in. I have videos of it happening. She denied me a vascular referral and prescribe me gabapentin. I filled the prescription and never took any. I did see a rheumatologist and she ordered a gamet of testing. She took me serious because she she also had numbness in her arm for an hour or two after her shot. (b) (6)

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Interested on hearing your thoughts!

Thanks

(b) (6)

To: (b) (6)
From: Safavi, Farinaz (NIH/NINDS) [E]/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246-(b) (6)
Sent: Mon 7/26/2021 7:06:56 PM (UTC-05:00)
Subject: RE: Testing

Here is Amanda FAX number
Fax: 301-408-5594

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

From: (b) (6)
Sent: Monday, July 26, 2021 8:04 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

What is your Fax number (required) for records? Although, I'm going to ask they be sent electronically.

Sent from my iPhone

On Jul 26, 2021, at 4:53 PM, (b) (6) wrote:

I just wrote him and gave him your email address.
Thank you for trying to help me.

(b) (6)

Sent from my iPhone

On Jul 26, 2021, at 4:50 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

I am not sure I left my cell phone number though. It would be great you give him my email address.
Thank you

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

From: (b) (6)
Sent: Monday, July 26, 2021 7:42 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Absolutely, I will ask for the tests results to be emailed to you. It is strange to me that (b) (6) has not returned your call as he was highly interested in gaining your opinion on (b) (6). I will email him and provide him with your email.

Thank you,

On Jul 26, 2021, at 4:34 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi

I have not spoke or got email from him yet.

Can you do me a favor and send me (b) (6) ?

We need to save it in our file.

Thank you

Farinaz

From: (b) (6)
Sent: Friday, July 23, 2021 2:31 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Hello!! So, (b) (6) did not return your call?
Thank you for advocating for me and helping educate my community doctor.

Warmly,
(b) (6)

Sent from my iPhone

On Jul 23, 2021, at 6:45 AM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Thank you for the update.I will be happy to discuss with him.Let see how things go with your insurance process.
Farinaz

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

From: (b) (6)
Sent: Tuesday, July 20, 2021 2:52 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Hello.
I saw (b) (6) this morning and clarified my worsening symptoms. He has agreed (b) (6). I told him you had called and left a message and that you were willing to discuss treatment to help me. He would

like to talk with you and welcomes your input and recommendations on dosage etc. I feel hopeful for the first time in (b) (6). I hope you and (b) (6) are able to connect. I also hope my insurance approves.

(b) (6)

Sent from my iPhone

On Jul 19, 2021, at 5:11 PM, (b) (6) wrote:

(b) (6)

Thank you for trying to reach him! I will send him your email contact through the patient portal and when I see him tomorrow morning I will tell him you tried to contact him this afternoon.

Thank you!

(b) (6)

Sent from my iPhone

On Jul 19, 2021, at 2:33 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Thank you.

I tried to call him but his MA did not respond the phone. Please let him know and I will definitely speak with him.

Just remind me about one thing, (b) (6)

Thank you

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

From: (b) (6)
Sent: Monday, July 19, 2021 5:26 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Farinaz,
I am seeing my neurologist again tomorrow

morning to update him on my symptoms. His name is (b) (6) and his number is (b) (6). I will share your email with him and you have a signed ROI with my permission to discuss my case.

THANK YOU!!

(b) (6)

Sent from my iPhone

On Jul 19, 2021, at 9:09 AM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

(b) (6)

I would like to speak with your neurologist to see how we can help you. Can you send me his contact and share with him my email.
Thank you!
Best

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

From: (b) (6)
Sent: Monday, July 19, 2021 3:49 AM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Thank you for responding. I feel like I'm running out of time and options at this (b) (6) mark post-vaccine. I think my neurologist would be willing to explore (b) (6) with a bit of encouragement. I am certain he would speak to you.

I know early treatment is essential. In your (off the record) opinion... do you think I'm too far out from my initial reaction or do you think I may benefit from (b) (6)? I trust your opinion and your judgement.

(b) (6)

On Jul 18, 2021, at 7:56 PM, Safavi, Farinaz (NIH/NINDS) [E]

<[REDACTED] (b) (6)>
> wrote:

Hi [REDACTED] (b) (6),
Thanks for the update. Research work takes time and I don't have any result from your samples yet.
What's your neurologist opinion about [REDACTED] (b) (6)? I can speak with him if you think that may help.
Please let me know.
Farinaz

Farinaz

<425E7D44381946D6827F2FA0F2E232CA.png>

From: [REDACTED] (b) (6)

Sent: Friday, July 16, 2021 8:22:25 PM

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

<[REDACTED] (b) (6)>

Subject: Re: Testing

Hello Farinaz,

To date, here is a list of my worsening symptoms: increased nerve pain in scalp, left thigh, left forearm, left hand. Internal tremor occurs more days than not. I feel this shakiness in my limbs, hands, and head. Increased muscle weakness and I fatigue easily. I am

no longer able to walk more than a 1/2 mile which is a significant decline from the 3-5 miles I was able to walk shortly up to about (b) (6) post vaccine. Muscle twitching in both calves 24/7. L/R foot neuropathy. Left hand neuropathy and burning right hand fingertips. I continue to be severely constipated and am unable to have a bowel movement with the use of glycerin suppositories. This has remained the same since (b) (6).

Continued and constant facial paresthesia and burning lips. I am unable to withstand normal life stressors without my hands shaking and experiencing worsening brain fog. Intermittent bladder pain. Continued heat/cold intolerance.

I am not able to ride my mountain bike or fly fish. I am not able to babysit my grandchildren alone due to lack of stamina.

My daily life has been severely impacted by my physical limitations.

(b) (6)



In your opinion, would
I benefit from (b) (6)?
My symptoms seem to
be worsening. I am
really scared by the
downward turn.
Was there any
indication
of abnormalities in the
blood I sent to NIH
months ago?

My best to you,
(b) (6)

On Jun 14,
2021, at
8:14 PM,
Safavi,
Farinaz
(NIH/NIND
S) [E]

(b) (6)

wrote:

Hi (b) (6)
Thank
you very
much for
the
update. I
am out of
office
currently
and will
be back
next
week.
Can you
please
send me
the result
of (b) (6)

Please
update
me with
your
symptom
s? If your
symptom

s are still
severe I
can
dprak
with
(b) (6)
and
share our
understa
nding
about this
process.
Best

Farinaz

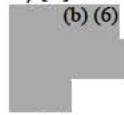
<6355AF7
10D83453
6860FCA4
D001DAC
AC.png>

From: (b) (6)



Sent: Tues
day, June
15, 2021
2:49:23
AM

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



Subject: R
e: Testing

Hello
Farinaz,
I haven't
wanted to
bother
you, but I
wanted to
follow-up
on my
blood
work
results to
learn if
there was
an
indication
of

abnormali
ty or an
area that
needs
further
follow-up.

In an
earlier
email, You
also
mentione
d other
tests you
were
suggesting

(b)
(6)
(b)
(6)
(b)
(6)
(b)
(6)

I hope you
are doing
well.

Warmly,
(b) (6)

Sent from
my iPhone

On Apr 29, 2021, at 8:19 PM, Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)> wrote:

Hi (b) (6)

Thank you very much for update. I completely agree with
your neurologist and I believe you are in good
hands. Unfortunately I can not bring non local patients easily
due to COVID restriction but I can speak with (b) (6) and
share our understanding about your symptoms with him. (b) (6)

(b) (6) also can send you list of tests
that I am sending for patients and your physician can check
them.

If (b) (6) helps your symptoms I think you certainly
should continue it.

Please let me know if I can be any help.

Best

Farinaz

<086E01E723E44FE794462A76AEC331F6.png>

From: (b) (6)

Sent: Thursday, April 29, 2021 11:09:56 PM

To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>

Subject: Testing

Hello Farinaz,

I saw my neurologist today (b) (6) and he reviewed past and current symptoms, in addition to all blood work and test results and scans. (b) (6)

(b) (6)

(b) (6) told me his concerns related to my symptoms are

(b) (6)

(b) (6). Is this the testing protocol you recommend? Also, I received my blood box today and will have a draw on Monday and ship back to you overnight. I started (b) (6) I've noticed a reduction of symptoms, but it doesn't last so I may need to (b) (6). Is there a benefit to having these tests performed at NIH? I'm open to your input.

Thank you,

(b) (6)

Sent from my iPhone

To: (b) (6)
From: Safavi, Farinaz (NIH/NINDS) [E]/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246-(b) (6)
Sent: Wed 7/28/2021 11:27:08 AM (UTC-05:00)
Subject: Re: Testing

Thank you very much (b) (6) for kind words.

I hope we also can publish our findings soon to help more patients with immune mediated neurological complications similar to you.

Best

Farinaz

From: (b) (6)
Sent: Wednesday, July 28, 2021 12:17:47 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Testing

Absolutely, I'll fill out paperwork. I requested my medical records be sent to you. Thank you for your willingness to confirm my treatment protocol. I know you work crazy long hours and I'm not sure how often you get a pat on the back for a job well-done, but I appreciate you and the hours you spend researching for answers to COVID vaccine injury.

Warmly,

(b) (6)

Sent from my iPhone

On Jul 28, 2021, at 8:58 AM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

(b) (6)

emailed me and I completely agree with him regarding (b) (6). You are in good hands.

Can you please fill out attached file weekly before and after treatment to give us some idea how you are doing?

Thank you

Farinaz

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

From: (b) (6)
Sent: Monday, July 26, 2021 8:04 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

What is your Fax number (required) for records? Although, I'm going to ask they be sent electronically.

Sent from my iPhone

On Jul 26, 2021, at 4:53 PM, (b) (6) wrote:

I just wrote him and gave him your email address.
Thank you for trying to help me.

REL0000230826

Sent from my iPhone

On Jul 26, 2021, at 4:50 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

I am not sure I left my cell phone number though. It would be great you give him my email address.

Thank you

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

From: (b) (6)
Sent: Monday, July 26, 2021 7:42 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Absolutely, I will ask for the tests results to be emailed to you. It is strange to me that (b) (6) has not returned your call as he was highly interested in gaining your opinion on (b) (6). I will email him and provide him with your email.

Thank you,
(b) (6)

On Jul 26, 2021, at 4:34 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi
I have not spoke or got email from him yet.
Can you do me a favor and send me your skin biopsy and autonomic testing reports?
We need to save it in our file.
Thank you

Farinaz

From: (b) (6)
Sent: Friday, July 23, 2021 2:31 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Hello!! So, (b) (6) did not return your call?
Thank you for advocating for me and helping educate my community doctor.

Warmly,

(b) (6)

Sent from my iPhone

On Jul 23, 2021, at 6:45 AM, Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)> wrote:

Thank you for the update. I will be happy to discuss with him. Let
see how things go with your insurance process.
Farinaz

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

From: (b) (6)
Sent: Tuesday, July 20, 2021 2:52 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Hello.
I saw (b) (6) this morning and clarified my worsening
symptoms. He has agreed (b) (6). I
told him you had called and left a message and that you were
willing to discuss treatment to help me. He would like to talk
with you and welcomes your input and recommendations on
dosage etc. I feel hopeful for the first time in (b) (6). I hope
you and (b) (6) are able to connect. I also hope my insurance
approves.

(b) (6)

Sent from my iPhone

On Jul 19, 2021, at 5:11 PM, (b) (6)
(b) (6) wrote:

(b) (6)

Thank you for trying to reach him! I will send him
your email contact through the patient portal and
when I see him tomorrow morning I will tell him
you tried to contact him this afternoon.

Thank you!
(b) (6)

Sent from my iPhone

On Jul 19, 2021, at 2:33 PM, Safavi, Farinaz (NIH/NINDS) [E]

<[REDACTED] (b) (6)> wrote:

Thank you.

I tried to call him but his MA did not respond the phone. Please let him know and I will definitely speak with him.

Just remind me about one thing,

[REDACTED] (b) (6)

Thank you

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

From: [REDACTED] (b) (6)
Sent: Monday, July 19, 2021 5:26 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Farinaz,

I am seeing my neurologist again tomorrow morning to update him on my symptoms. His name is [REDACTED] (b) (6) and his number is [REDACTED] (b) (6). I will share your email with him and you have a signed ROI with my permission to discuss my case.

THANK YOU!!

[REDACTED] (b) (6)

Sent from my iPhone

On Jul 19, 2021, at 9:09 AM, Safavi, Farinaz (NIH/NINDS) [E]

<[REDACTED] (b) (6)>

REL0000230826

> wrote:

(b) (6)

I would like to speak
with your neurologist to
see how we can help
you. Can you send me
his contact and share
with him my email.
Thank you!
Best

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

From: (b) (6)
Sent: Monday, July 19,
2021 3:49 AM
To: [Safavi, Farinaz](#)
[\(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Thank you for
responding. I feel like
I'm running out of time
and options at this (b) (6)
(b) (6) mark post-
vaccine. I think my
neurologist would be
willing to explore (b) (6)
with a bit of
encouragement. I am
certain he would speak
to you.

I know early treatment
is essential. In your (off
the record) opinion...
do you think I'm too far
out from my initial
reaction or do you think
I may benefit from
(b) (6)? I trust your
opinion and your
judgement.

(b) (6)

Sent from my iPhone

On Jul 18,
2021, at
7:56 PM,
Safavi,
Farinaz
(NIH/NIND
S) [E]

(b) (6)

wrote:

Hi (b) (6)

Thanks
for the
update. Research
work
takes
time and
I don't
have any
result
from your
samples
yet.

What's
your
neurologist
t opinion
about
(b) (6)? I

can
speak
with him
if you
think that
may help.
please let
me know.
Farinaz

Farinaz

<425E7D4
4381946D
6827F2FA
0F2E232C
A.png>

From: (b) (6)

(b) (6)

Sent: Friday, July 16, 2021 8:22:25 PM

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

(b) (6)

Subject: Re: Testing

Hello Farinaz,

To date, here is a list of my worsening symptoms: increased nerve pain in scalp, left thigh, left forearm, left hand. Internal tremor occurs more days than not. I feel this shakiness in my limbs, hands, and head. Increased muscle weakness and I fatigue easily. I am no longer able to walk more than a 1/2 mile which is a significant decline from the 3-5 miles I

was able
to walk
shortly up
to about (b

(b))

post
vaccine.
Muscle
twitching
in both
calves
24/7. L/R
foot
neuropath
y. Left
hand
neuropath
y and
burning
right hand
fingertips.

I
continue
to be
severely
constipated
and am
unable to
have a
bowel
movement
with the
use of
glycerin
suppositories.
This
has
remained
the same
since

(b) (6).

Continued
and
constant
facial
paresthesia
and
burning
lips. I am
unable to
withstand
normal
life
stressors
without
my hands
shaking
and
experiencing
worsening
brain fog.
Intermittent
bladder

pain.
Continued
heat/cold
intoleranc
e. I am
not able
to ride my
mountain
bike or fly
fish. I am
not able
to babysit
my
grandchil
dren
alone due
to lack of
stamina.
My daily
life has
been
severely
impacted
by my
physical
limitations

.

(b) (6)



(b) (6)



(b) (6)



In your opinion, would I benefit from (b) (6)? My symptoms seem to be worsening. I am really scared by the downward turn. Was there any indication of abnormalities in the blood I sent to NIH months ago?

My best to you,
(b) (6)

On Jun 14, 2021, at 8:14 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)
Thank you very much for the update. I am out of office currently and will be back next week.
Can you please send me the result of (b) (6)?

Please update me with your symptoms? If your symptoms are still severe I can speak with (b) (6) and share our understanding about this process.
Best

Farinaz

<6355AF710D834536860FCA4D001DACAC.png>

From: (b) (6)

Sent: Tuesday, June 15, 2021 2:49:23 AM

To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>

Subject: Re: Testing

Hello Farinaz,
I haven't wanted to bother you, but I wanted to follow-up on my blood work results to learn if there was an indication of

abnormality or an area that needs further follow-up. In an earlier email, You also mentioned other tests you were suggesting. (b) (6)

I hope you are doing well.

Warmly,

(b) (6)

Sent from my iPhone

On Apr 29, 2021, at 8:19 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6),

Thank you very much for update. I completely agree with your neurologist and I believe you are in good hands. Unfortunately I can not bring non local patients easily due to COVID restriction but I can speak with (b) (6) and share our understanding about your symptoms with him. (b) (6)

I also can send you list of tests that I am sending for patients and your physician can check them.

If (b) (6) helps your symptoms I think you certainly should continue it.

Please let me know if I can be any help.

Best

Farinaz

<086E01E723E44FE794462A76AEC331F6.png>

From: (b) (6)

Sent: Thursday, April 29, 2021 11:09:56 PM

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

<(b) (6)>

Subject: Testing

Hello Farinaz,

I saw my neurologist today (b) (6) and he reviewed past and current symptoms, in addition to all blood work and test results and scans. (b) (6)

(b) (6) told me his concerns related to my symptoms

are (b) (6)

(b) (6) Is this the testing protocol you recommend? Also, I received my blood box today and will have a draw on Monday and ship back to you overnight. I started (b) (6). I've noticed a reduction of symptoms, but it doesn't last so I may need to (b) (6). Is there a benefit to having these tests performed at NIH? I'm open to your input.

Thank you,

(b) (6)

Sent from my iPhone

<WHO scale post-COVID.docx>

To: (b) (6)
From: Safavi, Farinaz (NIH/NINDS) [E]/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246-(b) (6)
Sent: Wed 7/28/2021 10:58:00 AM (UTC-05:00)
Subject: RE: Testing
[WHO scale post-COVID.docx](#)

Hi (b) (6)

(b) (6) emailed me and I completely agree with him regarding (b) (6). You are in good hands.
Can you please fill out attached file weekly before and after treatment to give us some idea how you are doing?
Thank you
Farinaz

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

From: (b) (6)
Sent: Monday, July 26, 2021 8:04 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

What is your Fax number (required) for records? Although, I'm going to ask they be sent electronically.

Sent from my iPhone

On Jul 26, 2021, at 4:53 PM, (b) (6) wrote:

I just wrote him and gave him your email address.
Thank you for trying to help me.
(b) (6)

Sent from my iPhone

On Jul 26, 2021, at 4:50 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

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Thank you

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Division of Neuroimmunology and Neurovirology
NINDS, NIH, Bethesda, MD

From: (b) (6)
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To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

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Thank you,

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I have not spoke or got email from him yet.

Can you do me a favor and send me (b) (6)?

We need to save it in our file.

Thank you

Farinaz

From: (b) (6)

Sent: Friday, July 23, 2021 2:31 PM

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

Subject: Re: Testing

Hello!! So, (b) (6) did not return your call?

Thank you for advocating for me and helping educate my community doctor.

Warmly,

(b) (6)

Sent from my iPhone

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Thank you for the update.I will be happy to discuss with him.Let see how things go with your insurance process.

Farinaz

Farinaz Safavi MD, PhD

Division of Neuroimmunology and Neurovirology

NINDS, NIH, Bethesda, MD

From: (b) (6)

Sent: Tuesday, July 20, 2021 2:52 PM

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

Subject: Re: Testing

Hello.

I saw (b) (6) this morning and clarified my worsening symptoms. He has agreed (b) (6). I told him you had called and left a message and that you were willing to discuss treatment to help me. He would like to talk with you and welcomes your input and recommendations on dosage etc. I feel hopeful for the first time in (b) (6). I hope you and (b) (6) are able to connect. I also hope my insurance approves.

(b) (6)

Sent from my iPhone

On Jul 19, 2021, at 5:11 PM, (b) (6) wrote:

(b) (6).

Thank you for trying to reach him! I will send him your email contact through the patient portal and when I see him tomorrow morning I will tell him you tried to contact him this afternoon.

Thank you!

(b) (6)

Sent from my iPhone

On Jul 19, 2021, at 2:33 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Thank you.

I tried to call him but his MA did not respond the phone. Please let him know and I will definitely speak with him.

Just remind me about one thing, (b) (6) ?

Thank you

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

From: (b) (6)
Sent: Monday, July 19, 2021 5:26 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Farinaz,
I am seeing my neurologist again tomorrow morning to update him on my symptoms. His name is (b) (6) and his number is (b) (6). I will share your email with him and you have a signed ROI with my permission to discuss my case.

THANK YOU!!

(b) (6)

Sent from my iPhone

On Jul 19, 2021, at 9:09 AM, Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)> wrote:

(b) (6)

I would like to speak with your neurologist to see how we can help you. Can you send me his contact and share with him my email.

Thank you!

Best

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

From: (b) (6)
Sent: Monday, July 19, 2021 3:49 AM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Thank you for responding. I feel like I'm running out of time and options at this (b) (6) mark post-vaccine. I think my neurologist would be willing to explore (b) (6) with a bit of encouragement. I am certain he would speak to you.

I know early treatment is essential. In your (off the record) opinion... do you think I'm too far out from my initial reaction or do you think I may benefit from (b) (6)? I trust your

opinion and your judgement.

(b) (6)

Sent from my iPhone

On Jul 18, 2021, at 7:56 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)
Thanks for the update. Research work takes time and I don't have any result from your samples yet.
What's your neurologist's opinion about (b) (6)? I can speak with him if you think that may help.
Please let me know.
Farinaz

Farinaz

<425E7D44381946D6827F2FA0F2E232CA.png>

From: (b) (6)

Sent: Friday, July 16, 2021 8:22:25 PM

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

<(b) (6)>

Subject: Re: Testing

Hello Farinaz,

To date, here is a list of my worsening symptoms: increased nerve pain in scalp, left thigh, left forearm, left hand. Internal tremor occurs more days than not. I feel this shakiness in

my limbs, hands, and head. Increased muscle weakness and I fatigue easily. I am no longer able to walk more than a 1/2 mile which is a significant decline from the 3-5 miles I was able to walk shortly up to about (b) (6) post vaccine. Muscle twitching in both calves 24/7. L/R foot neuropathy. Left hand neuropathy and burning right hand fingertips. I continue to be severely constipated and am unable to have a bowel movement with the use of glycerin suppositories. This has remained the same since (b) (6). Continued and constant facial paresthesia and burning lips. I am unable to withstand normal life stressors without my hands shaking and experiencing worsening brain fog. Intermittent bladder pain. Continued heat/cold intolerance. I am not able to ride my mountain bike or fly fish. I am not able to babysit my grandchildren alone due to lack of stamina. My daily life has been severely impacted by my physical limitations.

(b) (6)



In your opinion, would
I benefit from (b) (6)?
My symptoms seem to
be worsening. I am
really scared by the
downward turn.
Was there any
indication
of abnormalities in the
blood I sent to NIH
months ago?

My best to you,
(b) (6)

On Jun 14,
2021, at
8:14 PM,
Safavi,
Farinaz
(NIH/NIND
S) [E]

(b) (6)

wrote:

Hi (b) (6)
Thank
you very
much for
the
update. I
am out of
office
currently
and will
be back
next
week.
Can you
please
send me
the result
of (b) (6)

?

Please
update
me with

your
symptom
s? If your
symptom
s are still
severe I
can
dprak
with

(b) (6)

and
share our
understa
nding
about this
process.
Best

Farinaz

<6355AF7
10D83453
6860FCA4
D001DAC
AC.png>

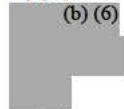
From: (b) (6)



Sent: Tues
day, June
15, 2021
2:49:23
AM

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

(b) (6)



Subject: R
e: Testing

Hello
Farinaz,
I haven't
wanted to
bother
you, but I
wanted to
follow-up
on my
blood
work
results to
learn if

there was
an
indication
of
abnormali
ty or an
area that
needs
further
follow-up.

In an
earlier
email, You
also
mentione
d other
tests you
were
suggesting

(b)
(6)
[REDACTED]

I hope you
are doing
well.

Warmly,
(b) (6)
[REDACTED]

Sent from
my iPhone

On Apr 29, 2021, at 8:19 PM, Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)> wrote:

Hi (b) (6)

Thank you very much for update. I completely agree with
your neurologist and I believe you are in good
hands. Unfortunately I can not bring non local patients easily
due to COVID restriction but I can speak with (b) (6) and
share our understanding about your symptoms with him. (b) (6)

[REDACTED] also can send you list of tests
that I am sending for patients and your physician can check
them.

If (b) (6) helps your symptoms I think you certainly
should continue it.

Please let me know if I can be any help.
Best

Farinaz

<086E01E723E44FE794462A76AEC331F6.png>

From: (b) (6)

Sent: Thursday, April 29, 2021 11:09:56 PM

To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>

Subject: Testing

Hello Farinaz,

I saw my neurologist today (b) (6) and he reviewed past and current symptoms, in addition to all blood work and test results and scans. (b) (6)

(b) (6)

(b) (6) told me his concerns related to my symptoms are

(b) (6)

(b) (6) Is this the testing protocol you recommend? Also, I received my blood box today and will have a draw on Monday and ship back to you overnight. I started (b) (6). I've noticed a reduction of symptoms, but it doesn't last so I may need to (b) (6). Is there a benefit to having these tests performed at NIH? I'm open to your input.

Thank you,

(b) (6)

Sent from my iPhone

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

Score:

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

To: (b) (6)
Cc: Nath, Avindra (NIH/NINDS) [E] (b) (6)
From: Safavi, Farinaz (NIH/NINDS) [E]/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246- (b) (6)
Sent: Wed 9/1/2021 8:52:36 PM (UTC-05:00)
Subject: Fwd: WHO Scale

Dear (b) (6)

I am sorry about (b) (6) denial by insurance.
Unfortunately there is no clinical trial to confirm the efficacy of (b) (6).

(b) (6) can be an alternative treatment to be discussed with your neurologist. I would be happy to share our experience with him if needed.

I cc Dr.Nath in this email for further comment.

Hope it helps.

Farinaz

From: (b) (6)
Sent: Tuesday, August 31, 2021, 9:01 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
Subject: Re: WHO Scale

Hello! I hope you are well. :)
I received notice today that my insurance company denied (b) (6) because "it does not meet medical necessity." Further, "The information provided by your doctor does not meet (b) (6) guideline." "There is not enough support for (b) (6). And then it goes on to say "this use is not supported by the FDA."

I can appeal and can choose someone to represent me. Is this something you are able to do since this is a treatment utilized by the NIH? The more time that goes on the less hope I have to be healed.

Thank you,
(b) (6)

Sent from my iPhone

On Aug 15, 2021, at 10:22 AM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)
We received your medical records.Thank you for WHO scale.You just need to fill it out weekly.It would be great if you keep filling them out specially when you (b) (6) giving us the assess your improvement.
Best

Farinaz

From: (b) (6)
Sent: Friday, August 13, 2021 8:08 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: WHO Scale

Hi Farinaz,

I am attaching The Who Scale

Begin forwarded message:

From: "Safavi, Farinaz (NIH/NINDS) [E]" <(b) (6)>
Subject: RE: Testing
Date: August 4, 2021 at 7:44:41 AM PDT
To: (b) (6)

Thanks (b) (6)

If you can get those records and email it to us that might be faster approach.

For WHO scale, you just need to fill out the form I sent you. That gives us an idea your baseline scale.

Thank you

Farinaz

From: (b) (6)
Sent: Wednesday, August 4, 2021 10:42 AM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Good morning! I hand delivered the signed release to my neurologist office last week. I will call this morning to request a quick send-off to you.

Still waiting for insurance approval of (b) (6). IN the meantime, I had (b) (6). I imagine it couldn't hurt.

I hope you are well in the midst of so much going on around us.

(b) (6)

Sent from my iPhone

On Aug 4, 2021, at 7:31 AM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

Hope all is ok!

I have not received result of (b) (6) and WHO scaling yet.

Can you please update me?

Thank you

Farinaz

From: (b) (6)
Sent: Wednesday, July 28, 2021 12:18 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Absolutely, I'll fill out paperwork. I requested my medical records be sent to you. Thank you for your willingness to confirm my treatment protocol. I know you work crazy long hours and I'm not sure how often you get a pat on the back for a job well-done, but I appreciate you and the hours you spend researching for answers to COVID vaccine injury.

Warmly,

(b) (6)

Sent from my iPhone

On Jul 28, 2021, at 8:58 AM, Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)> wrote:

Hi (b) (6)
(b) (6) emailed me and I completely agree with him regarding (b) (6). You are in good hands.

Can you please fill out attached file weekly before and after treatment to give us some idea how you are doing?

Thank you
Farinaz

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

From: (b) (6)
Sent: Monday, July 26, 2021 8:04 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

What is your Fax number (required) for records? Although, I'm going to ask they be sent electronically.

Sent from my iPhone

On Jul 26, 2021, at 4:53 PM, (b) (6)

REL0000230845

< (b) (6) wrote:

I just wrote him and gave him your email address.
Thank you for trying to help me.

(b) (6)

Sent from my iPhone

On Jul 26, 2021, at 4:50 PM, Safavi, Farinaz
(NIH/NINDS) [E] < (b) (6) wrote:

I am not sure I left my cell phone number
though. It would be great you give him my email
address.
Thank you

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

From: (b) (6)
Sent: Monday, July 26, 2021 7:42 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Absolutely, I will ask for the tests results to be
emailed to you. It is strange to me that (b) (6)
has not returned your call as he was highly
interested in gaining your opinion on (b) (6)
(b) (6). I will email him and provide him with your
email.

Thank you,
(b) (6)

On Jul 26, 2021, at 4:34 PM, Safavi,
Farinaz (NIH/NINDS) [E]
< (b) (6) wrote:

Hi
I have not spoke or got email from
him yet.
Can you do me a favor and send me
your (b) (6)
(b) (6)
We need to save it in our file.

Thank you

Farinaz

From: (b) (6)
Sent: Friday, July 23, 2021 2:31 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Testing

Hello!! So, (b) (6) did not return your call?
Thank you for advocating for me and helping educate my community doctor.

Warmly,

(b) (6)

Sent from my iPhone

On Jul 23, 2021, at 6:45 AM, Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)>
> wrote:

Thank you for the update. I will be happy to discuss with him. Let see how things go with your insurance process.
Farinaz

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

From: (b) (6)
Sent: Tuesday, July 20, 2021 2:52 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)

Subject: Re: Testing

Hello.

I saw (b) (6) this morning and clarified my worsening symptoms. He has agreed (b) (6).

I told him you had called and left a message and that you were willing to discuss treatment to help me. He would like to talk with you and welcomes your input and recommendations on dosage etc. I feel hopeful for the first time in (b) (6). I hope you and (b) (6) are able to connect. I also hope my insurance approves.

(b) (6)

Sent from my iPhone

On Jul 19,
2021, at
5:11 PM,
(b) (6)

wrote:

(b) (6)

Thank you for trying to reach him! I will send him your email contact through the

REL0000230845

patient
portal and
when I see
him
tomorrow
morning I
will tell
him you
tried to
contact
him this
afternoon.

Thank
you!

(b) (6)

Sent from
my iPhone

On Jul 19, 2021, at 2:33 PM, Safavi, Farinaz (NIH/NINDS) [E]

<(b) (6)> wrote:

Thank you.

I tried to call him but his MA did not respond the phone. Please
let him know and I will definitely speak with him.

Just remind me about one thing, (b) (6)

Thank you

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

From: (b) (6)

Sent: Monday, July 19, 2021 5:26 PM

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

Subject: Re: Testing

Farinaz,
I am seeing my neurologist again tomorrow morning to update
him on my symptoms. His name is (b) (6) and his
number is (b) (6) I will share your email with him and
you have a signed ROI with my permission to discuss my case.

THANK YOU!!

(b) (6)

Sent from my iPhone

On Jul 19, 2021, at 9:09 AM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

(b) (6)

I would like to speak with your neurologist to see how we can help you. Can you send me his contact and share with him my email.

Thank you!

Best

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

From: (b) (6)

Sent: Monday, July 19, 2021 3:49 AM

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

Subject: Re: Testing

Thank you for responding. I feel like I'm running out of time and options at this (b) (6) mark post-vaccine. I think my neurologist would be willing to explore (b) (6) with a bit of encouragement. I am certain he would speak to you.

I know early treatment is essential. In your (off the record) opinion... do you think I'm too far out from my initial reaction or do you think I may benefit from (b) (6)? I trust your opinion and your judgement.

(b) (6)

Sent from my iPhone

On Jul 18, 2021, at 7:56 PM, Safavi, Farinaz
(NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

Thanks for the update. Research work takes time and I don't have any result from your samples yet.

What's your neurologist opinion about (b) (6)? I can speak with him if you think that may help. please let me know.

Farinaz

Farinaz

<425E7D44381946D6827F2FA0F2E232CA.png>

From: (b) (6)

Sent: Friday, July 16, 2021 8:22:25 PM

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

<(b) (6)>

Subject: Re: Testing

Hello Farinaz,

To date, here is a list of my worsening symptoms: increased nerve pain in scalp, left thigh, left forearm, left hand. Internal tremor occurs more days than not. I feel this shakiness in my limbs, hands, and head.

Increased muscle weakness and I fatigue easily.

I am no longer able to walk more than a 1/2 mile which is a significant decline from the 3-5 miles I was able to walk shortly up to about (b) (6) post vaccine. Muscle twitching in both calves 24/7. L/R foot neuropathy. Left hand neuropathy and burning right hand fingertips. I continue to be severely constipated and am unable to have a bowel movement with the use of glycerin suppositories. This has remained the same since

(b) (6). Continued and constant facial paresthesia and burning lips. I am unable to withstand normal life stressors without my hands shaking and experiencing worsening brain fog. Intermittent bladder pain. Continued heat/cold intolerance. I am not able to ride my mountain bike or fly fish. I am not able to babysit my grandchildren alone due to lack of stamina. My daily life has been severely impacted by my physical limitations.

(b) (6)

In your opinion, would I benefit from (b) (6)? My symptoms seem to be worsening. I am really scared by the downward turn. Was there any indication of abnormalities in the blood I sent to NIH months ago?

My best to you,
(b) (6)

On Jun 14, 2021, at 8:14 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)
Thank you very much for the update. I am out of office currently and will be back next week.
Can you please send me the result of (b) (6)?
Please update me with your symptoms? If your symptoms are still severe I can dprak with (b) (6) and share our understanding about this process.

Best

Farinaz

<6355AF710D834536860FCA4D001DACAC.p
ng>

From: (b) (6)

Sent: Tuesday, June 15, 2021 2:49:23 AM

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

<(b) (6)>

Subject: Re: Testing

Hello Farinaz,
I haven't wanted to bother you, but I wanted to follow-up on my blood work results to learn if there was an indication of abnormality or an area that needs further follow-up. In an earlier email, You also mentioned other tests you were suggesting. (

(b) (6)
)
(
6

I hope you are doing well.
Warmly,

(b) (6)

On Apr 29, 2021, at 8:19 PM, Safavi,
Farinaz (NIH/NINDS) [E]

<[REDACTED] (b) (6)> wrote:

Hi [REDACTED] (b) (6)

Thank you very much for update. I completely agree with your neurologist and I believe you are in good hands. Unfortunately I can not bring non local patients easily due to COVID restriction but I can speak with [REDACTED] (b) (6) and share our understanding about your symptoms with him. [REDACTED] (b) (6)

[REDACTED] I also can send you list of tests that I am sending for patients and your physician can check them.

If [REDACTED] (b) (6) helps your symptoms I think you certainly should continue it.

Please let me know if I can be any help.

Best

Farinaz

<086E01E723E44FE794462A76AEC331

F6.png>

From: [REDACTED] (b) (6)

Sent: Thursday, April 29, 2021

11:09:56 PM

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

<[REDACTED] (b) (6)>

Subject: Testing

Hello Farinaz,

I saw my neurologist today [REDACTED] (b) (6)

[REDACTED] and he reviewed past and current symptoms, in addition to all blood work and test results and scans.

[REDACTED] (b) (6)

(b) (6)

(b) (6) told me his concerns related to my symptoms are (b) (6)

Is

this the testing protocol you recommend? Also, I received my blood box today and will have a draw on Monday and ship back to you overnight. I started (b) (6)

I've noticed a reduction of symptoms, but it doesn't last so I may need to (b) (6)

Is there a benefit to having these tests performed at NIH? I'm open to your input.

Thank you,

(b) (6)

Sent from my iPhone

<WHO scale post-COVID.docx>

Cc: Wiebold, Amanda (NIH/NINDS) [E] (b) (6)
To: Safavi, Farinaz (NIH/NINDS) [E] (b) (6)
From: (b) (6)
Sent: Wed 4/28/2021 12:48:23 PM (UTC-05:00)
Subject: Re: Neurological Vaccine Issue

Hello Dr. Farinaz,

I was looking forward to coming down there to be evaluated but I understand if there are restrictions put in place due to Covid. I will be traveling down to the DC area in May so if anything changes I will always be available to come in. I have an appointment with my new neurologist on May 20 and if it is okay with you I will provide your email to correspond with?

(b) (6)

On Apr 28, 2021, at 1:37 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Hi (b) (6)

Unfortunately due to COVID restrictions we can not bring non-local patients easily to NIH. I would be more than happy to speak with your neurologist and share our understanding about these symptoms with him/her. please let me know

Farinaz

From: (b) (6)
Sent: Wednesday, April 28, 2021 1:28:16 PM
To: Wiebold, Amanda (NIH/NINDS) [E] <(b) (6)>
Cc: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Neurological Vaccine Issue

Hello Amanda,

Just following up to see if it is possible to still come out there to be evaluated? I am still experiencing numbness, tingling, twitching and pins and needles feeling. I have visited another Neurologist and (b) (6). I and I am following up with an ENT doctor to understand the allergic reaction I feel in my mouth.

(b) (6)

On Apr 23, 2021, at 1:26 PM, (b) (6) wrote:

Hello,

I am still having pins/needles with numbness in my hands and feet. I have twitching throughout my body and headaches. I have been also starting to feel very fatigued even with adequate sleep.

(b) (6)

On Apr 23, 2021, at 12:55 PM, Wiebold, Amanda (NIH/NINDS) [E]

<(b) (6)> wrote:

Hello (b) (6),

Sorry for the delay in responding! In order for us to better decide which protocol to enroll you on could you give us an update on how you are doing (what symptoms are you still dealing with and any changes to the care you are receiving)?

Thank you,
Amanda

From: (b) (6)
Sent: Wednesday, April 21, 2021 1:46 PM
To: Wiebold, Amanda (NIH/NINDS) [E] <(b) (6)>
Cc: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Neurological Vaccine Issue

Hello Amanda,

I am just following up to see if everything was okay with the paperwork I sent for consent? During my meeting with Dr. Safavi I talked about coming out there to do testing if that was an option. I am planning to travel there (DC/Maryland) next month and hopefully I can be seen there if possible. I am open to whatever date that is available.

(b) (6)
(b) (6)

On Apr 12, 2021, at 8:54 AM, Wiebold, Amanda (NIH/NINDS) [E]

<(b) (6)> wrote:

Thank you.
Amanda

From: (b) (6)
Sent: Friday, April 9, 2021 6:18 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Cc: Wiebold, Amanda (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Neurological Vaccine Issue

Sorry for the delay. I sent the signed documents to request my medical records.

(b) (6)
(b) (6)

On Apr 9, 2021, at 5:39 PM, Safavi, Farinaz (NIH/NINDS) [E]

<(b) (6)> wrote:

Hi (b) (6)

Amanda sent you the medical release form and I appreciate if you fill it out as soon as you can.

Thanks

From: (b) (6)

Sent: Wednesday, April 7, 2021 3:06 PM

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

Subject: Re: Neurological Vaccine Issue

Hello Farinaz,

Sorry for the delay. I thought I sent the email with my last lab results, film of me twitching and a pictures of the rash on my ankle.

<3A2DF72C4B2445FD84323BEE216034CE.jpg>

<386A45C12830442F91BC818024225466.jpg>

<1AB9F867E65D4F02B9401E0DE9CD64DD.jpg>

(b) (6)

On Apr 2, 2021, at 8:55 PM, (b) (6)

(b) (6) wrote:

I received it, thank you so much!

(b) (6)

On Apr 2, 2021, at 8:54 PM, Safavi,
Farinaz (NIH/NINDS) [E]

<(b) (6)> wrote:

Great,I sent you microsoft team link.

Farinaz

<78FA98D33D8642C6824617D3424D
701D.png>

From: (b) (6)

(b) (6)

Sent: Friday, April 2, 2021 8:49:36 PM
To: Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)>
Subject: Re: Neurological Vaccine Issue

Hello,

Yes, that time will work. Thank you so much for taking the time to meet with me.

(b) (6)

On Apr 2, 2021, at 8:20 PM, Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)>
> wrote:

Dear (b) (6)
Sorry to hear about your illness. I can meet with you through televisit on Monday at 2:30 pm ET. Please let me know if this time works for you?
Thank you

Farinaz

<E6D937FEDE834DFE82BDCD6DB2AAE3F3.png>

From: (b) (6)

Sent: Friday, April 2, 2021 12:07:40 PM

To: Safavi, Farinaz (NIH/NINDS) [E]
<(b) (6)>

Subject: Re: Neurological Vaccine Issue

Hello Dr. Farinaz,

I am following up on my message below

concerning the post-vaccination neuropathy symptoms I am having. I apologize if this is not the normal way to get a consultation with you but I am desperately looking for answers on how I can resolve these issues I am having after my vaccination. If there is a better way to be evaluated please let me know. I would greatly appreciate it.

(b) (6)

On Mar
30, 2021,
at 6:44
PM, (b) (6)

wrote:

Hello,

I received
your
informatio
n from
(b) (6)

and I am
looking
for some
help
desperatel
y. I
received
my
second
dose of
the Pfizer
COVID-19
vaccine
(b) (6)

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

(b) (6)

[REDACTED]

. My
symptoms
are now
going on
for over

(b) (6)

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?

(b) (6)

A large rectangular area of the document is redacted with a solid gray block.A large rectangular area of the document is redacted with a solid gray block.A small rectangular area of the document is redacted with a solid gray block.

(b)
)
(6
)

(b) (6)

<Video.mov>

To: Wiebold, Amanda (NIH/NINDS) [REDACTED] (b) (6)
From: Safavi, Farinaz (NIH/NINDS) [E]/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=94807CE146E045D4B61655DA26A0C246-[REDACTED] (b) (6)
Sent: Fri 4/9/2021 4:38:56 PM (UTC-05:00)
Subject: FW: Neurological Vaccine Issue
[REDACTED] (b) (6)

[Video.mov](#)

Hi [REDACTED] (b) (6)

Amanda sent you the medical release form and I appreciate if you fill it out as soon as you can.

Thanks

From: [REDACTED] (b) (6)
Sent: Wednesday, April 7, 2021 3:06 PM
To: [Safavi, Farinaz \(NIH/NINDS\) \[E\]](#)
Subject: Re: Neurological Vaccine Issue

Hello Farinaz,

Sorry for the delay. I thought I sent the email with my last lab results, film of me twitching and a pictures of the rash on my ankle.



(b) (6)

(b) (6)

On Apr 2, 2021, at 8:55 PM, (b) (6) wrote:

I received it, thank you so much!

(b) (6)

On Apr 2, 2021, at 8:54 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Great,I sent you microsoft team link.

Farinaz

REL0000231127

From: (b) (6)
Sent: Friday, April 2, 2021 8:49:36 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Neurological Vaccine Issue

Hello,

Yes, that time will work. Thank you so much for taking the time to meet with me.

(b) (6)

On Apr 2, 2021, at 8:20 PM, Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)> wrote:

Dear (b) (6)
Sorry to hear about your illness. I can meet with you through televisit on Monday at 2:30 pm ET.
Please let me know if this time works for you?
Thank you

Farinaz

From: (b) (6)
Sent: Friday, April 2, 2021 12:07:40 PM
To: Safavi, Farinaz (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Neurological Vaccine Issue

Hello Dr. Farinaz,

I am following up on my message below concerning the post-vaccination neuropathy symptoms I am having. I apologize if this is not the normal way to get a consultation with you but I am desperately looking for answers on how I can resolve these issues I am having after my vaccination. If there is a better way to be evaluated please let me know. I would greatly appreciate it.

(b) (6)

On Mar 30, 2021, at 6:44 PM, (b) (6) wrote:

Hello,

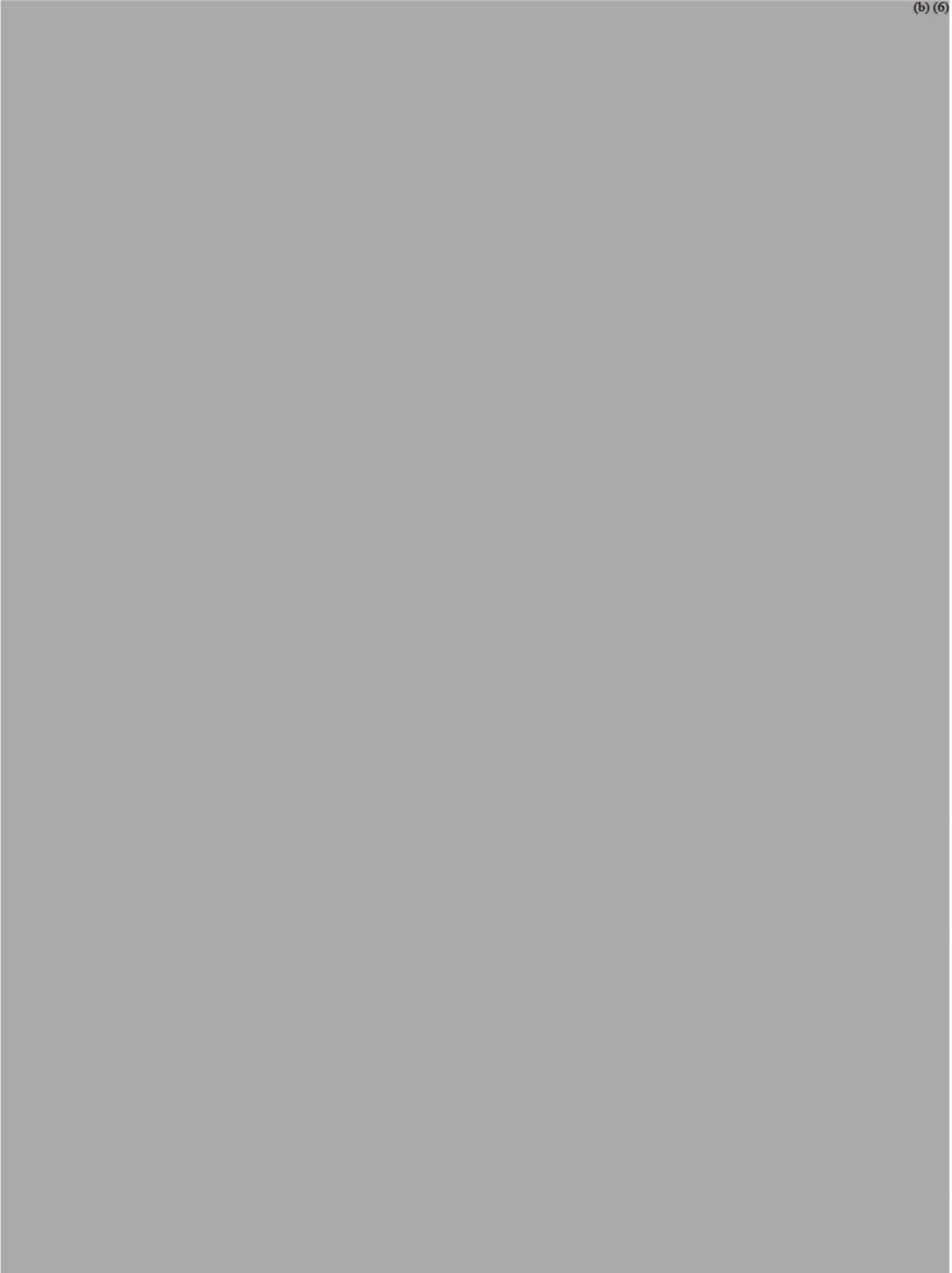
I received your information from (b) (6) and I am looking for some help desperately. I received my second dose of the Pfizer COVID-19 vaccine (b) (6). Two weeks following my 2nd vaccination I started to have neurological symptoms of twitching in my legs and arms; numbness, pins and needle feeling in 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 (b) (6)
(b) (6) My symptoms are now going on for over (b) (6) continuously without an answer and they are starting to get

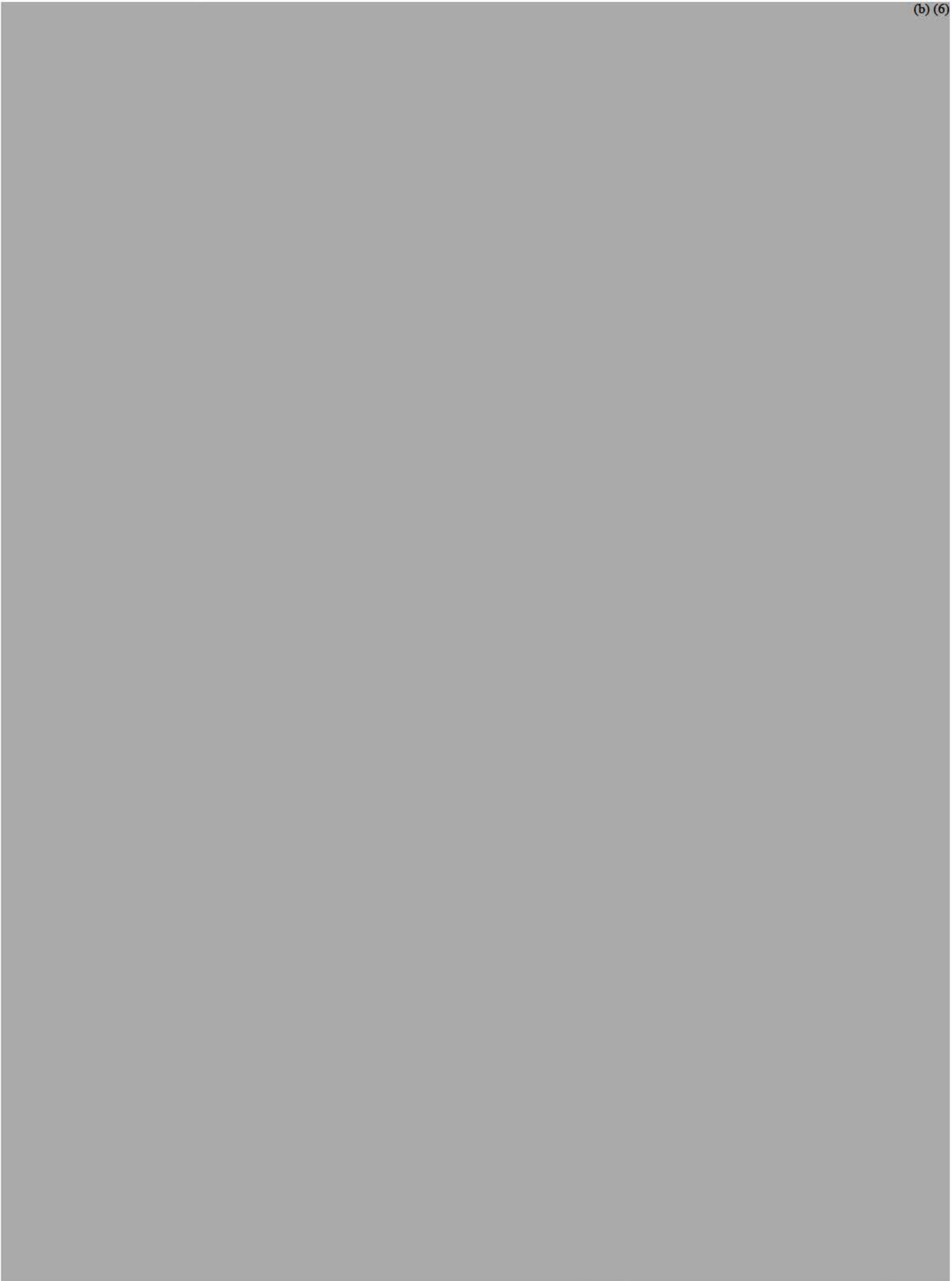
worse. I've been to two neurologists, my primary care doctor, and an allergist to see if they can figure out the issue but nothing.

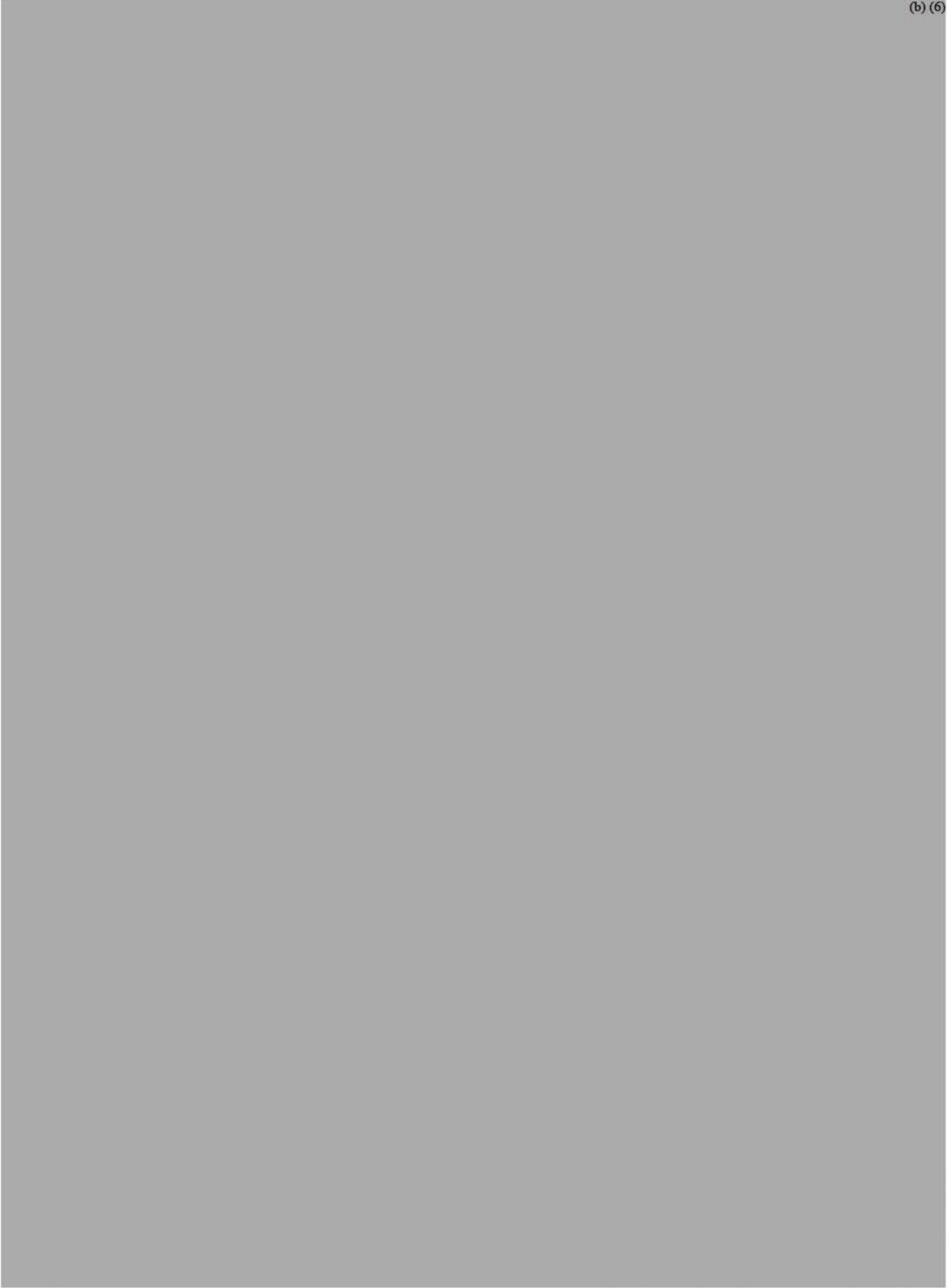
I am not sure what can be done reaching out but at this point, I am desperate and honestly very scared. Hoping you have some insight working with this I would like to know is there anything that can be done?

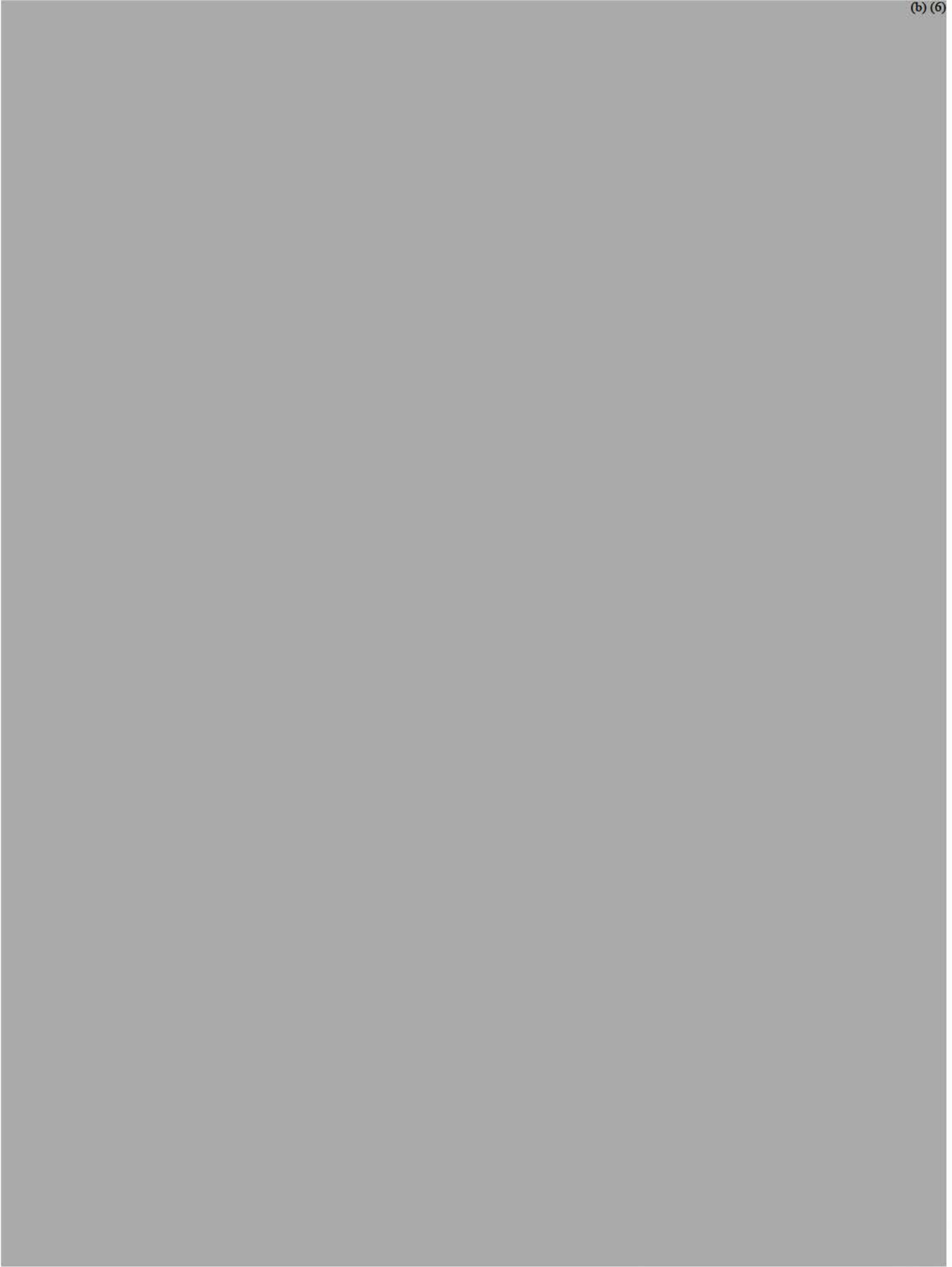
(b) (6)

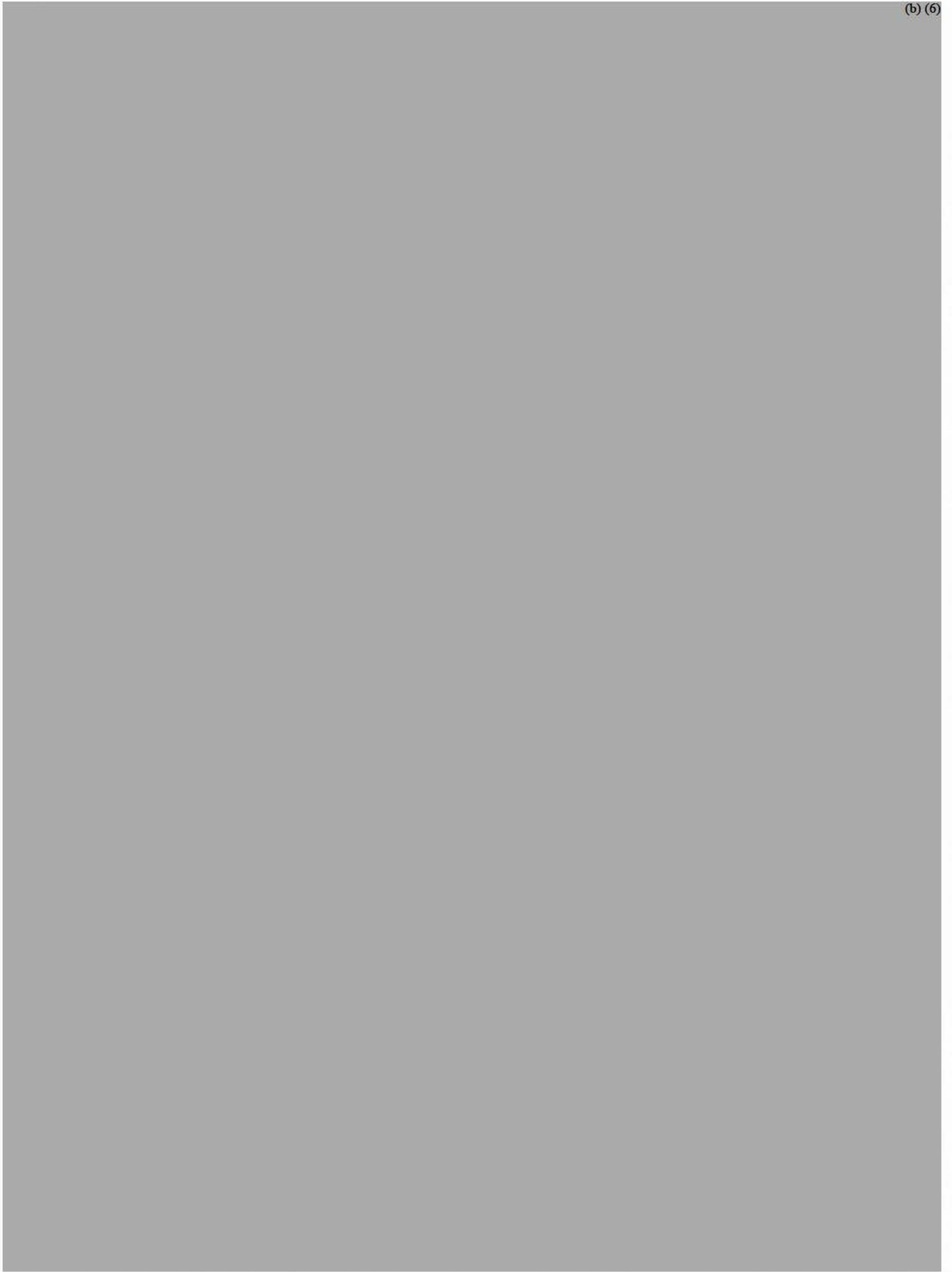
(b) (6)

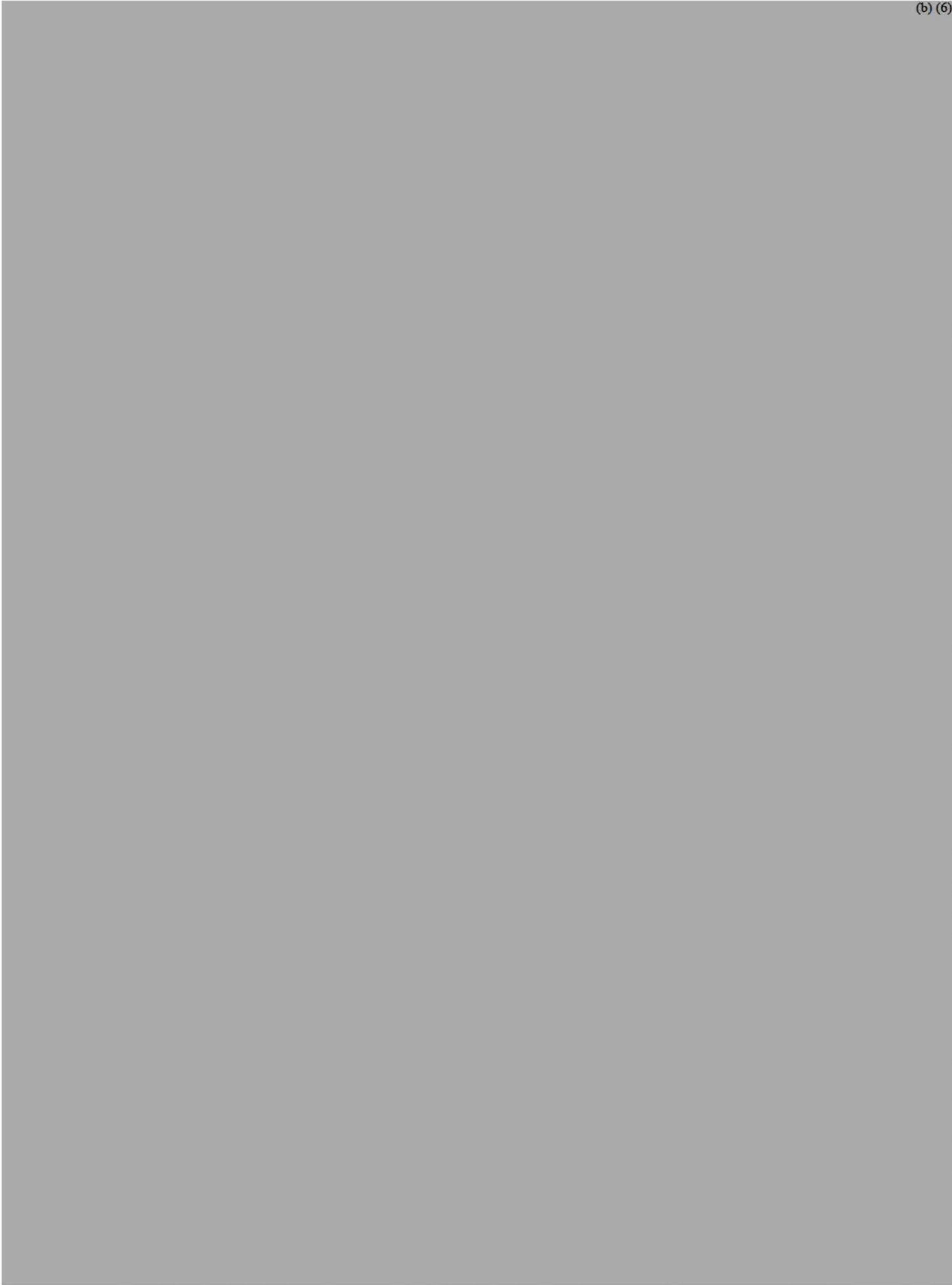


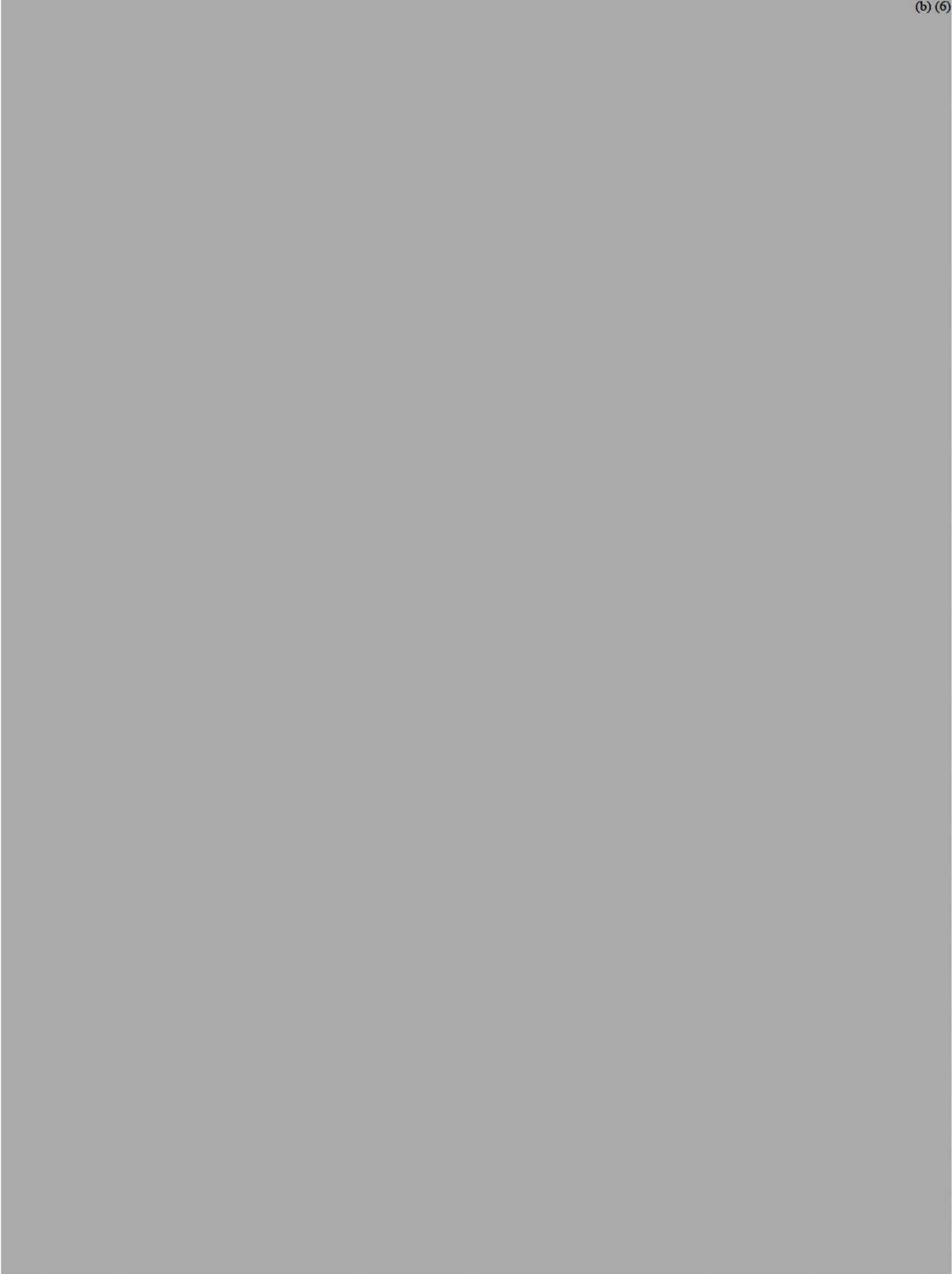














To: Nath, Avindra (NIH/NINDS) [E] (b) (6)
From: (b) (6)
Sent: Tue 9/28/2021 10:53:05 AM (UTC-05:00)
Subject: Re: Consult request from (b) (6)

Hi Dr Nath,

This is a nonspecific question that I'm not sure you can answer, but if the vaccine is causing some nonspecific CNS inflammation that doesn't really show clinically or on imaging, would you expect this to resolve over time? I spoke to another physician who I think spoke with you or one of your partners and she was found to have (b) (6) and I think she mentioned that you guys thought the inflammation would take awhile, but eventually resolve.

Final question- I know you mentioned that you haven't found any specific autoantibodies- have you found any evidence of some sort of autoimmune CNS issue induced by the vaccine?

As I mentioned in prior emails, it is thought that I have (b) (6), but I also feel as though there is something going on with my central nervous system that no clinicians seem to be impressed by. Since I know the general neuros aren't as aware of what is going on with the vaccine, I just wanted to check in with you before I ignore it all. If my (b) (6)

Thanks again for your help and responses.

(b) (6)

On Tue, Sep 14, 2021 at 4:50 PM Nath, Avindra (NIH/NINDS) [E] <(b) (6)> wrote:

Maybe (b) (6).

Avi

From: (b) (6)
Date: Tuesday, September 14, 2021 at 4:19 PM
To: Nath, Avindra (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Consult request from (b) (6)

Thanks again

Do you have any recs for neuros in (b) (6)?

Thanks again

Sent from my iPhone

On Sep 14, 2021, at 3:14 PM, Nath, Avindra (NIH/NINDS) [E] <(b) (6)> wrote:

(b) (6)

Avi

From: (b) (6)
Date: Tuesday, September 14, 2021 at 3:11 PM
To: Nath, Avindra (NIH/NINDS) [E] <(b) (6)>
Subject: Re: Consult request from (b) (6)

Hi Dr Nath

Hope you're well

I had one quick question: are you seeing any trend of MRI changes in patients who have had reactions to the vaccine? We emailed back and forth last week about my muscle fatigability/dysphagia and intermittent jerky movements - I followed up with my Neuro today who is completely unimpressed and told me to ignore my symptoms. (b) (6)

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Thanks again

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Any recommendations?

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. What city do you live in?

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Date: Wednesday, September 8, 2021 at 4:07 PM

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Thank you so much. The one consistent thing I've had since the vaccine is the feeling that my muscles are not right- heavy, not yet weak. I then developed dysphagia and (b) (6)

(b) (6) I subsequently developed some mild bulbar weakness that is not yet detectable on exam. So overall, the primary issue seems to be somewhat muscular and of some sort of muscular fatigue as after rest, they improve. The overall trend is a bit of a worsening in the last few weeks however. (b) (6)

Are you seeing any myopathy? Wondering if I need (b) (6)

Thanks again- I feel like I'm driving my own ship here since (b) (6)
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Best,

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Neurologist might be able to tell if the movements are really myoclonic or not. If so, then depending on the type (gen/multifocal/segmental), other investigations would be necessary.

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I have one more quick question

Is there anything you would recommend I ask my physicians to check?
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Thanks again for your help

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Okay,thank you so much

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Best wishes.

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Sorry to hear of your illness. Yes, there are several people who are complaining of similar symptoms. We do not have any treatment protocol at the moment. (b) (6)

This may be worthy of consideration.

With best wishes.

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Avindra Nath MD

Chief, Section of
Infections of the
Nervous System

Clinical Director,

National Institute of
Neurological
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National Institutes of
Health, Bethesda,
MD

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(Office)

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From: (b) (6)

Date: Tuesday,
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To: Nath, Avindra

11

Hi Dr. Nath,

by (b) (6)
who has been in
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she was diagnosed with after receiving the covid vaccine. I am (b) (6) and after receiving my 2nd covid vaccine in (b) (6) have had a number of strange neurologic symptoms- paresthesias, limb muscle fatigue, and (b) (6)

I now have some mild perceived bulbar weakness (though my Neuro isn't impressed) that waxes and wanes. I saw a neuropathy physician at (b) (6)

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I am quite concerned about the proximal esophageal dysmotility and waxing and waning bulbar symptoms in addition to the systemic muscle fatigue and was hoping to consult with you if possible.

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

Best,

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Sent from my iPhone

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From: (b) (6)
Sent: Tue 9/14/2021 2:16:16 PM (UTC-05:00)
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