

From: [b6]
Sent: 6/15/2021 6:13:12 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246; [b6]
CC: Gustafson, Lindsey (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=5bcc895932d544e4a2f36eb6f9388adb; [b6] Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540; [b6]
Subject: Re: List of labs for post COVID vaccine patient

Dear All,

Thank you. My Dr ordered these, and they were drawn before [b6]

You should be getting the FedEx of lab samples you wanted hopefully today.

Thanks so much for your help. When I have all the lab results of the tests you suggested we have drawn, I can send them to you.

I am in [b6]

FYI [b6] had WES done with the NIAID and never got results, but it was done [b6] Dr Goldbach-Mansky can release our WES for your team to use it. We still await the raw data, and none of these things were looked into for neuro stuff.

[b6] has been the contact for the WES (still waiting for our raw data and more info on what was done) but he might be able to release it to you. [b6] would consent to their data being shared with your team too.

I also had [b6] in my past. [b6]
[b6] Last summer, the [b6]
[b6]

[b6]

[b6]

[b6]

[b6]

[b6]

b6

b6

b6

b6

b6

He got his second Pfizer dose on [b6] He reacted to dose #1 with chills, fatigue, headache, etc. Dose #2 he got a fever, severe headache with notable bilateral leg weakness that lasted for hours. fatigue, joint pains and body aches in the first 24 hrs after dose #2, but the leg weakness improved once the fever and bad headache reduced. He has had a few days of the usual fatigue, headache, aches and pains, etc. The leg weakness was bilateral and has not returned after the issues in the first 24 hours post vaccine. He had some mild leg weakness relapses last year with flare ups last summer, but he had not done this in a long time. It only happened on day #1. I am doing the CDC vSafe reporting on him.

Thank you,

b6

On Thu, Jun 10, 2021, 3:10 PM [b6] wrote:
Dear All,

Thank you! I am going to ask for my neurologist to order these.

Best regards,

b6

b6

b6

b6

On Thu, Jun 10, 2021 at 9:50 AM Safavi, Farinaz (NIH/NINDS) [E] **b6** wrote:
Here is the list

- o Serum:
- § Hematology:
 - CBC with differential (daily)
- § Coagulation Studies:
 - PT, PTT (admission)
 - Lupus Anticoagulant (admission)
- § Chemistry:
 - ESR (admission)
 - Acute Care Panel (daily)
 - Mineral Panel (admission)
 - Hepatic Panel (admission)
 - Aldosterone, Serum (admission)
 - CK-MB Immunoassay (admission)
 - CRP, high sensitivity comprehensive (admission)
 - Cryoglobulins (admission)
 - Ferritin (admission)
 - Gamma Glutamyl Transferase (admission)
 - Thyroglobulin Panel (admission)
 - Thyroid Stimulating Hormone (admission)
 - Vitamin B12, Serum Level (admission)
 - Vitamin D, 1,25-Dihydroxy (admission)
 - IgG subclass Serum (Send out Mayo contract test not in CRIS)
- o Mayo Test Name: IgG subclass Serum, Mayo Test ID: IGGS, Red top, refrigerate
 - IgE (Send out Mayo contract test not in CRIS)
- o Mayo Test Name: IgE, Mayo Test ID: IgE, Red top, refrigerate
 - SARS cov2 spike Ab semi quantitative serum (Send out Mayo contract test not in CRIS)
- o Mayo Test Name: SAR cov2 spike Ab semi quantitative serum, Mayo Test ID: COVSQ, red top, refrigerate
 - SARS-COV2 Nucleocapsid Total Ab (Send out Mayo contract test not in CRIS)
- o Mayo Test Name: SARS-COV2 Nucleocapsid Total Ab, Mayo Test ID: COVTA, red top, refrigerate
 - Cytokine Panel 13 (Send out Mayo contract test not in CRIS)
- o Mayo Test Name: Cytokine Panel 13, Mayo Test ID: FCYTP, red top tube, spin down within 2hrs and send in frozen plastic vial
 - Cytokine panel plasma (Send out Mayo contract test not in CRIS)
- o Mayo Test Name: Cytokine panel plasma, Mayo Test ID: CYPAN, Lavender top, spin down and freeze in 30min and place in plastic
 - Encephalopathy autoimmune evaluation serum (Send out Mayo contract test not in CRIS)
- o Mayo Test Name: encephalopathy autoimmune evaluation serum, Mayo Test ID: ens2, red top, serum gel
- § Immunology
 - Anti-CCP AB x1
 - C3/4 x1
 - IgA Serum (Send out Mayo contract test not in CRIS) x1 before IVIG
- o Mayo ID: IGA, Red top
 - IgG Index CSF and serum x1

- Lyme Disease Ab, Serum x1
 - Rheumatoid Factor x1
 - Antibody to extractable nuclear antigen eval, serum (Send out Mayo contract test not in CRIS) x1
 - o Mayo Test Name: Antibody to extractable nuclear antigen eval, serum, Mayo Test ID: ENAE, Red top, refrigerate
 - dsDNA antibodies by crithidia lucilae IFA, IgG serum (Send out Mayo contract test not in CRIS) x1
 - o Mayo Test Name: dsDNA antibodies by crithidia lucilae IFA, IgG serum, Test ID: CRITH, Red top tube, refrigerated
 - Antinuclear Antibodies, Hep2 Substrate, IgG serum (Send out Mayo contract test not in CRIS) x1
 - o Mayo Test Name: Antinuclear Antibodies, Hep2 Substrate, IgG serum, Mayo ID: NAIFA, Red Top, refrigerate
- § Microbiology (Misc):
- Carbapenemase Surveillance Cultures (admission)
 - SARS-CoV-2 PCR, Surveillance, NP Swab (admission)

She may already got some of them done but this is a complete list.

Farinaz

From: Wiebold, Amanda (NIH/NINDS) [E] b6
Sent: Thursday, June 10, 2021 9:16:21 PM
To: Gustafson, Lindsey (NIH/NINDS) [E] b6 Safavi, Farinaz (NIH/NINDS) [E]
 b6
Cc: b6
Subject: List of labs for post COVID vaccine patient

Dr. Safavi and Lee,

Dr. Safavi in your email below to b6 there was mention that a list of labs will be sent to her. Labs that you have been recommending for post vaccine patients having complications. I want to close the loop because I am not sure if Lee was actually copied on that email or not but b6 b6 has not received the list of labs yet. She is scheduled for b6

Thanks,

Amanda

On Tue, Jun 8, 2021, 6:20 PM Safavi, Farinaz (NIH/NINDS) [E] b6 wrote:

b6

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

I cc our NP Lee to send you the list.

Lee, Can you please send the list of labs we usually send for post vaccine complications to [b6]

however based on your symptoms you may not need all of them and require others that I defer to your neurologist.

Unfortunately I can not provide further information until ai return and speak with you and [b6] most likely affect many tests if we dont run them beforehand.

Can you send us some serum before [b6] (red top or SST, spun down and frozen serum)?

Thanks

Farinaz

From: [b6]
Sent: Tuesday, June 8, 2021 11:27:43 PM
To: Safavi, Farinaz (NIH/NINDS) [E]; [b6]
Cc: Nath, Avindra (NIH/NINDS) [E]; [b6] Smith, Bryan (NIH/NINDS) [E]
[b6] Wiebold, Amanda (NIH/NINDS) [E]; [b6]
Subject: Re: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

Dear Dr Safavi,

I have done the consent with Ms Wiebold RN, and have submitted the forms, and consent to review my medical records.

I also have requested that my medical records, and [b6] be sent to you from [b6] and will follow up on that, but I gave you most of the essential documents for 2021 in the past attachment.

Dr Safavi said in a prior email: "I can send you the list of labworks we usually send for post vaccine adverse events before [b6] Hope it helps."

[b6] is still scheduled for [b6] Mr neurologist is willing to order any labs that are wanted, but he would need a list to do that in the next few days.

I am not sure if you contacted him, but if you make a list, or a letter with a list, I can get that to him to order for me. He has nothing planned for pre-labs

at this time. [b6] is my neurologist, and his office number is [b6]

I will also be working on getting my lab drawn at Quest for your study lab, and will try to set up an appointment to get that done before [b6]

I can even get labs drawn on a Sunday with [b6] but the sample would not be able to be shipped out until Monday, and I am not sure

if that is acceptable for your study, but [b6] lab is open on weekends, and I know them well.

Thanks,

[b6]

[b6]

[b6]

b6

b6

b6

On Sun, Jun 6, 2021 at 5:00 PM **b6** wrote:

Dear Dr Farinaz and Dr Nath,

Thanks so much for your help, even on a weekend! Sorry for more info coming your way. Hopefully this will help to get things going, and your nurse can call me at **b6** or my cell at **b6** to consent anytime tomorrow (Pacific time zone, but I will answer anytime.)

To answer your questions:

b6

My neurologist is willing to do anything recommended. Here are the only labs done on me since my fFizer vaccine reactions

My **b6** dates are for **b6** I could not get anything sooner.

I have attached a full document of all the **b6** and also some info from the past 14 months on anything of relevance.

I did not include much on my resolved issues, but focused more on the neuro-related stuff, but I can send you much more if you want on more details of my complex, prolonged, relapsing post viral issues since **b6** that I had most of the common COVID-19 type symptoms, including the loss of taste and smell,, diarrhea around day 6 onwards, when my lung issues and shortness of breath got worse, fever, brain fog, weird red tips of the fingers for weeks, cardiac arrhythmias, tachycardia, deep lung pain but no wheezing, dry cough, severe headaches, and so much more.

Note also past issues with **b6** in the document, and past issues with **b6** **b6** is in the document.

LABS DONE in 2021:

b6

b6

Current medications:

b6

b6

Are you working with the COVID-Neuro Network - Vaccine neurological adverse events following immunisation (AEFI)?

<https://www.liverpool.ac.uk/covid-vaccine-neuro-ae/>

I asked my Dr to submit, but I don't think he has, but I think it would be good.

I really appreciate your help, and caring. Sorry for the info overload, but I thought it would help to decide on what you wanted to do.

Thanks so much. It really means a lot to have your willingness to help in any way possible. And I hope my info can help your research to benefit others too.

Best regards,

b6

On Sun, Jun 6, 2021, 12:36 AM Safavi, Farinaz (NIH/NINDS) [E] **b6** wrote:

Dear **b6**

Thank you for your comprehensive history.

I havr afew questions.

b6

I cc our research nurse Amanda to send you paperworks for medical release form and sample only consent.

I can send you the list of labworks we usually send for post vaccine adverse events before [b6] Hope it helps.

Thank you!

Farinaz

From: Nath, Avindra (NIH/NINDS) [E] [b6]
Sent: Saturday, June 5, 2021 6:57:21 PM
To: [b6] Smith, Bryan (NIH/NINDS) [E]
[b6] Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Re: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

Dear [b6]

Thanks for all the information below. We will review the information and then get back to you.

Avi

Avindra Nath MD

Chief, Section of Infections of the Nervous System

Clinical Director,

National Institute of Neurological Disorders and Stroke

National Institutes of Health, Bethesda, MD

[b6]

From: [b6]
Date: Friday, June 4, 2021 at 1:36 AM
To: Nath, Avindra (NIH/NINDS) [E] [b6] Smith, Bryan (NIH/NINDS) [E]
[b6] Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

Dear Doctors,

I tried to call and leave a message, but I know you all must be so busy, especially after the holiday weekend. My cell phone is [b6] and my land line is [b6] Sorry if the details below are more than expected.

I have my story below, and give you permission to use it as needed. I have shared a lot of this in the VAERS report too. No one ever has followed up with me from the CDC.

I also [b6] I was [b6]
[b6] until after I had my bad and persistent issues after dose #2 of the Pfizer COVID vaccine, but I had reactions to both doses that were intense and unusual. My vaccines were [b6]
[b6] and I have had issues ever since!

My WES is at the NIH NIAID, along with [b6]
[b6] You are welcome to look at that too.

I could send you more info, imaging, labs, etc.

Currently: I am still currently dealing with the issues of vertigo, R cranial neuropathy, R facial droop, R outer leg weakness and neurologic changes, R arm and hand still weaker, and have had [b6] on my face (both sides last week), leg, R arm, R wrist.

I use walking sticks due to my R leg issues, and vertigo that makes me unstable, and to be able to walk around more, when not at home. At home, I can grab at narrow hallway walls, chairs etc as needed. I am still on [b6] for the vertigo, and [b6] for the headache [b6]
[b6] and have not dared stop [b6] I have used a R wrist splint but am getting stronger but at half strength (left handed, thank goodness), and also [b6] and trying my best to be overcoming this, and got my R leg to half strength too.

My neurologist is willing to do any suggested testing, treatments, anything. He wants me to have [b6] but it has been difficult to [b6] [b6] so if you want labs, let me know.

b6

b6

Pfizer dose #1 [b6]

Onset of symptoms [b6] around 1.5 hrs post vaccine: severe headache, stiff neck ache, dizziness, nausea, chills, extreme fatigue, feverish but below 100.4, severe muscle aches, loss of taste and smell. Loose bowels at times, slept all the rest of the day and night, drank lots of fluids and electrolytes (low sugar). Felt more weak and dizzy the next day, and when walking felt veering right more, more issues with extended activity after the next dose on [b6] onwards, and it has never gone away fully.

R arm pain and raised, tender area at vaccine site continued to hurt for weeks, even into the next dose on [b6] onwards, and has never gone away fully.

[b6] I woke up at 5:30 am: sudden-onset shortness of breath, deep lung pain in the center of the chest. I felt like my R lung blocked, and started to cough up large amounts of clear mucus, and vomiting mucus due to my R side middle airway feeling blocked. I [b6] to try to open my airway, but I was not wheezing, and did not have any respiratory symptoms or illness at the time before this started. (I have [b6] and have not needed it in over a year) I had been having continued less lung capacity for many months prior due to having been very sick in [b6] onwards, including loss of sense of smell and taste, shortness of breath, deep lung pain, fever, No wheezing, not sick.

Pfizer dose #2 [b6] after work. Onset of symptoms by 5:30 pm with headache, dizziness, nausea, extreme fatigue, increased R arm pain at the vaccine site, but it was still hurting at the site from the [b6] shot too, before this dose. Drank fluids and went to

bed. Loss of smell and taste returned [b6] Had continued bad headache from [b6] onwards, with nausea and feeling more dizzy at times, and on [b6] I was at work with increased headache, dizziness and nausea, and went home early from my shift [b6] due to symptoms. Went to bed early, due to continued nausea and headache and dizziness at times. [b6] continued bad headache, then in the afternoon around 3 pm, GI felt bloated, bad nausea, and then felt shortness of breath around 4 pm and faster heart rate [b6] lasting for minutes, despite laying down in bed, so I too used my oximeter (I have photos) and the sats were [b6], and had shortness of breath and return of deep internal mid lung pain, and this lasted for over 10 min. I used [b6] to try to recover, and the sats [b6] No wheezing. Not sick. I had a bad headache and nausea, and was not feeling good and went to bed.

On [b6] I woke up at 5:30 with severe vertigo and dizziness, nausea and a bad headache and could not walk due to the vertigo, and vomited when I was trying to have my head up. I had to crawl to the bathroom on my hands and knees. I called out sick for work due to this and contacted my Dr. I was started [b6] for vertigo, and was taking [b6] to help. [b6] noted my Re upper eyelid was doing a lot of spastic twitching at times, that would stop and start, but did not think about it much. The vertigo was unrelenting and then I started to have Right arm and hand weakness noted on [b6] and was still very dizzy, nauseated and had a constant headache since I got dose #2 of the COVID vaccine on [b6] I was using a walking stick for the dizziness to be stable, and also felt weaker on the R side, and drifting to the right when walking. On [b6] and noticed I could not fully shut my Right eye [b6] and by [b6] my face was drooping. I still had the constant headache, nausea and dizziness, and increased R hand, arm and R leg weakness and R hip weakness. I could not lift my R leg up to walk well, cannot grip well with the R hand, and uncoordinated, and cannot walk straight, and am unstable when trying to walk heel to toe, or even stand still with my eyes shut, and have had some double vision with the R eye. I was started on [b6] for the vertigo on [b6] after seeing my neurologist. I took [b6] and did not have improvement with the R facial droop or R side weakness and the headaches have persisted, along with some dizziness and nausea. On [b6] I had increased shortness of breath and R lung felt like it was not inflating much, and [b6] and went onto [b6] which did help my lungs to improve, and I was able to breathe better, and got my Right lung capacity back.

I stopped the [b6] to manage through the symptoms without it, and have been doing [b6] (but the Dr does not think it is that sort of issue, but that [b6] would help). I had [b6] after an in-person neurology appointment, and was having some improvement with the vertigo, so I [b6] but I was still having the constant headache, nausea, and some dizziness, R face droop, R hand weakness, R leg weakness and walk with a walking stick, and have increased issues with exertion, but have been walking and doing therapies to get stronger.3 I started to have increased R facial droop [b6] of my R arm. Worse headache, nausea, dizziness at the desk, and fatigue, but R side weakness issues increased, so I started back onto [b6] [b6] but had increasingly bad headache, nausea and increasing R facial droop, and much worse R hand weakness, R arm weakness and pain, and R hip pain and weakness, worse walking, cannot lift my R leg or foot as high as the L, again, and am struggling to walk, and get worse with exertion with R side walking and weakness. I also had shooting pains in my R jaw start on [b6] along with R jaw and face pain and increased

numbness, more face droop shooting pains in my R hip, and arm and body pain and a worse headache making it hard to even sleep, and some increased issues with my R eye that I need to have checked. R hip jerking and awakening me multiple times a night the last few days on the [b6]

[b6] after a video visit with the neurologist. Increased R leg weakness, R weak hip vs left, R foot drag/drop, with increased issues to maintain walking with progressive walking, still using walking stick to try to walk, but now for stability and to keep from drifting, R facial droop increasing and now some R eye blurring [b6] onwards, that is new. R eye found to have some tear film issues, so I have [b6] for that.

History from last year.

I also was sick from very early in [b6] (but I had what I thought was allergies 6 days prior which I now question) with significant respiratory cough but no wheezing, deep pain in the low center of my chest, fever, headache, increasing shortness of breath by day 6, diarrhea, was getting worse and my Drs had me [b6] which halted my lung issue progression enough, plus [b6] I had the loss of taste and smell, then red tips of my fingers and weaker grip on the fingers bilaterally with cardiac arrhythmias, tachycardia, dizziness [b6] constant headaches, heart rate issues, skipped beats [b6] continued low lung capacity and [b6] brain fog, and relapses of all these issues, including my sense of taste and smell going away with each relapse. I also lost hair in clumps in [b6] after being so sick.

I have weird patches of rash that reappear in the same places, that never existed before this illness, that started in [b6] on my back of my neck, chest, wrists and arms. I shared photos to my Drs, and they prescribed [b6]

I was [b6] until the cardiac issues resolved, and [b6] but still was dealing with headaches, brain fog, fatigue, and feeling less stable after more exertion, so I asked for my husband to buy me hiking sticks for my birthday [b6] mostly because I was just still not feeling great, and was trying to do more exercise and get stronger. After stationary biking in [b6] light amount, for 10 min, later that night I would start to cause shooting nerve pains up and down my leg, keeping me up at night for a few days. I never had that before. So, I did not use a stationary bike for a month, then tried it again, the same thing happened, so I never biked again, and did not have that since the nerve stuff.

I never fully recovered from the [b6] sequelae and issues, but pushed through [b6] [b6] and would come home and collapse, barely able to bathe and then rest, then cook dinner and go to bed, so I was not exactly "recovered" before I got my COVID vaccines, but was managing, and still had the fatigue, brain fog and such, but did not expect this. I have never had vertigo in my life until now.

b6

b6

b6 and had a significant systemic inflammatory, mostly neuro and respiratory inflammatory phase from 5 weeks onwards that involved a relapse of severe deep lung pain, pallor, cracked lips, severe headache for over 6 weeks, **b6** **b6** with progressive neuro issues with the constant headache that involved bilateral numb fingers and toes, that led to progressive hand and leg weakness, and not being able to support his weight on his legs, and weakness to above his knees bilaterally, and having some very odd absence-seizure-like issues with all of this, which thankfully the leg weakness started to reverse, and the issues calmed down but he had a few relapses over the summer, but not as severe as this. So, he saw a neurologist for that, and had lots of tests.

He also has an unusual history and **b6** **b6** past history of triggered flaring of joint, GI, lung, headache, sometimes odd rashes, sometimes elevated inflammatory markers triggered after infections, and can be very prolonged, but he had been doing well prior to getting sick in **b6**

b6

He has had one dose of the Pfizer vaccine, and did have a headache, chills and fatigue, pain at the vaccine site for a few days, but nothing serious. He is due for dose #2 on **b6**

I have been trying to get help from the CDC CISA program, and submitted a request a few months ago. I also have asked my Dr to try to help on that too, as the CISA location for the west is at the **b6**. I am not sure who he has contacted, outside his neuro colleagues, but he is open to suggestions.

This is the person that I think is over the west coast CISA, that I have asked my Dr to contact, and I have tried to reach, but I have not yet emailed. I will try again, but have not dared email, as I had hoped that my Dr would reach out, as **b6** I have tried to call a few times. I called the CDC and emailed in a request for a referral too, with no luck for this program. I know they are busy, but I had hoped they would help me.

b6

b6

b6

I also asked my neurologist to submit my case to this registry for COVID vaccine neuro events too, but I am not sure that he has, but I think it makes sense to collaborate:

<https://www.liverpool.ac.uk/covid-neuro-network/>. Do you work with this group too?

Note that I am 100% pro-vaccine, and have kept my story private, and most of my family, outside my kids and my mom who has been sworn to secrecy have not heard, and I have hidden this from colleagues at work too, but they do know something happened, and about the vertigo and R side weakness, but I think "through the grapevine" as I have tried to keep it quiet, and have not gone to the media, etc.

But I need help, and also we are trying to figure out what to do for

b6

b6

From: [b6]
Sent: 6/7/2021 12:00:25 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
CC: Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6] Smith, Bryan (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=de7bf3d6ad0046288fd8c35f33de3e57 [b6] Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540 [b6]
Subject: Re: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine
Attachments: Info re [b6].docx
Flag: Flag for follow up

Dear Dr Farinaz and Dr Nath,

Thanks so much for your help, even on a weekend! Sorry for more info coming your way. Hopefully this will help to get things going, and your nurse can call me at [b6] or my cell at [b6] to consent anytime tomorrow (Pacific time zone, but I will answer anytime.)

To answer your questions:

[b6]

My neurologist is willing to do anything recommended. Here are the only labs done on me since my Pfizer vaccine reactions

My [b6] dates are for [b6] I could not get anything sooner.

I have attached a full document of all the [b6] and also some info from the past 14 months on anything of relevance.

I did not include much on my resolved issues, but focused more on the neuro-related stuff, but I can send you much more if you want on more details of my complex, prolonged, relapsing post viral issues since [b6] [b6] that I had most of the common COVID-19 type symptoms, including the loss of taste and smell,, diarrhea around day 6 onwards, when my lung issues and shortness of breath got worse, fever, brain fog, weird red tips of the fingers for weeks, cardiac arrhythmias, tachycardia, deep lung pain but no wheezing, dry cough, severe headaches, and so much more.

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LABS DONE in 2021:

[b6]

b6

Current medications:

b6

b6

Are you working. with the COVID-Neuro Network - Vaccine neurological adverse events following immunisation (AEFI)?

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Best regards,

b6

On Sun, Jun 6, 2021, 12:36 AM Safavi, Farinaz (NIH/NINDS) [E] **b6** wrote:

Dear **b6**

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I havr afew questions.

b6

I cc our research nurse Amanda to send you paperworks for medical release form and sample only consent. I can send you the list of labworks we usually send for post vaccine adverse events before **b6** Hope it helps. Thank you!

Farinaz

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

Sent: Saturday, June 5, 2021 6:57:21 PM

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

Subject: Re: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

REL0000231010

Dear [b6]

Thanks for all the information below. We will review the information and then get back to you.

Avi

Avindra Nath MD

Chief, Section of Infections of the Nervous System

Clinical Director,

National Institute of Neurological Disorders and Stroke

National Institutes of Health, Bethesda, MD

[b6]

From: [b6]

Date: Friday, June 4, 2021 at 1:36 AM

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

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

Subject: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

Dear Doctors,

I tried to call and leave a message, but I know you all must be so busy, especially after the holiday weekend. My cell phone is [b6] and my land line is [b6] Sorry if the details below are more than expected.

I have my story below, and give you permission to use it as needed. I have shared a lot of this in the VAERS report too. No one ever has followed up with me from the CDC.

I also [b6] I was [b6]
[b6] until after I had my bad and persistent issues after dose #2 of the Pfizer COVID

vaccine, but I had reactions to both doses that were intense and unusual. My vaccines were in **b6** and I have had issues ever since!

My WES is at the NIH NIAID, along with **b6**
b6 You are welcome to look at that too.

I could send you more info, imaging, labs, etc.

Currently: I am still currently dealing with the issues of vertigo, R cranial neuropathy, R facial droop, R outer leg weakness and neurologic changes, R arm and hand still weaker, and have had **b6**
b6 on my face (both sides last week), leg, R arm, R wrist.

I use walking sticks due to my R leg issues, and vertigo that makes me unstable, and to be able to walk around more, when not at home. At home, I can grab at narrow hallway walls, chairs etc as needed. I am still on **b6** for the vertigo, and **b6** for the headache, **b6**
b6 and have not dared stop **b6** I have used a R wrist splint but am getting stronger but at half strength (left handed, thank goodness), and also **b6** and trying my best to be overcoming this, and got my R leg to half strength too.

My neurologist is willing to do any suggested testing, treatments, anything. He wants me to have **b6** but it has been difficult **b6**
b6 so if you want labs, let me know.

b6

b6

Pfizer dose #1 **b6**

Onset of symptoms: [b6] around 1.5 hrs post vaccine: severe headache, stiff neck ache, dizziness, nausea, chills, extreme fatigue, feverish but below 100.4, severe muscle aches, loss of taste and smell. Loose bowels at times, slept all the rest of the day and night, drank lots of fluids and electrolytes (low sugar). Felt more weak and dizzy the next day, and when walking felt veering right more, more issues with extended activity after the next dose on [b6] onwards, and it has never gone away fully.

R arm pain and raised, tender area at vaccine site continued to hurt for weeks, even into the next dose on [b6] onwards, and has never gone away fully.

[b6] I woke up at 5:30 am: sudden-onset shortness of breath, deep lung pain in the center of the chest. I felt like my R lung blocked, and started to cough up large amounts of clear mucus, and vomiting mucus due to my R side middle airway feeling blocked. I did [b6] to try to open my airway, but I was not wheezing, and did not have any respiratory symptoms or illness at the time before this started. (I have [b6] and have not needed it in over a year) I had been having continued less lung capacity for many months prior due to having been very sick in [b6] onwards, including loss of sense of smell and taste, shortness of breath, deep lung pain, fever, No wheezing, not sick.

Pfizer dose #2 [b6] after work. Onset of symptoms by 5:30 pm with headache, dizziness, nausea, extreme fatigue, increased R arm pain at the vaccine site, but it was still hurting at the site from the [b6] shot too, before this dose. Drank fluids and went to bed. Loss of smell and taste returned [b6] Had continued bad headache from [b6] onwards, with nausea and feeling more dizzy at times, and on [b6] I was at work with increased headache, dizziness and nausea, and went home early from my shift [b6] due to symptoms. Went to bed early, due to continued nausea and headache and dizziness at times [b6] continued bad headache, then in the afternoon around 3 pm, GI felt bloated, bad nausea, and then felt shortness of breath around 4 pm and faster heart rate [b6] lasting for minutes, despite laying down in bed, so I too used my oximeter (I Have photos) and the sats were [b6] and had shortness of breath and return of deep internal mid lung pain, and this lasted for over 10 min. I used [b6] to try to recover, and the sats [b6] No wheezing. Not sick. I had a bad headache and nausea, and was not feeling good and went to bed.

On [b6] I woke up at 5:30 with severe vertigo and dizziness, nausea and a bad headache and could not walk due to the vertigo, and vomited when I was trying to have my head up. I had to crawl to the bathroom on my hands and knees. I called out sick for work due to this and contacted my Dr. I was started [b6] for vertigo, and was taking [b6] to help [b6] noted my Re upper eyelid was doing a lot of spastic twitching at times, that would stop and start, but did not think about it much. The vertigo was unrelenting and then I started to have Right arm and hand weakness noted on [b6] and was still very dizzy, nauseated and had a constant headache since I got dose #2 of the COVID vaccine on [b6] I was using a walking stick for the dizziness to be stable, and also felt weaker on the R side, and drifting to the right when walking. On [b6] [b6] and noticed I could not fully shut my Right eye [b6] and by [b6] my face was drooping. I still had the constant headache, nausea and dizziness, and increased R hand, arm and R leg weakness and R hip weakness. I could not lift my R leg up to walk well, cannot grip well with the R hand, and uncoordinated, and cannot walk straight, and am unstable

when trying to walk heel to toe, or even stand still with my eyes shut, and have had some double vision with the R eye. I was started on [b6] for the vertigo on [b6] after seeing my neurologist. I took [b6] and did not have improvement with the R facial droop or R side weakness and the headaches have persisted, along with some dizziness and nausea. On [b6] I had increased shortness of breath and R lung felt like it was not inflating much, and [b6] and went onto [b6] which did help my lungs to improve, and I was able to breathe better, and got my Right lung capacity back.

I stopped the [b6] to manage through the symptoms without it, and have been [b6] (but the Dr does not think it is that sort of issue, but that [b6] would help). I had [b6] after an in-person neurology appointment, and was having some improvement with the vertigo, so I [b6] [b6] but I was still having the constant headache, nausea, and some dizziness, R face droop, R hand weakness, R leg weakness and walk with a walking stick, and have increased issues with exertion, but have been walking and doing therapies to get stronger.3 I started to have increased R facial droop. [b6] of my R arm. Worse headache, nausea, dizziness at the desk, and fatigue, but R side weakness issues increased, so I started back onto [b6] [b6] but had increasingly bad headache, nausea and increasing R facial droop, and much worse R hand weakness, R arm weakness and pain, and R hip pain and weakness, worse walking, cannot lift my R leg or foot as high as the L, again, and am struggling to walk, and get worse with exertion with R side walking and weakness. I also had shooting pains in my R jaw start on [b6] along with R jaw and face pain and increased numbness, more face droop shooting pains in my R hip, and arm and body pain and a worse headache making it hard to even sleep, and some increased issues with my R eye that I need to have checked. R hip jerking and awakening me multiple times a night the last few days [b6] [b6] after a video visit with the neurologist. Increased R leg weakness, R weak hip vs left, R foot drag/drop, with increased issues to maintain walking with progressive walking, still using walking stick to try to walk, but now for stability and to keep from drifting, R facial droop increasing and now some R eye blurring [b6] onwards, that is new. R eye found to have some tear film issues, so I have [b6] for that.

History from last year.

I also was sick from very early in [b6] (but I had what I thought was allergies 6 days prior which I now question) with significant respiratory cough but no wheezing, deep pain in the low center of my chest, fever, headache, increasing shortness of breath by day 6, diarrhea, was getting worse and my Drs had me on [b6] which halted my lung issue progression enough, plus [b6] I had the loss of taste and smell, then red tips of my fingers and weaker grip on the fingers bilaterally with cardiac arrhythmias, tachycardia, dizziness [b6] constant headaches, heart rate issues, skipped beats [b6] [b6] continued low lung capacity and [b6] brain fog, and relapses of all these issues, including my sense of taste and smell going away with each relapse. I also lost hair in clumps in [b6] after being so sick.

I have weird patches of rash that reappear in the same places, that never existed before this illness, that started in [b6] on my back of my neck, chest, wrists and arms. I shared photos to my Drs, and they prescribed [b6]

I was [b6] until the cardiac issues resolved, and [b6] but still was dealing with headaches, brain fog, fatigue, and feeling less stable after more exertion, so I asked for my husband to buy me hiking sticks for my birthday [b6] mostly because I was just still not feeling great, and was trying to do more exercise and get stronger. After stationary biking in [b6] light amount, for 10 min, later that night I would start to cause shooting nerve pains up and down my leg, keeping me up at night for a few days. I never had that before. So, I did not use a stationary bike for a month, then tried it again, the same thing happened, so I never biked again, and did not have that since the nerve stuff.

I never fully recovered from the [b6] sequelae and issues, but pushed through [b6] [b6] and would come home and collapse, barely able to bathe and then rest, then cook dinner and go to bed, so I was not exactly "recovered" before I got my COVID vaccines, but was managing, and still had the fatigue, brain fog and such, but did not expect this. I have never had vertigo in my life until now.

b6

b6

[b6] and had a significant systemic inflammatory, mostly neuro and respiratory inflammatory phase from 5 weeks onwards that involved a relapse of severe deep lung pain, pallor, cracked lips, severe headache for over 6 weeks, [b6] [b6] with progressive neuro issues with the constant headache that involved bilateral numb fingers and toes, that led to progressive hand and leg weakness, and not being able to support his weight on his legs, and weakness to above his knees bilaterally, and having some very odd absence-seizure-like issues with all of this, which thankfully the leg weakness started to reverse, and the issues calmed down but he had a few relapses over the summer, but not as severe as this. So, he saw a neurologist for that, and had lots of tests.

He also has an unusual history and [b6] [b6] past history of triggered flaring of joint, GI, lung, headache, sometimes odd rashes, sometimes elevated inflammatory markers triggered after infections, and can be very prolonged, but he had been doing well prior to getting sick in [b6]

b6

He has had one dose of the Pfizer vaccine, and did have a headache, chills and fatigue, pain at the vaccine site for a few days, but nothing serious. He is due for dose #2 on [b6]

I have been trying to get help from the CDC CISA program, and submitted a request a few months ago. I also have asked my Dr to try to help on that too, as the CISA location for the west is at the [b6] I am not sure who he has contacted, outside his neuro colleagues, but he is open to suggestions.

This is the person that I think is over the west coast CISA, that I have asked my Dr to contact, and I have tried to reach, but I have not yet emailed. I will try again, but have not dared email, as I had hoped that my Dr would reach out, as [b6] have tried to call a few times. I called the CDC and emailed in a request for a referral too, with no luck for this program. I know they are busy, but I had hoped they would help me.

b6

b6

b6

I also asked my neurologist to submit my case to this registry for COVID vaccine neuro events too, but I am not sure that he has, but I think it makes sense to collaborate:

<https://www.liverpool.ac.uk/covid-neuro-network/>. Do you work with this group too?

Note that I am 100% pro-vaccine, and have kept my story private, and most of my family, outside my kids and my mom who has been sworn to secrecy have not heard, and I have hidden this from colleagues at work too, but they do know something happened, and about the vertigo and R side weakness, but I think "through the grapevine" as I have tried to keep it quiet, and have not gone to the media, etc.

But I need help, and also we are trying to figure out what to do for

b6

b6

b6

After what happened [b6] with our bad illness and prolonged issues for me about what could happen to [b6], so he really wants to get the vaccine, but has concerns about that too, with his history, and now what has happened to me.

Sorry for the novel. If you are able to help, that would be amazing, but if not, please share any suggestions, and feel free to contact my Dr, [b6] or anyone.

Thank you,

[b6]

On Mon, May 31, 2021 at 7:07 AM Goldbach-Mansky, Raphaela (NIH/NIAID) [E] [b6]

[b6] wrote:

Dear [b6]

I received an e-mail back from Dr Nath, a neurologist and his colleagues who are suggesting that you contact them for further advice and possibly consultation. Please go ahead. I highlighted the e-mail addresses.

Raphaela

Raphaela Goldbach-Mansky, M.D., MHS

TADS/LCIM/NIAID

REL0000231010

phone: [b6]

fax: 301 480 4953

e-mail: [b6]

From: "Nath, Avindra (NIH/NINDS) [E]" [b6]
Date: Monday, May 31, 2021 at 9:03 AM
To: "Goldbach-Mansky, Raphaela (NIH/NIAID) [E]" [b6]
Cc: "Smith, Bryan (NIH/NINDS) [E]" [b6] "Safavi, Farinaz (NIH/NINDS) [E]" [b6]
Subject: Re: Post COVID vaccine study

We do not have a specific protocol but have seen a number of them. Sounds like [b6]
[b6] We can talk to the patient to see what we can do to help. You can share our contact information with her

Avi

Avindra Nath MD

Dear Avi,

I hope you are enjoying the long weekend. Mike Sneller told me about you protocol assessing neurologic complications post COVID vaccine.

[b6] developed severe neck pain and headaches, dizziness, vertigo and nausea with in 48 hours after the first COVID shot which got better and then she developed [b6] after the second shot.

She is not getting much better after [b6] Would she qualify for your protocol and if so who should she contact?

Kind regards,

Raphaela

Raphaela Goldbach-Mansky, M.D., MHS

Senior Investigator

Chief, Translational Autoinflammatory Diseases Section (TADS)

Laboratory of Clinical Immunology and Microbiology, LCIM

NIAID/NIH

Bldg.10 room 11C205, MSC1960

10 Center Dr.

Bethesda, MD 20892

phone: b6

fax: 301 480 4953

e-mail: b6

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From: [b6]
Sent: 6/9/2021 2:15:42 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
CC: Gustafson, Lindsey (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=5bcc895932d544e4a2f36eb6f9388adb [b6] Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540 [b6]
Subject: Re: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

Dear Doctors,

Thank you, and sorry to bother you while out of the country!

I can do any labs that you want.

Amanda was going to FedEx a lab kit to me tomorrow to have labs done, that are to be drawn, centrifuged and put into 4 little aliquots and sent with frozen ice packs for research labs.

I added her to this email to see if other specimens and supplies can be added to this shipment..

I can get labs drawn before [b6] I contacted [b6] [b6] and I will be going to the lab first, early in the morning to do any labs, and they said they could process and ship them.

If you mail everything needed to me, for then to use for the samples to be put into vials, frozen, and shipped, that would be helpful. The labs can access dry ice, but need the instructions, shipping labels, etc.

b6

If there are additional labs wanted, please let me know.

If you prefer Quest to do the lab that needs to be frozen, I can do that this week. I just need the info for them. Since it would be frozen, it could ship next week.

I can also ask the neurologist to order tests, and try to get him to help with this. He has not added anything new to do, but he will do anything suggested.

I have had frozen samples sent in the past for [b6] but it been a long time. I can make it happen somehow.

I have to [b6] [b6] but will be up early if you need to call or after [b6]

I want to give you any samples wanted, and thank you for your dedication.

FYI my WES data [b6] is with the NAIAD and Dr Goldbach-Mansky can share it with you for the raw WES data.

REL0000231074

Thank you,

b6

On Tue, Jun 8, 2021, 6:20 PM Safavi, Farinaz (NIH/NINDS) [E] b6 wrote:

b6

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

I cc our NP Lee to send you the list.

Lee, Can you please send the list of labs we usually send for post vaccine complications to b6 however based on your symptoms you may not need all of them and require others that I defer to your neurologist.

Unfortunately I can not provide further information until ai return and speak with you and b6 most likely affect many tests if we dont run them beforehand.

Can you send us some serum before b6 (red top or SST, spun down and frozen serum)?

Thanks

Farinaz

From: b6
Sent: Tuesday, June 8, 2021 11:27:43 PM
To: Safavi, Farinaz (NIH/NINDS) [E] b6
Cc: Nath, Avindra (NIH/NINDS) [E] b6 Smith, Bryan (NIH/NINDS) [E] b6
Wiebold, Amanda (NIH/NINDS) [E] b6
Subject: Re: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

Dear Dr Safavi,

I have done the consent with Ms Wiebold RN, and have submitted the forms, and consent to review my medical records.

I also have requested that my medical records, and b6 be sent to you from b6 and will follow up on that, but I gave you most of the essential documents for 2021 in the past attachment.

Dr Safavi said in a prior email: "I can send you the list of labworks we usually send for post vaccine adverse events before b6 Hope it helps."

b6 is still scheduled for b6 Mr neurologist is willing to order any labs that are wanted, but he would need a list to do that in the next few days.

I am not sure if you contacted him, but if you make a list, or a letter with a list, I can get that to him to order for me. He has nothing planned for pre-labs at this time. b6 is my neurologist, and his office number is b6

I will also be working on getting my lab drawn at Quest for your study lab, and will try to set up an appointment to get that done before b6

I can even get labs drawn on a Sunday with [b6] but the sample would not be able to be shipped out until Monday, and I am not sure if that is acceptable for your study, but [b6] lab is open on weekends, and I know them well.

Thanks,

[b6]

[b6]

[b6]

[b6]

[b6]

[b6]

On Sun, Jun 6, 2021 at 5:00 PM [b6] wrote:
Dear Dr Farinaz and Dr Nath,

Thanks so much for your help, even on a weekend! Sorry for more info coming your way. Hopefully this will help to get things going, and your nurse can call me at [b6] or my cell at [b6] to consent anytime tomorrow (Pacific time zone, but I will answer anytime.)

To answer your questions:

[b6]

My neurologist is willing to do anything recommended. Here are the only labs done on me since my fFizer vaccine reactions

My [b6] dates are for [b6] I could not get anything sooner.

I have attached a full document of all the [b6] and also some info from the past 14 months on anything of relevance.

I did not include much on my resolved issues, but focused more on the neuro-related stuff, but I can send you much more if you want on more details of my complex, prolonged, relapsing post viral issues since [b6]

b6 that I had most of the common COVID-19 type symptoms, including the loss of taste and smell, diarrhea around day 6 onwards, when my lung issues and shortness of breath got worse, fever, brain fog, weird red tips of the fingers for weeks, cardiac arrhythmias, tachycardia, deep lung pain but no wheezing, dry cough, severe headaches, and so much more.

Note also past issues with **b6** in the document, and past issues with **b6** **b6** is in the document.

LABS DONE in 2021:

b6

Current medications:

b6

Are you working. with the COVID-Neuro Network - Vaccine neurological adverse events following immunisation (AEFI)?

<https://www.liverpool.ac.uk/covid-vaccine-neuro-ac/>

I asked my Dr to submit, but I don't think he has, but I think it would be good.

I really appreciate your help, and caring. Sorry for the info overload, but I thought it would help to decide on what you wanted to do.

Thanks so much. It really means a lot to have your willingness to help in any way possible. And I hope my info can help your research to benefit others too.

Best regards,

b6

On Sun, Jun 6, 2021, 12:36 AM Safavi, Farinaz (NIH/NINDS) [E] **b6** wrote:

Dear **b6**

Thank you for your comprehensive history.

I havr afew questions.

b6

b6

I cc our research nurse Amanda to send you paperworks for medical release form and sample only consent. I can send you the list of labworks we usually send for post vaccine adverse events before b6 Hope it helps.
Thank you!

Farinaz

From: Nath, Avindra (NIH/NINDS) [E] b6
Sent: Saturday, June 5, 2021 6:57:21 PM
To: b6 Smith, Bryan (NIH/NINDS) [E] b6 Safavi, Farinaz (NIH/NINDS) [E] b6
Subject: Re: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

Dear b6

Thanks for all the information below. We will review the information and then get back to you.

Avi

Avindra Nath MD

Chief, Section of Infections of the Nervous System

Clinical Director,

National Institute of Neurological Disorders and Stroke

National Institutes of Health, Bethesda, MD

b6

From: b6
Date: Friday, June 4, 2021 at 1:36 AM
To: Nath, Avindra (NIH/NINDS) [E] b6 Smith, Bryan (NIH/NINDS) [E] b6 Safavi, Farinaz (NIH/NINDS) [E] b6
Subject: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

REL0000231074

Dear Doctors,

I tried to call and leave a message, but I know you all must be so busy, especially after the holiday weekend. My cell phone is [b6] and my land line is [b6] Sorry if the details below are more than expected.

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I also [b6] I was [b6] [b6] until after I had my bad and persistent issues after dose #2 of the Pfizer COVID vaccine, but I had reactions to both doses that were intense and unusual. My vaccines were in [b6] and I have had issues ever since!

My WES is at the NIH NIAID, along with [b6]
[b6] You are welcome to look at that too.

I could send you more info, imaging, labs, etc.

Currently: I am still currently dealing with the issues of vertigo, R cranial neuropathy, R facial droop, R outer leg weakness and neurologic changes, R arm and hand still weaker, and have had [b6] on my face (both sides last week), leg, R arm, R wrist.

I use walking sticks due to my R leg issues, and vertigo that makes me unstable, and to be able to walk around more, when not at home. At home, I can grab at narrow hallway walls, chairs etc as needed. I am still on [b6] for the vertigo, and [b6] for the headache [b6] [b6] and have not dared stop the [b6] I have used a R wrist splint but am getting stronger but at half strength (left handed, thank goodness), and also [b6] and trying my best to be overcoming this, and got my R leg to half strength too.

My neurologist is willing to do any suggested testing, treatments, anything. He wants me to have [b6] but it has been difficult to [b6] [b6] so if you want labs, let me know.

[b6]

b6

b6

Pfizer dose #1 **b6**

Onset of symptoms **b6** around 1.5 hrs post vaccine: severe headache, stiff neck ache, dizziness, nausea, chills, extreme fatigue, feverish but below 100.4, severe muscle aches, loss of taste and smell. Loose bowels at times, slept all the rest of the day and night, drank lots of fluids and electrolytes (low sugar). Felt more weak and dizzy the next day, and when walking felt veering right more, more issues with extended activity after the next dose on **b6** onwards, and it has never gone away fully.

R arm pain and raised, tender area at vaccine site continued to hurt for weeks, even into the next dose on **b6** onwards, and has never gone away fully.

b6 I woke up at 5:30 am: sudden-onset shortness of breath, deep lung pain in the center of the chest. I felt like my R lung blocked, and started to cough up large amounts of clear mucus, and vomiting mucus due to my R side middle airway feeling blocked. I did **b6** to try to open my airway, but I was not wheezing, and did not have any respiratory symptoms or illness at the time before this started. (I have **b6** and have not needed it in over a year) I had been having continued less lung capacity for many months prior due to having been very sick in **b6** onwards, including loss of sense of smell and taste, shortness of breath, deep lung pain, fever, No wheezing, not sick.

Pfizer dose #2 **b6** after work. Onset of symptoms by 5:30 pm with headache, dizziness, nausea, extreme fatigue, increased R arm pain at the vaccine site, but it was still hurting at the site from the **b6** shot too, before this dose. Drank fluids and went to bed. Loss of smell and taste returned **b6**. Had continued bad headache from **b6** onwards, with nausea and feeling more dizzy at times, and on **b6** I was at work with increased headache, dizziness and nausea, and went home early from my shift **b6** due to symptoms. Went to bed early, due to continued nausea and headache and dizziness at times. **b6** continued bad headache, then in the afternoon around 3 pm, GI felt bloated, bad nausea, and then felt shortness of breath around 4 pm and faster heart rate **b6** lasting for minutes, despite laying down in bed, so I too used my oximeter (I Have photos) and the sats were **b6** **b6** and had shortness of breath and return of deep internal mid lung pain, and this

lasted for over 10 min. I used [b6] to try to recover, and the sats [b6] No wheezing. Not sick. I had a bad headache and nausea, and was not feeling good and went to bed.

On [b6] I woke up at 5:30 with severe vertigo and dizziness, nausea and a bad headache and could not walk due to the vertigo, and vomited when I was trying to have my head up. I had to crawl to the bathroom on my hands and knees. I called out sick for work due to this and contacted my Dr. I was started [b6] for vertigo, and was taking [b6] to help. [b6] noted my Re upper eyelid was doing a lot of spastic twitching at times, that would stop and start, but did not think about it much. The vertigo was unrelenting and then I started to have Right arm and hand weakness noted on [b6] and was still very dizzy, nauseated and had a constant headache since I got dose #2 of the COVID vaccine on [b6] I was using a walking stick for the dizziness to be stable, and also felt weaker on the R side, and drifting to the right when walking. On [b6] and noticed I could not fully shut my Right eye [b6] and by [b6] my face was drooping. I still had the constant headache, nausea and dizziness, and increased R hand, arm and R leg weakness and R hip weakness. I could not lift my R leg up to walk well, cannot grip well with the R hand, and uncoordinated, and cannot walk straight, and am unstable when trying to walk heel to toe, or even stand still with my eyes shut, and have had some double vision with the R eye. I was started on [b6] for the vertigo on [b6] after seeing my neurologist. I took [b6] and did not have improvement with the R facial droop or R side weakness and the headaches have persisted, along with some dizziness and nausea. On [b6] I had increased shortness of breath and R lung felt like it was not inflating much, and [b6] and went onto [b6] which did help my lungs to improve, and I was able to breathe better, and got my Right lung capacity back.

I stopped the [b6] to manage through the symptoms without it, and have been doing [b6] (but the Dr does not think it is that sort of issue, but that [b6] would help). I had [b6] after an in-person neurology appointment, and was having some improvement with the vertigo, so I started [b6] but I was still having the constant headache, nausea, and some dizziness, R face droop, R hand weakness, R leg weakness and walk with a walking stick, and have increased issues with exertion, but have been walking and doing therapies to get stronger. I started to have increased R facial droop. [b6] of my R arm. Worse headache, nausea, dizziness at the desk, and fatigue, but R side weakness issues increased, so I started back onto [b6] [b6] but had increasingly bad headache, nausea and increasing R facial droop, and much worse R hand weakness, R arm weakness and pain, and R hip pain and weakness, worse walking, cannot lift my R leg or foot as high as the L, again, and am struggling to walk, and get worse with exertion with R side walking and weakness. I also had shooting pains in my R jaw start on [b6] along with R jaw and face pain and increased numbness, more face droop shooting pains in my R hip, and arm and body pain and a worse headache making it hard to even sleep, and some increased issues with my R eye that I need to have checked. R hip jerking and awakening me multiple times a night the last few days on [b6] [b6] after a video visit with the neurologist. Increased R leg weakness, R weak hip vs left, R foot drag/drop, with increased issues to maintain walking with progressive walking, still using walking stick to try to walk, but now for stability and to keep from drifting, R facial droop increasing and now some R eye blurring [b6] onwards, that is new. R eye found to have some tear film issues, so I have [b6] for

that.

History from last year.

I also was sick from very early in [b6] (but I had what I thought was allergies 6 days prior which I now question) with significant respiratory cough but no wheezing, deep pain in the low center of my chest, fever, headache, increasing shortness of breath by day 6, diarrhea, was getting worse and my Drs had me on [b6] which halted my lung issue progression enough, plus [b6] I had the loss of taste and smell, then red tips of my fingers and weaker grip on the fingers bilaterally with cardiac arrhythmias, tachycardia, dizziness [b6] constant headaches, heart rate issues, skipped beats [b6] continued low lung capacity and [b6] brain fog, and relapses of all these issues, including my sense of taste and smell going away with each relapse. I also lost hair in clumps in [b6] after being so sick.

I have weird patches of rash that reappear in the same places, that never existed before this illness, that started in [b6] on my back of my neck, chest, wrists and arms. I shared photos to my Drs, and they prescribed [b6]

I was [b6] until the cardiac issues resolved, and [b6] but still was dealing with headaches, brain fog, fatigue, and feeling less stable after more exertion, so I asked for my husband to buy me hiking sticks for my birthday [b6] mostly because I was just still not feeling great, and was trying to do more exercise and get stronger. After stationary biking in [b6] light amount, for 10 min, later that night I would start to cause shooting nerve pains up and down my leg, keeping me up at night for a few days. I never had that before. So, I did not use a stationary bike for a month, then tried it again, the same thing happened, so I never biked again, and did not have that since the nerve stuff.

I never fully recovered from the [b6] sequelae and issues, but pushed through [b6] [b6] and would come home and collapse, barely able to bathe and then rest, then cook dinner and go to bed, so I was not exactly "recovered" before I got my COVID vaccines, but was managing, and still had the fatigue, brain fog and such, but did not expect this. I have never had vertigo in my life until now.

b6

b6

b6 and had a significant systemic inflammatory, mostly neuro and respiratory inflammatory phase from 5 weeks onwards that involved a relapse of severe deep lung pain, pallor, cracked lips, severe headache for over 6 weeks, **b6**
b6 with progressive neuro issues with the constant headache that involved bilateral numb fingers and toes, that led to progressive hand and leg weakness, and not being able to support his weight on his legs, and weakness to above his knees bilaterally, and having some very odd absence-seizure-like issues with all of this, which thankfully the leg weakness started to reverse, and the issues calmed down but he had a few relapses over the summer, but not as severe as this. So, he saw a neurologist for that, and had lots of tests.

He also has an unusual history and **b6**
b6 past history of triggered flaring of joint, GI, lung, headache, sometimes odd rashes, sometimes elevated inflammatory markers triggered after infections, and can be very prolonged, but he had been doing well prior to getting sick in **b6**

b6

He has had one dose of the Pfizer vaccine, and did have a headache, chills and fatigue, pain at the vaccine site for a few days, but nothing serious. He is due for dose #2 on **b6**

I have been trying to get help from the CDC CISA program, and submitted a request a few months ago. I also have asked my Dr to try to help on that too, as the CISA location for the west is at the **b6** I am not sure who he has contacted, outside his neuro colleagues, but he is open to suggestions.

This is the person that I think is over the west coast CISA, that I have asked my Dr to contact, and I have tried to reach, but I have not yet emailed. I will try again, but have not dared email, as I had hoped that my Dr would reach out, as **b6** I have tried to call a few times. I called the CDC and emailed in a request for a referral too, with no luck for this program. I know they are busy, but I had hoped they would help me.

b6

b6

b6

I also asked my neurologist to submit my case to this registry for COVID vaccine neuro events too, but I am not sure that he has, but I think it makes sense to collaborate:

<https://www.liverpool.ac.uk/covid-neuro-network/>. Do you work with this group too?

Note that I am 100% pro-vaccine, and have kept my story private, and most of my family, outside my kids and my mom who has been sworn to secrecy have not heard, and I have hidden this from colleagues at work too, but they do know something happened, and about the vertigo and R side weakness, but I think "through the grapevine" as I have tried to keep it quiet, and have not gone to the media, etc.

But I need help, and also we are trying to figure out what to do for:

b6

b6

After what happened **b6** with our bad illness and prolonged issues for me about what could happen to **b6** so he really wants to get the vaccine, but has concerns about that too, with his history, and now what has happened to me.

Sorry for the novel. If you are able to help, that would be amazing, but if not, please share any suggestions, and feel free to contact my Dr. **b6** or anyone.

Thank you,

b6

On Mon, May 31, 2021 at 7:07 AM Goldbach-Mansky, Raphaela (NIH/NIAID) [E]

b6

b6

wrote:

Dear

b6

I received an e-mail back from Dr Nath, a neurologist and his colleagues who are suggesting that you contact them for further advice and possibly consultation. Please go ahead. I highlighted the e-mail addresses.

Raphaela

Raphaela Goldbach-Mansky, M.D., MHS

TADS/LCIM/NIAID

phone:

b6

fax: 301 480 4953

e-mail:

b6

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

b6

Date: Monday, May 31, 2021 at 9:03 AM

To: "Goldbach-Mansky, Raphaela (NIH/NIAID) [E]"

b6

Cc: "Smith, Bryan (NIH/NINDS) [E]"

b6

"Safavi, Farinaz (NIH/NINDS) [E]"

b6

Subject: Re: Post COVID vaccine study

We do not have a specific protocol but have seen a number of them. Sounds like

b6

b6 We can talk to the patient to see what we can do to help. You can share our contact information with her

Avi

Avindra Nath MD

Dear Avi,

I hope you are enjoying the long weekend. Mike Sneller told me about your protocol assessing neurologic complications post COVID vaccine.

[b6] developed severe neck pain and headaches, dizziness, vertigo and nausea within 48 hours after the first COVID shot which got better and then she developed [b6] after the second shot.

She is not getting much better after [b6] Would she qualify for your protocol and if so who should she contact?

Kind regards,

Raphaella

Raphaella Goldbach-Mansky, M.D., MHS

Senior Investigator

Chief, Translational Autoinflammatory Diseases Section (TADS)

Laboratory of Clinical Immunology and Microbiology, LCIM

NIAID/NIH

Bldg. 10 room 11C205, MSC1960

10 Center Dr.

Bethesda, MD 20892

REL0000231074

phone: **b6**

fax: 301 480 4953

e-mail: **b6**

From: Wiebold, Amanda (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=4491EE2AE9804610899C741100150540] [b6]
Sent: 10/4/2021 3:40:39 PM
To: [b6]
Subject: RE: Hello-I did all the labs-Mayo ended up not running them. I have chased them down for months, Please advise

Ok. Thank you. I will send an invitation shortly.

Thanks,
Amanda

From: [b6]
Sent: Monday, October 4, 2021 11:20 AM
To: Wiebold, Amanda (NIH/NINDS) [E] [b6]
Subject: Re: Hello-I did all the labs-Mayo ended up not running them. I have chased them down for months, Please advise

Dear Amanda,

I can do either of those times. You can decide what is best.

Also, I will send you more labs that were done prior to [b6] that were not sent to Mayo, but I just got the results-somehow they were not sent to my Dr. These are some tests your team wanted.

I will get those to you all today.

Thanks,

[b6]

On Mon, Oct 4, 2021, 5:35 AM Wiebold, Amanda (NIH/NINDS) [E] [b6] wrote:

Hello [b6]

I will need to change your appointment. Are you available tomorrow at 4:00 PM EDT (1:00 PM PDT) or Wednesday at 2:00 PM EDT (11:00 AM PDT)?

Thanks,

Amanda

From: [b6]
Sent: Sunday, September 26, 2021 4:56 PM

REL0000231169

To: Wiebold, Amanda (NIH/NINDS) [E] [b6]

Subject: Re: Hello-I did all the labs-Mayo ended up not running them. I have chased them down for months, Please advise

Dear Ms Diebold,

Thank you! I can be available on October 8th at that time.

My neurologist is reordering the labs not able to be run at Mayo for me to do before [b6]

Also, I have asked the NIAID team under Dr Goldbach-Mansky to share the WES data for me with your team, and I am also willing to consent for them to look at [b6]

[b6]
[b6] His neurologist and rheumatologist are aware of my case, and I have said that they can talk to my neurologist as well. [b6] was vaccinated against COVID-19 in [b6] He has been found to have hypertrophy of his hip and back muscles on the L side of his torso, and less on the R, and we will be getting [b6] but his R leg was more weal last year after his post-viral inflammatory issues with a severe headache for 6 wks, with numbness and tingling of the fingers and toes, then progressing to hand and leg weakness, stopping above the knees bilaterally, [b6]
[b6] cracked lips, pallor, joint and body pain, fatigue and the headache was continuous, and he had a few flare ups after it, but has managed through for months with minor spells of headaches and joint pains, until the past few months.

[b6]

I have a [b6] and I have asked for [b6]

[b6]

[b6]

Thanks so much,

b6

On Fri, Sep 24, 2021, 3:39 PM Wiebold, Amanda (NIH/NINDS) [E] b6 wrote:

Hi b6

Dr. Nath and Dr. Safavi would like to set up a meeting to talk with you. Are you available Friday, October 8, 2021 at 3:00 PM EDT (12:00 noon PDT)?

Thanks,

Amanda

From: b6
Sent: Monday, September 13, 2021 5:06 PM
To: Wiebold, Amanda (NIH/NINDS) [E] b6 Nath, Avindra (NIH/NINDS) [E]
b6
Cc: Gustafson, Lindsey (NIH/NINDS) [E] b6 Safavi, Farinaz (NIH/NINDS) [E]
b6
Subject: Hello-I did all the labs-Mayo ended up not running them. I have chased them down for months, Please advise

Dear Doctors,

I am devastated to let you know that I did all the recommended Mayo sendout labs before b6 and my hospital had tried to find out what happened as the reports said Final, but I had to do my own work to find these labs, and got this message today from Mayo:

I am so sorry, and absolutely devastated. I have all the other labs ordered from b6 below this note. I wanted to contact you sooner, but had been trying to get all the results for you. I hope that you can still help me. Sorry for all the info below, but I wanted to update you, and ask for your help. Thank you for all you have done, and for your consideration.

I now have very little to give you from most of the tests you wanted, and I am not sure if your lab samples that were sent to you were able to be used.

Also, I am advised to get a booster dose #3 of my Pfizer COVID vaccine, yet I had all these now chronic neuro issues arise, starting with the vaccine, and some respiratory issues hit with each dose that were not long, but notable.

I am still not able to [b6] due to my continued, chronic and regressive neuro issues
[b6]

I do not know what to do for a booster dose! I need some help on sorting out the next steps, and really, really wanted to see the results of those Mayo COVID-19 labs you had ordered. I need help. Not getting much help on this, and I am asking for a referral to an immunologist, and would like some advice on next steps on [b6]

I am now getting [b6] how can I go about more testing? [b6] offered me a booster COVID vaccine dose this week, and I said I needed more advice before doing that, and with my history, I am not sure I should do that with [b6] but no one really seems to want to sort me out. I am so sorry. I am devastated.

The CDC VAERS wanted more of my files months ago, as I still have issues, and they were sent everything that I had before June. They have not responded, not asked for more info, and never got back to me for a referral to the CDC CISA program.

I have asked my neurologist to refer me to [b6] and immunologist and vaccine specialist at the [b6] [b6] that manages the west coast CDC CISA-no word on that. I have tried to call, but have not yet emailed, as I want to see if my Dr will try first.

The only good news is that the [b6]

[b6]

[b6]

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LABS THAT WE DID GET

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b6

Please note that these were done at Quest, and their reference range is NOT the same as Mayo, and on their site, they say to use their reference range for this test.

My neurologist has not really pursued [b6] and I think it is worth sorting out. I really need to sort out my unusual past medical history, even before last year and the current issues since my Pfizer COVID-19 vaccine in

[b6]

It was sent there by our lab, vs Mayo but I guess that is a blessing, since I got at least that lab result, and I would like more help on that.

Please help me if possible! I am [b6] but need to be better for me too, and also not get sick from COVID, and I just do not know my risk.

I have had a history of [b6]

b6

I have never been offered, nor had a [b6] I know that is used for immune studies. I will try to pursue this more.

Even [b6] has not been helpful for years, as I have felt that [b6]

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Best regards and with the deepest gratitude,

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b6

On Thu, Jun 10, 2021 at 9:46 AM Wiebold, Amanda (NIH/NINDS) [E] **b6** wrote:

Dr. Safavi and Lee,

Dr. Safavi in your email below to **b6** there was mention that a list of labs will be sent to her. Labs that you have been recommending for post vaccine patients having complications. I want to close the loop because I am not sure if Lee was actually copied on that email or not but **b6** has not received the list of labs yet. She is scheduled for **b6**

Thanks,

Amanda

On Tue, Jun 8, 2021, 6:20 PM Safavi, Farinaz (NIH/NINDS) [E] **b6** wrote:

b6

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

I cc our NP Lee to send you the list.

Lee, Can you please send the list of labs we usually send for post vaccine complications to [b6]

however based on your symptoms you may not need all of them and require others that I defer to your neurologist.

Unfortunately I can not provide further information until ai return and speak with you and [b6] most likely affect many tests if we dont run them beforehand.

Can you send us some serum before [b6] (red top or SST, spun down and frozen serum)?

Thanks

Farinaz

From: [b6]
Sent: Tuesday, June 8, 2021 11:27:43 PM
To: Safavi, Farinaz (NIH/NINDS) [E]; [b6]
Cc: Nath, Avindra (NIH/NINDS) [E]; [b6] Smith, Bryan (NIH/NINDS) [E]; [b6]
Wiebold, Amanda (NIH/NINDS) [E]; [b6]
Subject: Re: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

Dear Dr Safavi,

I have done the consent with Ms Wiebold RN, and have submitted the forms, and consent to review my medical records.

I also have requested that my medical records, and [b6] be sent to you from [b6] and will follow up on that, but I gave you most of the

essential documents for 2021 in the past attachment.

Dr Safavi said in a prior email: "I can send you the list of labworks we usually send for post vaccine adverse events before **b6** Hope it helps."

b6 is still scheduled for **b6** Mr neurologist is willing to order any labs that are wanted, but he would need a list to do that in the next few days.

I am not sure if you contacted him, but if you make a list, or a letter with a list, I can get that to him to order for me. He has nothing planned for pre-labs

at this time. **b6** is my neurologist, and his office number is **b6**

I will also be working on getting my lab drawn at Quest for your study lab, and will try to set up an appointment to get that done before **b6**

I can even get labs drawn on a Sunday with **b6** but the sample would not be able to be shipped out until Monday, and I am not sure

if that is acceptable for your study, but **b6** lab is open on weekends, and I know them well.

Thanks,

b6

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b6

b6

From: [b6]
Sent: 9/13/2021 9:06:12 PM
To: Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540 [b6] Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
CC: Gustafson, Lindsey (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=5bcc895932d544e4a2f36eb6f9388adb [b6] Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Hello-I did all the labs-Mayo ended up not running them. I have chased them down for months, Please advise
Attachments: [b6].pdf

Dear Doctors,

I am devastated to let you know that I did all the recommended Mayo sendout labs before [b6] and my hospital had tried to find out what happened as the reports said Final, but I had to do my own work to find these labs, and got this message today from Mayo:

b6

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[b6]

I am now [b6] how can I go about more testing? [b6] offered me a booster COVID vaccine dose this week, and I said I needed more advice before doing that, and with my history, I am not sure I should do that with [b6] but no one really seems to want to sort me out. I am so sorry. I am devastated.

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I have asked my neurologist to refer me to Dr Klein, and immunologist and vaccine specialist at the Kaiser Division of Research that manages the west coast CDC CISA-no word on that. I have tried to call, but have not yet emailed, as I want to see if my Dr will try first.

The only good news is that [b6]

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LABS THAT WE DID GET

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b6

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Best regards and with the deepest gratitude,

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Thanks,

Amanda

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[b6]

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

I cc our NP Lee to send you the list.

Lee, Can you please send the list of labs we usually send for post vaccine complications to [b6]

however based on your symptoms you may not need all of them and require others that I defer to your neurologist.

Unfortunately I can not provide further information until ai return and speak with you and [b6] most likely affect many tests if we dont run them beforehand.

Can you send us some serum before [b6] (red top or SST, spun down and frozen serum)?

Thanks

Farinaz

From: [b6]

Sent: Tuesday, June 8, 2021 11:27:43 PM

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

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

[b6] Wiebold, Amanda (NIH/NINDS) [E]: [b6]

Subject: Re: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

Dear Dr Safavi,

REL0000231170

I have done the consent with Ms Wiebold RN, and have submitted the forms, and consent to review my medical records.

I also have requested that my medical records, and [b6] be sent to you from [b6] and will follow up on that, but I gave you most of the

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I can even get labs drawn on a Sunday with [b6] but the sample would not be able to be shipped out until Monday, and I am not sure

if that is acceptable for your study, but [b6] lab is open on weekends, and I know them well.

Thanks,

[b6]

b6

b6

b6

b6

On Sun, Jun 6, 2021 at 5:00 PM, [b6] wrote:

Dear Dr Farinaz and Dr Nath,

Thanks so much for your help, even on a weekend! Sorry for more info coming your way. Hopefully this will help to get things going, and your nurse can call me at [b6] or my cell at [b6] to consent anytime tomorrow (Pacific time zone, but I will answer anytime.)

To answer your questions:

b6

My neurologist is willing to do anything recommended. Here are the only labs done on me since my fFizer vaccine reactions

My [b6] are for [b6] I could not get anything sooner.

I have attached a full document of all the [b6] and also some info from the past 14 months on anything of relevance.

I did not include much on my resolved issues, but focused more on the neuro-related stuff, but I can send you much more if you want on more details of my complex, prolonged, relapsing post viral issues since [b6] [b6] that I had most of the common COVID-19 type symptoms, including the loss of taste and smell,, diarrhea around day 6 onwards, when my lung issues and shortness of breath got worse, fever, brain fog, weird red tips of the fingers for weeks, cardiac arrhythmias, tachycardia, deep lung pain but no wheezing, dry cough, severe headaches, and so much more.

Note also past issues with [b6] in the document, and past issues with [b6] [b6] is in the document.

LABS DONE in 2021:

b6

b6

Current medications:

b6

b6

Are you working. with the COVID-Neuro Network - Vaccine neurological adverse events following immunisation (AEFI)?

<https://www.liverpool.ac.uk/covid-vaccine-neuro-ae/>

I asked my Dr to submit, but I don't think he has, but I think it would be good.

I really appreciate your help, and caring. Sorry for the info overload, but I thought it would help to decide on what you wanted to do.

Thanks so much. It really means a lot to have your willingness to help in any way possible. And I hope my info can help your research to benefit others too.

Best regards,

b6

On Sun, Jun 6, 2021, 12:36 AM Safavi, Farinaz (NIH/NINDS) [E] b6 wrote:

Dear b6

Thank you for your comprehensive history.

I havr afew questions.

b6

b6

I cc our research nurse Amanda to send you paperworks for medical release form and sample only consent.

I can send you the list of labworks we usually send for post vaccine adverse events before **b6** Hope it helps.

Thank you!

Farinaz

From: Nath, Avindra (NIH/NINDS) [E] **b6**
Sent: Saturday, June 5, 2021 6:57:21 PM
To: **b6** Smith, Bryan (NIH/NINDS) [E]
b6 Safavi, Farinaz (NIH/NINDS) [E] **b6**
Subject: Re: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

Dear **b6**

Thanks for all the information below. We will review the information and then get back to you.

Avi

Avindra Nath MD

Chief, Section of Infections of the Nervous System

Clinical Director,

National Institute of Neurological Disorders and Stroke

National Institutes of Health, Bethesda, MD

b6

From: [b6]
Date: Friday, June 4, 2021 at 1:36 AM
To: Nath, Avindra (NIH/NINDS) [E]; [b6] Smith, Bryan (NIH/NINDS) [E]
[b6] Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

Dear Doctors,

I tried to call and leave a message, but I know you all must be so busy, especially after the holiday weekend. My cell phone is [b6] and my land line is [b6] Sorry if the details below are more than expected.

I have my story below, and give you permission to use it as needed. I have shared a lot of this in the VAERS report too. No one ever has followed up with me from the CDC.

I also [b6] I was [b6]
[b6] until after I had my bad and persistent issues after dose #2 of the Pfizer COVID vaccine, but I had reactions to both doses that were intense and unusual. My vaccines were [b6]
[b6] and I have had issues ever since!

My WES is at the NIH NIAID, along with [b6]
[b6] You are welcome to look at that too.

I could send you more info, imaging, labs, etc.

Currently: I am still currently dealing with the issues of vertigo, R cranial neuropathy, R facial droop, R outer leg weakness and neurologic changes, R arm and hand still weaker, and have had [b6] on my face (both sides last week), leg, R arm, R wrist.

I use walking sticks due to my R leg issues, and vertigo that makes me unstable, and to be able to walk around more, when not at home. At home, I can grab at narrow hallway walls, chairs etc as needed. I am still on [b6] for the vertigo, and [b6] for the headache, [b6]
[b6] and have not dared stop the [b6] I have used a R wrist splint but am getting stronger but at half strength (left handed, thank goodness), and also [b6] and trying my best to be overcoming this, and got my R leg to half strength too.

My neurologist is willing to do any suggested testing, treatments, anything. He wants me to have [b6] but it has been difficult to [b6] [b6] so if you want labs, let me know.

b6

b6

Pfizer dose #1 [b6]

Onset of symptoms [b6] around 1.5 hrs post vaccine: severe headache, stiff neck ache, dizziness, nausea, chills, extreme fatigue, feverish but below 100.4, severe muscle aches, loss of taste and smell. Loose bowels at times, slept all the rest of the day and night, drank lots of fluids and electrolytes (low sugar). Felt more weak and dizzy the next day, and when walking felt veering right more, more issues with extended activity after the next dose on [b6] onwards, and it has never gone away fully.

R arm pain and raised, tender area at vaccine site continued to hurt for weeks, even into the next dose on [b6] onwards, and has never gone away fully.

[b6] I woke up at 5:30 am: sudden-onset shortness of breath, deep lung pain in the center of the chest. I felt like my R lung blocked, and started to cough up large amounts of clear mucus, and vomiting mucus due to my R side middle airway feeling blocked. I did [b6] to try to open my airway, but I was not wheezing, and did not have any respiratory symptoms or illness at the time before this started. (I have [b6] and have not needed it in over a year) I had been having continued less lung capacity for many months prior due to having been very sick in [b6] onwards, including loss of sense of smell and taste, shortness of breath, deep lung pain, fever, No wheezing, not sick.

Pfizer dose #2 [b6] after work. Onset of symptoms by 5:30 pm with headache, dizziness, nausea, extreme fatigue, increased R arm pain at the vaccine site, but it was still hurting at the site from the [b6] shot too, before this dose. Drank fluids and went to bed. Loss of smell and taste returned [b6] Had continued bad headache from [b6] onwards, with nausea and feeling more dizzy at times, and on [b6] I was at work with increased headache, dizziness and nausea, and went home early from my shift [b6] due to symptoms. Went to bed early, due to continued nausea and headache and dizziness at times. [b6] continued bad headache, then in the afternoon around 3 pm, GI felt bloated, bad nausea, and then felt shortness of breath around 4 pm and faster heart rate [b6] lasting for minutes, despite laying down in bed, so I too used my oximeter (I have photos) and the sats were [b6] and had shortness of breath and return of deep internal mid lung pain, and this lasted for over 10 min. I used [b6] to try to recover, and the sats [b6] No wheezing. Not sick. I had a bad headache and nausea, and was not feeling good and went to bed.

On [b6] I woke up at 5:30 with severe vertigo and dizziness, nausea and a bad headache and could not walk due to the vertigo, and vomited when I was trying to have my head up. I had to crawl to the bathroom on my hands and knees. I called out sick for work due to this and contacted my Dr. I was started [b6] for vertigo, and was taking [b6] to help. [b6] noted my Re upper eyelid was doing a lot of spastic twitching at times, that would stop and start, but did not think about it much. The vertigo was unrelenting and then I started to have Right arm and hand weakness noted on [b6] and was still very dizzy, nauseated and had a constant headache since I got dose #2 of the COVID vaccine on [b6] I was using a walking stick for the dizziness to be stable, and also felt weaker on the R side, and drifting to the right when walking. On [b6] and noticed I could not fully shut my Right eye [b6] my face was drooping. I still had the constant headache, nausea and dizziness, and increased R hand, arm and R leg weakness and R hip weakness. I could not lift my R leg up to walk well, cannot grip well with the R hand, and uncoordinated, and cannot walk straight, and am unstable when trying to walk heel to toe, or even stand still with my eyes shut, and have had some double vision with the R eye. I was started on [b6] [b6] for the vertigo on [b6] after seeing my neurologist. I took [b6] [b6] and did not have improvement with the R facial droop or R side weakness and the headaches have persisted, along with some dizziness and nausea. On [b6] [b6] I had increased shortness of breath and R lung felt like it was not inflating much, and got [b6] and went onto [b6] which did help my lungs to improve, and I was able to breathe better, and got my Right lung capacity back.

I stopped the [b6] to manage through the symptoms without it, and have been doing [b6] (but the Dr does not think it is that sort of issue, but that [b6] would help). I had [b6] after an in-person neurology appointment, and was having some improvement with the vertigo, so I [b6] but I was still having the constant headache, nausea, and some dizziness, R face droop, R hand weakness, R leg weakness and walk with a walking stick, and have increased issues with exertion, but have been walking and doing therapies to get stronger.3 I started to have increased R facial droop. [b6] of my R arm. Worse headache, nausea, dizziness at the desk, and fatigue, but R side weakness issues increased, so I started back onto [b6] [b6] but had increasingly bad headache, nausea and increasing R facial droop, and much worse R hand weakness, R arm weakness and pain, and R

hip pain and weakness, worse walking, cannot lift my R leg or foot as high as the L, again, and am struggling to walk, and get worse with exertion with R side walking and weakness. I also had shooting pains in my R jaw start on [b6] along with R jaw and face pain and increased numbness, more face droop shooting pains in my R hip, and arm and body pain and a worse headache making it hard to even sleep, and some increased issues with my R eye that I need to have checked. R hip jerking and awakening me multiple times a night the last few days on [b6] [b6] and stopped due to the symptoms I was having, after a video visit with the neurologist. Increased R leg weakness, R weak hip vs left, R foot drag/drop, with increased issues to maintain walking with progressive walking, still using walking stick to try to walk, but now for stability and to keep from drifting, R facial droop increasing and now some R eye blurring [b6] onwards, that is new. R eye found to have some tear film issues, so I have [b6] for that.

History from last year.

I also was sick from very early in [b6] (but I had what I thought was allergies 6 days prior which I now question) with significant respiratory cough but no wheezing, deep pain in the low center of my chest, fever, headache, increasing shortness of breath by day 6, diarrhea, was getting worse and my Drs had me on [b6] which halted my lung issue progression enough, plus [b6] I had the loss of taste and smell, then red tips of my fingers and weaker grip on the fingers bilaterally with cardiac arrhythmias, tachycardia, dizziness [b6] constant headaches, heart rate issues, skipped beats [b6] continued low lung capacity and [b6] brain fog, and relapses of all these issues, including my sense of taste and smell going away with each relapse. I also lost hair in clumps in [b6] after being so sick.

I have weird patches of rash that reappear in the same places, that never existed before this illness, that started in [b6] on my back of my neck, chest, wrists and arms. I shared photos to my Drs, and they prescribed [b6]

I was [b6] until the cardiac issues resolved, and [b6] but still was dealing with headaches, brain fog, fatigue, and feeling less stable after more exertion, so I asked for my husband to buy me hiking sticks for my birthday [b6] mostly because I was just still not feeling great, and was trying to do more exercise and get stronger. After stationary biking in [b6] light amount, for 10 min, later that night I would start to cause shooting nerve pains up and down my leg, keeping me up at night for a few days. I never had that before. So, I did not use a stationary bike for a month, then tried it again, the same thing happened, so I never biked again, and did not have that since the nerve stuff.

I never fully recovered from the [b6] sequelae and issues, but pushed through [b6] [b6] and would come home and collapse, barely able to bathe and then rest, then cook dinner and go to bed, so I was not exactly "recovered" before I got my COVID vaccines, but was managing, and still had the fatigue, brain fog and such, but did not expect this. I have never had vertigo in my life until now.

b6

b6

b6 and had a significant systemic inflammatory, mostly neuro and respiratory inflammatory phase from 5 weeks onwards that involved a relapse of severe deep lung pain, pallor, cracked lips, severe headache for over 6 weeks, **b6**
b6 with progressive neuro issues with the constant headache that involved bilateral numb fingers and toes, that led to progressive hand and leg weakness, and not being able to support his weight on his legs, and weakness to above his knees bilaterally, and having some very odd absence-seizure-like issues with all of this, which thankfully the leg weakness started to reverse, and the issues calmed down but he had a few relapses over the summer, but not as severe as this. So, he saw a neurologist for that, and had lots of tests.

He also has an unusual history and **b6**
b6 past history of triggered flaring of joint, GI, lung, headache, sometimes odd rashes, sometimes elevated inflammatory markers triggered after infections, and can be very prolonged, but he had been doing well prior to getting sick in **b6**

b6

He has had one dose of the Pfizer vaccine, and did have a headache, chills and fatigue, pain at the vaccine site for a few days, but nothing serious. He is due for dose #2 on **b6**

I have been trying to get help from the CDC CISA program, and submitted a request a few months ago. I also have asked my Dr to try to help on that too, as the CISA location for the west is at the **b6** am not sure who he has contacted, outside his neuro colleagues, but he is open to suggestions.

This is the person that I think is over the west coast CISA, that I have asked my Dr to contact, and I have tried to reach, but I have not yet emailed. I will try again, but have not dared email, as I had hoped that my Dr would reach out, as **b6** I have tried to call a few times. I called the CDC and emailed in a request for a referral too, with no luck for this program. I know they are busy, but I had hoped they would help me.

b6

b6

b6

I also asked my neurologist to submit my case to this registry for COVID vaccine neuro events too, but I am not sure that he has, but I think it makes sense to collaborate:

<https://www.liverpool.ac.uk/covid-neuro-network/>. Do you work with this group too?

Note that I am 100% pro-vaccine, and have kept my story private, and most of my family, outside my kids and my mom who has been sworn to secrecy have not heard, and I have hidden this from colleagues at work too, but they do know something happened, and about the vertigo and R side weakness, but I think "through the grapevine" as I have tried to keep it quiet, and have not gone to the media, etc.

But I need help, and also we are trying to figure out what to do for

b6

b6

After what happened **b6** with our bad illness and prolonged issues for me about what could happen to **b6** so he really wants to get the vaccine, but has concerns about that too, with his history, and now what has happened to me.

Sorry for the novel. If you are able to help, that would be amazing, but if not, please share any suggestions, and feel free to contact my Dr. **b6** or anyone.

Thank you,

b6

On Mon, May 31, 2021 at 7:07 AM Goldbach-Mansky, Raphaela (NIH/NIAID) [E] **b6**
b6 wrote:

Dear **b6**

I received an e-mail back from Dr Nath, a neurologist and his colleagues who are suggesting that you contact them for further advice and possibly consultation. Please go ahead. I highlighted the e-mail addresses.

Raphaela

Raphaela Goldbach-Mansky, M.D., MHS

TADS/LCIM/NIAID

phone: **b6**

fax: 301 480 4953

e-mail: **b6**

From: "Nath, Avindra (NIH/NINDS) [E]" **b6**
Date: Monday, May 31, 2021 at 9:03 AM
To: "Goldbach-Mansky, Raphaela (NIH/NIAID) [E]" **b6**
Cc: "Smith, Bryan (NIH/NINDS) [E]" **b6** "Safavi, Farinaz (NIH/NINDS) [E]"

b6

Subject: Re: Post COVID vaccine study

We do not have a specific protocol but have seen a number of them. Sounds like b6

b6 We can talk to the patient to see what we can do to help. You can share our contact information with her

Avi

Avindra Nath MD

Dear Avi,

I hope you are enjoying the long weekend. Mike Sneller told me about you protocol assessing neurologic complications post COVID vaccine.

b6 developed severe neck pain and headaches, dizziness, vertigo and nausea with in 48 hours after the first COVID shot which got better and then she developed b6 after the second shot.

She is not getting much better after b6 Would she qualify for your protocol and if so who should she contact?

Kind regards,

Raphaela

Raphaela Goldbach-Mansky, M.D., MHS

Senior Investigator

Chief, Translational Autoinflammatory Diseases Section (TADS)

REL0000231170

Laboratory of Clinical Immunology and Microbiology, LCIM

NIAID/NIH

Bldg.10 room 11C205, MSC1960

10 Center Dr.

Bethesda, MD 20892

phone: b6

fax: 301 480 4953

e-mail: b6

b6

From: [b6]
Sent: 10/4/2021 7:14:22 PM
To: Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540-[b6] Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6-[b6]
CC: Gustafson, Lindsey (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=5bcc895932d544e4a2f36eb6f9388adb-[b6] Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246-[b6]
Subject: More labs from [b6] were located [b6] In the attached files-a few new labs in the message as image captures
Attachments: [b6].pdf; [b6]
[b6].pdf

Dear All,

I have had new labs done [b6] which were supposed to be sent to Mayo to get the results that you had wanted [b6]

My neurologist located some labs done [b6] that were sent out to other labs [b6] (but not to Mayo) that are attached as files, which includes [b6] [b6] not the testing you wanted from Mayo, but it shows [b6] but I am hoping that the labs sent last week do get run at Mayo for the more specific testing. Other tests also included in the files.

I also had a [b6] so that is good news, but I did not attach it.

Note that these labs for [b6]
[b6]

[b6] helps with the vertigo, headache, brain fog, Right sided weakness and especially fixes my R face droop dramatically each time, but it wears off [b6] and gets worse until the [b6] is given, but now that I am getting it [b6] I think that it has helped more. I can send photos if you want to see the progression, and how things reverse with my face after [b6] [b6] Let me know and I can send some. If we are on zoom, you will see me looking in my better form, since I got [b6]

Thanks,

[b6]

b6

b6

b6

b6

b6

On Mon, Sep 13, 2021 at 2:06 PM **b6** wrote:
Dear Doctors,

I am devastated to let you know that I did all the recommended Mayo sendout labs before **b6** and my hospital had tried to find out what happened as the reports said Final, but I had to do my own work to find these labs, and got this message today from Mayo:

b6

I am so sorry, and absolutely devastated. I have all the other labs ordered from **b6** below this note. I wanted to contact you sooner, but had been trying to get all the results for you. I hope that you can still help me. Sorry for all the info below, but I wanted to update you, and ask for your help. Thank you for all you have done, and for your consideration.

I now have very little to give you from most of the tests you wanted, and I am not sure if your lab samples that were sent to you were able to be used.

Also, I am advised to get a booster dose #3 of my Pfizer COVID vaccine, yet I had all these now chronic neuro issues arise, starting with the vaccine, and some respiratory issues hit with each dose that were not long, but notable.

I am still not able to **b6** **due to my continued, chronic and regressive neuro issues** **b6**

I do not know what to do for a booster dose! I need some help on sorting out the next steps, and really, really wanted to see the results of those Mayo COVID-19 labs you had ordered. I need help. Not getting much help on this, and I am asking for a referral to an immunologist, and would like some advice on next steps on

b6

I am now getting [b6] how can I go about more testing? [b6] offered me a booster COVID vaccine dose this week, and I said I needed more advice before doing that, and with my history, I am not sure I should do that with [b6] but no one really seems to want to sort me out. I am so sorry. I am devastated.

The CDC VAERS wanted more of my files months ago, as I still have issues, and they were sent everything that I had [b6] They have not responded, not asked for more info, and never got back to me for a referral to the CDC CISA program.

I have asked my neurologist to refer me to [b6] and immunologist and vaccine specialist at the [b6] that manages the west coast CDC CISA-no word on that. I have tried to call, but have not yet emailed, as I want to see if my Dr will try first.

b6

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b6

LABS THAT WE DID GET

b6

b6

Please note that these were done at Quest, and their reference range in NOT the same as Mayo, and on their site, they say to use their reference range for this test.

My neurologist has not really pursued b6 more, and I think it is worth sorting out. I really need to sort out my unusual past medical history, even before last year and the current issues since my Pfizer COVID-19 vaccine b6

It was sent there by our lab, vs Mayo but I guess that is a blessing, since I got at least that lab result, and I would like more help on that.

Please help me if possible! I am b6 but need to be better for me too, and also not get sick from COVID, and I just do not know my risk.

b6

I have had a history of

b6

b6

I have never been offered, nor had

b6

I know that is used for immune studies. I will try to pursue this more.

Even my b6 has not been helpful for years, as I have felt that

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Best regards and with the deepest gratitude,

b6

b6

b6

b6

On Thu, Jun 10, 2021 at 9:46 AM Wiebold, Amanda (NIH/NINDS) [E] **b6** wrote:

Dr. Safavi and Lee,

Dr. Safavi in your email below to **b6** there was mention that a list of labs will be sent to her. Labs that you have been recommending for post vaccine patients having complications. I want to close the loop because I am not sure if Lee was actually copied on that email or not but **b6** **b6** has not received the list of labs yet. She is scheduled for **b6**

Thanks,

Amanda

On Tue, Jun 8, 2021, 6:20 PM Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

[b6]

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

I cc our NP Lee to send you the list.

Lee, Can you please send the list of labs we usually send for post vaccine complications to [b6]

however based on your symptoms you may not need all of them and require others that I defer to your neurologist.

Unfortunately I can not provide further information until ai return and speak with you and [b6] most likely affect many tests if we dont run them beforehand.

Can you send us some serum before [b6] (red top or SST, spun down and frozen serum)?

Thanks

Farinaz

From: [b6]

Sent: Tuesday, June 8, 2021 11:27:43 PM

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

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

[b6]

Wiebold, Amanda (NIH/NINDS) [E]

[b6]

Subject: Re: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

REL0000231172

Dear Dr Safavi,

I have done the consent with Ms Wiebold RN, and have submitted the forms, and consent to review my medical records.

I also have requested that my medical records, and [b6] be sent to you from [b6] and will follow up on that, but I gave you most of the

essential documents for 2021 in the past attachment.

Dr Safavi said in a prior email: "I can send you the list of labworks we usually send for post vaccine adverse events before [b6] Hope it helps."

[b6] is still scheduled for [b6] Mr neurologist is willing to order any labs that are wanted, but he would need a list to do that in the next few days.

I am not sure if you contacted him, but if you make a list, or a letter with a list, I can get that to him to order for me. He has nothing planned for pre-labs

at this time. [b6] is my neurologist, and his office number is [b6]

I will also be working on getting my lab drawn at Quest for your study lab, and will try to set up an appointment to get that done before [b6]

I can even get labs drawn on a Sunday with [b6] but the sample would not be able to be shipped out until Monday, and I am not sure

if that is acceptable for your study, but [b6] lab is open on weekends, and I know them well.

Thanks,

[b6]

b6

b6

b6

b6

b6

On Sun, Jun 6, 2021 at 5:00 PM, [b6] wrote:

Dear Dr Farinaz and Dr Nath,

Thanks so much for your help, even on a weekend! Sorry for more info coming your way. Hopefully this will help to get things going, and your nurse can call me at [b6] or my cell at [b6] to consent anytime tomorrow (Pacific time zone, but I will answer anytime.)

To answer your questions:

b6

My neurologist is willing to do anything recommended. Here are the only labs done on me since my fFizer vaccine reactions

My [b6] dates are for [b6] I could not get anything sooner.

I have attached a full document of all the [b6] and also some info from the past 14 months on anything of relevance.

I did not include much on my resolved issues, but focused more on the neuro-related stuff, but I can send you much more if you want on more details of my complex, prolonged, relapsing post viral issues since [b6] that I had most of the common COVID-19 type symptoms, including the loss of taste and smell,, diarrhea around day 6 onwards, when my lung issues and shortness of breath got worse, fever, brain fog, weird red tips of the fingers for weeks, cardiac arrhythmias, tachycardia, deep lung pain but no wheezing, dry cough, severe headaches, and so much more.

Note also past issues with [b6] in the document, and past issues with [b6] [b6] is in the document.

LABS DONE in 2021:

b6

b6

Current medications:

b6

b6

Are you working with the COVID-Neuro Network - Vaccine neurological adverse events following immunisation (AEFI)?

<https://www.liverpool.ac.uk/covid-vaccine-neuro-ae/>

I asked my Dr to submit, but I don't think he has, but I think it would be good.

I really appreciate your help, and caring. Sorry for the info overload, but I thought it would help to decide on what you wanted to do.

Thanks so much. It really means a lot to have your willingness to help in any way possible. And I hope my info can help your research to benefit others too.

Best regards,

b6

On Sun, Jun 6, 2021, 12:36 AM Safavi, Farinaz (NIH/NINDS) [E] **b6** wrote:

Dear **b6**

Thank you for your comprehensive history.

I havr afew questions.

b6

I cc our research nurse Amanda to send you paperworks for medical release form and sample only consent.

I can send you the list of labworks we usually send for post vaccine adverse events before **b6** Hope it helps.

Thank you!

Farinaz

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

Sent: Saturday, June 5, 2021 6:57:21 PM

To: **b6** Smith, Bryan (NIH/NINDS) [E]

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

Subject: Re: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

Dear **b6**

Thanks for all the information below. We will review the information and then get back to you.

Avi

Avindra Nath MD

Chief, Section of Infections of the Nervous System

Clinical Director,

National Institute of Neurological Disorders and Stroke

National Institutes of Health, Bethesda, MD

b6

From: [b6]
Date: Friday, June 4, 2021 at 1:36 AM
To: Nath, Avindra (NIH/NINDS) [E] [b6] Smith, Bryan (NIH/NINDS) [E]
[b6] Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

Dear Doctors,

I tried to call and leave a message, but I know you all must be so busy, especially after the holiday weekend. My cell phone is [b6] and my land line is [b6] Sorry if the details below are more than expected.

I have my story below, and give you permission to use it as needed. I have shared a lot of this in the VAERS report too. No one ever has followed up with me from the CDC.

I also [b6] I was [b6]
[b6] until after I had my bad and persistent issues after dose #2 of the Pfizer COVID vaccine, but I had reactions to both doses that were intense and unusual. My vaccines were [b6]
[b6] and I have had issues ever since!

My WES is at the NIH NIAID, along with [b6]
[b6] You are welcome to look at that too.

I could send you more info, imaging, labs, etc.

Currently: I am still currently dealing with the issues of vertigo, R cranial neuropathy, R facial droop, R outer leg weakness and neurologic changes, R arm and hand still weaker, and have had [b6] on my face (both sides last week), leg, R arm, R wrist.

I use walking sticks due to my R leg issues, and vertigo that makes me unstable, and to be able to walk around more, when not at home. At home, I can grab at narrow hallway walls, chairs etc

as needed. I am still on [b6] for the vertigo, and [b6] for the headache, [b6] [b6] and have not dared stop the [b6] I have used a R wrist splint but am getting stronger but at half strength (left handed, thank goodness), and also [b6] and trying my best to be overcoming this, and got my R leg to half strength too.

My neurologist is willing to do any suggested testing, treatments, anything. He wants me to have [b6] but it has been difficult to [b6] [b6] so if you want labs, let me know.

b6

b6

Pfizer dose #1 [b6]

Onset of symptoms [b6] around 1.5 hrs post vaccine: severe headache, stiff neck ache, dizziness, nausea, chills, extreme fatigue, feverish but below 100.4, severe muscle aches, loss of taste and smell. Loose bowels at times, slept all the rest of the day and night, drank lots of fluids and electrolytes (low sugar). Felt more weak and dizzy the next day, and when walking felt veering right more, more issues with extended activity after the next dose on [b6] onwards, and it has never gone away fully.

R arm pain and raised, tender area at vaccine site continued to hurt for weeks, even into the next dose on [b6] onwards, and has never gone away fully.

[b6] I woke up at 5:30 am: sudden-onset shortness of breath, deep lung pain in the center of the chest. I felt like my R lung blocked, and started to cough up large amounts of clear mucus, and vomiting mucus due to my R side middle airway feeling blocked. I [b6] to try to open my airway, but I was not wheezing, and did not have any respiratory symptoms or illness at the time before this started. (I have [b6] and have not needed it in over a year) I had been having continued less lung capacity for many months prior

due to having been very sick in [b6] onwards, including loss of sense of smell and taste, shortness of breath, deep lung pain, fever, No wheezing, not sick.

Pfizer dose #2 [b6] after work. Onset of symptoms by 5:30 pm with headache, dizziness, nausea, extreme fatigue, increased R arm pain at the vaccine site, but it was still hurting at the site from the [b6] shot too, before this dose. Drank fluids and went to bed. Loss of smell and taste returned [b6] Had continued bad headache from [b6] onwards, with nausea and feeling more dizzy at times, and on [b6] I was at work with increased headache, dizziness and nausea, and went home early from my shift [b6] due to symptoms. Went to bed early, due to continued nausea and headache and dizziness at times. [b6] continued bad headache, then in the afternoon around 3 pm, GI felt bloated, bad nausea, and then felt shortness of breath around 4 pm and faster heart rate [b6] lasting for minutes, despite laying down in bed, so I too used my oximeter (I have photos) and the sats were [b6] and had shortness of breath and return of deep internal mid lung pain, and this lasted for over 10 min. I used [b6] to try to recover, and the sats [b6] No wheezing. Not sick. I had a bad headache and nausea, and was not feeling good and went to bed.

On [b6] I woke up at 5:30 with severe vertigo and dizziness, nausea and a bad headache and could not walk due to the vertigo, and vomited when I was trying to have my head up. I had to crawl to the bathroom on my hands and knees. I called out sick for work due to this and contacted my Dr. I was started [b6] for vertigo, and was taking [b6] to help. [b6] noted my Re upper eyelid was doing a lot of spastic twitching at times, that would stop and start, but did not think about it much. The vertigo was unrelenting and then I started to have Right arm and hand weakness noted on [b6] and was still very dizzy, nauseated and had a constant headache since I got dose #2 of the COVID vaccine on [b6] I was using a walking stick for the dizziness to be stable, and also felt weaker on the R side, and drifting to the right when walking. On [b6] and noticed I could not fully shut my Right eye [b6] my face was drooping. I still had the constant headache, nausea and dizziness, and increased R hand, arm and R leg weakness and R hip weakness. I could not lift my R leg up to walk well, cannot grip well with the R hand, and uncoordinated, and cannot walk straight, and am unstable when trying to walk heel to toe, or even stand still with my eyes shut, and have had some double vision with the R eye. I was started on [b6] for the vertigo on [b6] after seeing my neurologist. I took [b6] and did not have improvement with the R facial droop or R side weakness and the headaches have persisted, along with some dizziness and nausea. On [b6] I had increased shortness of breath and R lung felt like it was not inflating much, and got [b6] and went onto [b6] which did help my lungs to improve, and I was able to breathe better, and got my Right lung capacity back.

I stopped the [b6] to manage through the symptoms without it, and have been doing [b6] (but the Dr does not think it is that sort of issue, but that [b6] would help). I had [b6] after an in-person neurology appointment, and was having some improvement with the vertigo, so I [b6] but I was still having the constant headache, nausea, and some dizziness, R face droop, R hand weakness, R leg weakness and walk with a walking stick, and have increased issues with exertion, but have been walking and doing

therapies to get stronger.3 I started to have increased R facial droop [b6] of my R arm. Worse headache, nausea, dizziness at the desk, and fatigue, but R side weakness issues increased, so I started [b6] [b6] but had increasingly bad headache,nausea and increasing R facial droop, and much worse R hand weakness, R arm weakness and pain, and R hip pain and weakness, worse walking, cannot lift my R leg or foot as high as the L, again, and am struggling to walk, and get worse with exertion with R side walking and weakness. I also had shooting pains in my R jaw start on [b6] along with R jaw and face pain and increased numbness, more face droop shooting pains in my R hip, and arm and body pain and a worse headache making it hard to even sleep, and some increased issues with my R eye that I need to have checked. R hip jerking and awakening me multiple times a night the last few days on [b6] [b6] due to the symptoms I was having, after a video visit with the neurologist. Increased R leg weakness, R weak hip vs left, R foot drag/drop, with increased issues to maintain walking with progressive walking, still using walking stick to try to walk, but now for stability and to keep from drifting, R facial droop increasing and now some R eye blurring [b6] onwards, that is new. R eye found to have some tear film issues, so I have [b6] for that.

History from last year.

I also was sick from very early in [b6] (but I had what I thought was allergies 6 days prior which I now question) with significant respiratory cough but no wheezing, deep pain in the low center of my chest, fever, headache, increasing shortness of breath by day 6, diarrhea, was getting worse and my Drs had me on [b6] which halted my lung issue progression enough, plus [b6] had the loss of taste and smell, then red tips of my fingers and weaker grip on the fingers bilaterally with cardiac arrhythmias, tachycardia, dizziness [b6] constant headaches, heart rate issues, skipped beats (never had these issues prior), continued low lung capacity and [b6] brain fog, and relapses of all these issues, including my sense of taste and smell going away with each relapse. I also lost hair in clumps in [b6] after being so sick.

I have weird patches of rash that reappear in the same places, that never existed before this illness, that started in [b6] on my back of my neck, chest, wrists and arms. I shared photos to my Drs, and they prescribed [b6]

I was [b6] until the cardiac issues resolved, and [b6] but still was dealing with headaches, brain fog, fatigue, and feeling less stable after more exertion, so I asked for my husband to buy me hiking sticks for my birthday [b6] mostly because I was just still not feeling great, and was trying to do more exercise and get stronger. After stationary biking in [b6] light amount, for 10 min, later that night I would start to cause shooting nerve pains up and down my leg, keeping me up at night for a few days. I never had that before. So, I did not use a stationary bike for a month, then tried it again, the same thing happened, so I never biked again, and did not have that since the nerve stuff.

I never fully recovered from the [b6] sequelae and issues, but pushed through [b6] [b6] and would come home and collapse, barely able to bathe and then rest, then cook

dinner and go to bed, so I was not exactly "recovered" before I got my COVID vaccines, but was managing, and still had the fatigue, brain fog and such, but did not expect this. I have never had vertigo in my life until now.

b6

b6

b6 and had a significant systemic inflammatory, mostly neuro and respiratory inflammatory phase from 5 weeks onwards that involved a relapse of severe deep lung pain, pallor, cracked lips, severe headache for over 6 weeks, **b6**

b6 with progressive neuro issues with the constant headache that involved bilateral numb fingers and toes, that led to progressive hand and leg weakness, and not being able to support his weight on his legs, and weakness to above his knees bilaterally, and having some very odd absence-seizure-like issues with all of this, which thankfully the leg weakness started to reverse, and the issues calmed down but he had a few relapses over the summer, but not as severe as this. So, he saw a neurologist for that, and had lots of tests.

He also has an unusual history and **b6**
b6 past history of triggered flaring of joint, GI, lung, headache, sometimes odd rashes, sometimes elevated inflammatory markers triggered after infections, and can be very prolonged, but he had been doing well prior to getting sick in **b6**

b6

He has had one dose of the Pfizer vaccine, and did have a headache, chills and fatigue, pain at the vaccine site for a few days, but nothing serious. He is due for dose #2 on **b6**

I have been trying to get help from the CDC CISA program, and submitted a request a few months ago. I also have asked my Dr to try to help on that too, as the CISA location for the west is at the **b6** I am not sure who he has contacted, outside his neuro colleagues, but he is open to suggestions.

This is the person that I think is over the west coast CISA, that I have asked my Dr to contact, and I have tried to reach, but I have not yet emailed. I will try again, but have not dared email, as I had hoped that my Dr would reach out, as **b6** I have tried to call a few times. I called the CDC and emailed in a request for a referral too, with no luck for this program. I know they are busy, but I had hoped they would help me.

b6

b6

b6

I also asked my neurologist to submit my case to this registry for COVID vaccine neuro events too, but I am not sure that he has, but I think it makes sense to collaborate:

<https://www.liverpool.ac.uk/covid-neuro-network/>. Do you work with this group too?

Note that I am 100% pro-vaccine, and have kept my story private, and most of my family, outside my kids and my mom who has been sworn to secrecy have not heard, and I have hidden this from colleagues at work too, but they do know something happened, and about the vertigo and R side weakness, but I think "through the grapevine" as I have tried to keep it quiet, and have not gone to the media, etc.

But I need help, and also we are trying to figure out what to do for

b6

b6

After what happened [b6] with our bad illness and prolonged issues for me about what could happen to [b6] so he really wants to get the vaccine, but has concerns about that too, with his history, and now what has happened to me.

Sorry for the novel. If you are able to help, that would be amazing, but if not, please share any suggestions, and feel free to contact my Dr, [b6] or anyone.

Thank you,

[b6]

On Mon, May 31, 2021 at 7:07 AM Goldbach-Mansky, Raphaela (NIH/NIAID) [E]

[b6]

[b6] wrote:

Dear [b6]

I received an e-mail back from Dr Nath, a neurologist and his colleagues who are suggesting that you contact them for further advice and possibly consultation. Please go ahead. I highlighted the e-mail addresses.

Raphaela

Raphaela Goldbach-Mansky, M.D., MHS

TADS/LCIM/NIAID

phone: [b6]

fax: 301 480 4953

e-mail: [b6]

From: "Nath, Avindra (NIH/NINDS) [E]" [b6]
Date: Monday, May 31, 2021 at 9:03 AM
To: "Goldbach-Mansky, Raphaela (NIH/NIAID) [E]" [b6]
Cc: "Smith, Bryan (NIH/NINDS) [E]" [b6] "Safavi, Farinaz (NIH/NINDS) [E]" [b6]
Subject: Re: Post COVID vaccine study

We do not have a specific protocol but have seen a number of them. Sounds like [b6]
[b6] We can talk to the patient to see what we can do to help. You can share our contact information with her

Avi

Avindra Nath MD

Dear Avi,

I hope you are enjoying the long weekend. Mike Sneller told me about you protocol assessing neurologic complications post COVID vaccine.

[b6] developed severe neck pain and headaches, dizziness, vertigo and nausea with in 48 hours after the first COVID shot which got better and then she developed [b6] after the second shot.

She is not getting much better after [b6] Would she qualify for your protocol and if so who should she contact?

Kind regards,

Raphaela

Raphaella Goldbach-Mansky, M.D., MHS

Senior Investigator

Chief, Translational Autoinflammatory Diseases Section (TADS)

Laboratory of Clinical Immunology and Microbiology, LCIM

NIAID/NIH

Bldg.10 room 11C205, MSC1960

10 Center Dr.

Bethesda, MD 20892

phone: b6

fax: 301 480 4953

e-mail: b6

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From: [b6]
Sent: 11/5/2021 4:04:27 PM
To: Wiebold, Amanda (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=4491ee2ae9804610899c741100150540 [b6] Nath, Avindra (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b81ca051950b4d458d74037a6a86ead6 [b6]
CC: Gustafson, Lindsey (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=5bcc895932d544e4a2f36eb6f9388adb [b6] Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Labs done at Mayo attached, [b6]
Attachments: [b6].pdf

Dear Doctors,

Thanks so much for all your help. A special thanks to Dr Safavi for the phone appointment almost a month ago. I wanted to get you the rest of these labs.

I got all the labs done at Mayo from [b6] These were done before my [b6] but [b6] and these are the labs that were not run as hoped, Including the [b6] Lab file is attached and labeled with Mayo in the name for that file for labs drawn on [b6]

I am still getting [b6] and it helps with the Right sided weakness and droop in my face to get to a much better, almost 90% or more of normal look in the eye and mouth area, and improvement w/ my R hand grip and R arm strength, and R upper leg too, and it helps to reduce my constant vertigo and headache, but by [b6] I regress with progressively more vertigo, headache, R side weakness and progressively worse facial droop and need for a cane or forearm crutch to manage to get around due to the issues, and terrible vertigo at times.

I have asked to be referred to immunology and rheumatology, and have not been able to [b6] [b6] I am trying to apply for [b6] and [b6] but when the vertigo is bad, it is harder, but I push on. Still taking [b6] for the vertigo [b6] for the headache, [b6] and doing my best for [b6] and to be strong, and doing things daily to get better. Hopefully I can get [b6]

b6

Thanks,

[b6]

[b6]

b6

b6

b6

On Mon, Oct 4, 2021 at 12:14 PM [b6] wrote:
Dear All,

I have had new labs done prior to [b6] which were supposed to be sent to Mayo to get the results that you had wanted prior to [b6]

My neurologist located some labs done in [b6] that were sent out to other labs prior to [b6] (but not to Mayo) that are attached as files, which Includes [b6] [b6] not the testing you wanted from Mayo, but it shows [b6] but I am hoping that the labs sent last week do get run at Mayo for the more specific testing. Other tests also included in the files.

I also had a [b6] so that is good news, but I did not attach it.

Note that these labs for [b6]

b6

[b6] helps with the vertigo, headache, brain fog, Right sided weakness and especially fixes my R face droop dramatically each time, but it wears off [b6] and gets worse until [b6] is given, but now that I am getting it [b6] I think that it has helped more. I can send photos if you want to see the progression, and how things reverse with my face after 2 days of [b6] Let me know and I can send some. If we are on zoom, you will see me looking in my better form, since [b6]

Thanks,

b6

b6

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b6

b6

On Mon, Sep 13, 2021 at 2:06 PM **b6** wrote:
Dear Doctors,

I am devastated to let you know that I did all the recommended Mayo sendout labs before **b6** and my hospital had tried to find out what happened as the reports said FInal, but I had to do my own work to find these labs, and got this message today from Mayo:

b6

I am so sorry, and absolutely devastated. I have all the other labs ordered from **b6** below this note. I wanted to contact you sooner, but had been trying to get all the results for you. I hope that you can still help me. Sorry for all the info below, but I wanted to update you, and ask for your help. Thank you for all you have done, and for your consideration.

I now have very little to give you from most of the tests you wanted, and I am not sure if your lab samples that were sent to you were able to be used.

Also, I am advised to get a booster dose #3 of my Pfizer COVID vaccine, yet I had all these now chronic neuro issues arise, starting with the vaccine, and some respiratory issues hit with each dose that were not long, but notable.

I am still not able to **b6** **due to my continued, chronic and regressive neuro issues (notable improvement** **b6**

I do not know what to do for a booster dose! I need some help on sorting out the next steps, and really, really wanted to see the results of those Mayo COVID-19 labs you had ordered. I need help. Not getting much help on this, and I am asking for a referral to an immunologist, and would like some advice on next steps on

b6

I am now getting: [b6] how can I go about more testing? [b6] offered me a booster COVID vaccine dose this week, and I said I needed more advice before doing that, and with my history, I am not sure I should do that with [b6] but no one really seems to want to sort me out. I am so sorry. I am devastated.

The CDC VAERS wanted more of my files months ago, as I still have issues, and they were sent everything that I had before June. They have not responded, not asked for more info, and never got back to me for a referral to the CDC CISA program.

I have asked my neurologist to refer me to [b6] and immunologist and vaccine specialist at the [b6] that manages the west coast CDC CISA-no word on that. I have tried to call, but have not yet emailed, as I want to see if my Dr will try first.

The only good news is that [b6]

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LABS THAT WE DID GET

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b6

Please note that these were done at Quest, and their reference range is NOT the same as Mayo, and on their site, they say to use their reference range for this test.

My neurologist has not really pursued b6 more, and I think it is worth sorting out. I really need to sort out my unusual past medical history, even before last year and the current issues since my Pfizer COVID-19 vaccine in b6

It was sent there by our lab, vs Mayo but I guess that is a blessing, since I got at least that lab result, and I would like more help on that.

Please help me if possible! I am b6 but need to be better for me too, and also not get sick from COVID, and I just do not know my risk.

b6

I have had a history of

b6

b6

I have never been offered, nor had a b6 I know that is used for immune studies. I will try to pursue this more.

Even my b6 has not been helpful for years, as I have felt that the

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Best regards and with the deepest gratitude,

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b6

b6

On Thu, Jun 10, 2021 at 9:46 AM Wiebold, Amanda (NIH/NINDS) [E] **b6** wrote:

Dr. Safavi and Lee,

Dr. Safavi in your email below to **b6** there was mention that a list of labs will be sent to her. Labs that you have been recommending for post vaccine patients having complications. I want to close the loop because I am not sure if Lee was actually copied on that email or not but **b6** has not received the list of labs yet. She is scheduled for **b6**

Thanks,

Amanda

On Tue, Jun 8, 2021, 6:20 PM Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

[b6]

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

I cc our NP Lee to send you the list.

Lee, Can you please send the list of labs we usually send for post vaccine complications to

[b6]

however based on your symptoms you may not need all of them and require others that I defer to your neurologist.

Unfortunately I can not provide further information until ai return and speak with you and [b6] most likely affect many tests if we dont run them beforehand.

Can you send us some serum before [b6] (red top or SST, spun down and frozen serum)?

Thanks

Farinaz

From: [b6]

Sent: Tuesday, June 8, 2021 11:27:43 PM

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

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

[b6] Wiebold, Amanda (NIH/NINDS) [E] [b6]

Subject: Re: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

REL0000231173

Dear Dr Safavi,

I have done the consent with Ms Wiebold RN, and have submitted the forms, and consent to review my medical records.

I also have requested that my medical records, and [b6] be sent to you from [b6] and will follow up on that, but I gave you most of the

essential documents for 2021 in the past attachment.

Dr Safavi said in a prior email: "I can send you the list of labworks we usually send for post vaccine adverse events before [b6] Hope it helps."

[b6] is still scheduled for [b6] Mr neurologist is willing to order any labs that are wanted, but he would need a list to do that in the next few days.

I am not sure if you contacted him, but if you make a list, or a letter with a list, I can get that to him to order for me. He has nothing planned for pre-labs

at this time. [b6] is my neurologist, and his office number is [b6]

I will also be working on getting my lab drawn at Quest for your study lab, and will try to set up an appointment to get that done before the [b6]

I can even get labs drawn on a Sunday with [b6] but the sample would not be able to be shipped out until Monday, and I am not sure

if that is acceptable for your study, but [b6] lab is open on weekends, and I know them well.

Thanks,

[b6]

b6

b6

b6

b6

b6

On Sun, Jun 6, 2021 at 5:00 PM **b6** wrote:

Dear Dr Farinaz and Dr Nath,

Thanks so much for your help, even on a weekend! Sorry for more info coming your way. Hopefully this will help to get things going, and your nurse can call me at **b6** or my cell at **b6** to consent anytime tomorrow (Pacific time zone, but I will answer anytime.)

To answer your questions:

b6

b6

My neurologist is willing to do anything recommended. Here are the only labs done on me since my fFizer vaccine reactions

My **b6** dates are for **b6** I could not get anything sooner.

I have attached a full document of all the **b6** and also some info from the past 14 months on anything of relevance.

I did not include much on my resolved issues, but focused more on the neuro-related stuff, but I can send you much more if you want on more details of my complex, prolonged, relapsing post viral issues since **b6** that I had most of the common COVID-19 type symptoms, including the loss of taste and smell,, diarrhea around day 6 onwards, when my lung issues and shortness of breath got worse, fever, brain fog, weird red tips of the fingers for weeks, cardiac arrhythmias, tachycardia, deep lung pain but no wheezing, dry cough, severe headaches, and so much more.

Note also past issues with **b6** in the document, and past issues with **b6** **b6** is in the document.

LABS DONE in 2021:

b6

b6

b6

Current medications:

b6

b6

Are you working. with the COVID-Neuro Network - Vaccine neurological adverse events following immunisation (AEFI)?

<https://www.liverpool.ac.uk/covid-vaccine-neuro-ae/>

I asked my Dr to submit, but I don't think he has, but I think it would be good.

I really appreciate your help, and caring. Sorry for the info overload, but I thought it would help to decide on what you wanted to do.

Thanks so much. It really means a lot to have your willingness to help in any way possible. And I hope my info can help your research to benefit others too.

Best regards,

b6

On Sun, Jun 6, 2021, 12:36 AM Safavi, Farinaz (NIH/NINDS) [E] **b6** wrote:

Dear **b6**

REL0000231173

Thank you for your comprehensive history.

I havr afew questions.

b6

I cc our research nurse Amanda to send you paperworks for medical release form and sample only consent.

I can send you the list of labworks we usually send for post vaccine adverse events before **b6** Hope it helps.

Thank you!

Farinaz

From: Nath, Avindra (NIH/NINDS) [E] **b6**
Sent: Saturday, June 5, 2021 6:57:21 PM
To: **b6** Smith, Bryan (NIH/NINDS) [E]
b6 Safavi, Farinaz (NIH/NINDS) [E] **b6**
Subject: Re: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

Dear **b6**

Thanks for all the information below. We will review the information and then get back to you.

Avi

Avindra Nath MD

Chief, Section of Infections of the Nervous System

Clinical Director,

National Institute of Neurological Disorders and Stroke

National Institutes of Health, Bethesda, MD

REL0000231173

b6

From: [b6]
Date: Friday, June 4, 2021 at 1:36 AM
To: Nath, Avindra (NIH/NINDS) [E] [b6] Smith, Bryan (NIH/NINDS) [E]
[b6] Safavi, Farinaz (NIH/NINDS) [E] [b6]
Subject: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

Dear Doctors,

I tried to call and leave a message, but I know you all must be so busy, especially after the holiday weekend. My cell phone is [b6] and my land line is [b6] Sorry if the details below are more than expected.

I have my story below, and give you permission to use it as needed. I have shared a lot of this in the VAERS report too. No one ever has followed up with me from the CDC.

I also [b6] I was [b6]
[b6] until after I had my bad and persistent issues after dose #2 of the Pfizer COVID vaccine, but I had reactions to both doses that were intense and unusual. My vaccines were [b6]
[b6] and I have had issues ever since!

My WES is at the NIH NIAID, along with [b6]
[b6] You are welcome to look at that too.

I could send you more info, imaging, labs, etc.

Currently: I am still currently dealing with the issues of vertigo, R cranial neuropathy, R facial droop, R outer leg weakness and neurologic changes, R arm and hand still weaker, and have had [b6] on my face (both sides last week), leg, R arm, R wrist.

REL0000231173

I use walking sticks due to my R leg issues, and vertigo that makes me unstable, and to be able to walk around more, when not at home. At home, I can grab at narrow hallway walls, chairs etc as needed. I am still on [b6] for the vertigo, and [b6] for the headache, [b6] [b6] and have not dared stop the [b6] I have used a R wrist splint but am getting stronger but at half strength (left handed, thank goodness), and also [b6] and trying my best to be overcoming this, and got my R leg to half strength too.

My neurologist is willing to do any suggested testing, treatments, anything. He wants me to have [b6] but it has been difficult to [b6] [b6] so if you want labs, let me know.

b6

b6

Pfizer dose #1 [b6]

Onset of symptoms [b6] around 1.5 hrs post vaccine: severe headache, stiff neck ache, dizziness, nausea, chills, extreme fatigue, feverish but below 100.4, severe muscle aches, loss of taste and smell. Loose bowels at times, slept all the rest of the day and night, drank lots of fluids and electrolytes (low sugar). Felt more weak and dizzy the next day, and when walking felt veering right more, more issues with extended activity after the next dose on [b6] onwards, and it has never gone away fully.

R arm pain and raised, tender area at vaccine site continued to hurt for weeks, even into the next dose on [b6] onwards, and has never gone away fully.

[b6] I woke up at 5:30 am: sudden-onset shortness of breath, deep lung pain in the center of the chest. I felt like my R lung blocked, and started to cough up large amounts of clear mucus, and vomiting mucus due to my R side middle airway feeling blocked. I did [b6]

b6 to try to open my airway, but I was not wheezing, and did not have any respiratory symptoms or illness at the time before this started. (I have b6 and have not needed it in over a year) I had been having continued less lung capacity for many months prior due to having been very sick in b6 onwards, including loss of sense of smell and taste, shortness of breath, deep lung pain, fever, No wheezing, not sick.

Pfizer dose #2 b6 after work. Onset of symptoms by 5:30 pm with headache, dizziness, nausea, extreme fatigue, increased R arm pain at the vaccine site, but it was still hurting at the site from the b6 shot too, before this dose. Drank fluids and went to bed. Loss of smell and taste returned b6 Had continued bad headache from b6 onwards, with nausea and feeling more dizzy at times, and on b6 I was at work with increased headache, dizziness and nausea, and went home early from my shift b6 due to symptoms. Went to bed early, due to continued nausea and headache and dizziness at times. b6 continued bad headache, then in the afternoon around 3 pm, GI felt bloated, bad nausea, and then felt shortness of breath around 4 pm and faster heart rate b6 b6 lasting for minutes, despite laying down in bed, so I too used my oximeter (I Have photos) and the sats were b6 and had shortness of breath and return of deep internal mid lung pain, and this lasted for over 10 min. I used b6 b6 to try to recover, and the sats b6 No wheezing. Not sick. I had a bad headache and nausea, and was not feeling good and went to bed.

On b6 I woke up at 5:30 with severe vertigo and dizziness, nausea and a bad headache and could not walk due to the vertigo, and vomited when I was trying to have my head up. I had to crawl to the bathroom on my hands and knees. I called out sick for work due to this and contacted my Dr. I was started b6 for vertigo, and was taking b6 to help. b6 noted my Re upper eyelid was doing a lot of spastic twitching at times, that would stop and start, but did not think about it much. The vertigo was unrelenting and then I started to have Right arm and hand weakness noted on b6 and was still very dizzy, nauseated and had a constant headache since I got dose #2 of the COVID vaccine on b6 I was using a walking stick for the dizziness to be stable, and also felt weaker on the R side, and drifting to the right when walking. On b6 I had b6 b6 and noticed I could not fully shut my Right eye b6 and by b6 my face was drooping. I still had the constant headache, nausea and dizziness, and increased R hand, arm and R leg weakness and R hip weakness. I could not lift my R leg up to walk well, cannot grip well with the R hand, and uncoordinated, and cannot walk straight, and am unstable when trying to walk heel to toe, or even stand still with my eyes shut, and have had some double vision with the R eye. I was started on b6 for the vertigo on b6 after seeing my neurologist. I took b6 and did not have improvement with the R facial droop or R side weakness and the headaches have persisted, along with some dizziness and nausea. On b6 I had increased shortness of breath and R lung felt like it was not inflating much, and got b6 and went onto b6 which did help my lungs to improve, and I was able to breathe better, and got my Right lung capacity back.

I stopped the b6 to manage through the symptoms without it, and have been doing b6 (but the Dr does not think it is that sort of issue, but that b6 would help). I had b6

after an in-person neurology appointment, and was having some improvement with the vertigo, so I [b6] but I was still having the constant headache, nausea, and some dizziness, R face droop, R hand weakness, R leg weakness and walk with a walking stick, and have increased issues with exertion, but have been walking and doing therapies to get stronger. I started to have increased R facial droop. [b6] of my R arm. Worse headache, nausea, dizziness at the desk, and fatigue, but R side weakness issues increased, so I started back onto [b6] [b6] but had increasingly bad headache, nausea and increasing R facial droop, and much worse R hand weakness, R arm weakness and pain, and R hip pain and weakness, worse walking, cannot lift my R leg or foot as high as the L, again, and am struggling to walk, and get worse with exertion with R side walking and weakness. I also had shooting pains in my R jaw start on [b6] along with R jaw and face pain and increased numbness, more face droop shooting pains in my R hip, and arm and body pain and a worse headache making it hard to even sleep, and some increased issues with my R eye that I need to have checked. R hip jerking and awakening me multiple times a night the last few days on [b6] [b6] after a video visit with the neurologist. Increased R leg weakness, R weak hip vs left, R foot drag/drop, with increased issues to maintain walking with progressive walking, still using walking stick to try to walk, but now for stability and to keep from drifting, R facial droop increasing and now some R eye blurring [b6] that is new. R eye found to have some tear film issues, so I have [b6] for that.

History from last year.

I also was sick from very early in [b6] (but I had what I thought was allergies 6 days prior which I now question) with significant respiratory cough but no wheezing, deep pain in the low center of my chest, fever, headache, increasing shortness of breath by day 6, diarrhea, was getting worse and my Drs had me on [b6] which halted my lung issue progression enough, plus [b6] I had the loss of taste and smell, then red tips of my fingers and weaker grip on the fingers bilaterally with cardiac arrhythmias, tachycardia, dizziness [b6] constant headaches, heart rate issues, skipped beats [b6] continued low lung capacity and [b6] brain fog, and relapses of all these issues, including my sense of taste and smell going away with each relapse. I also lost hair in clumps in [b6] after being so sick.

I have weird patches of rash that reappear in the same places, that never existed before this illness, that started in [b6] on my back of my neck, chest, wrists and arms. I shared photos to my Drs, and they prescribed [b6]

I was [b6] until the cardiac issues resolved, and [b6] but still was dealing with headaches, brain fog, fatigue, and feeling less stable after more exertion, so I asked for my husband to buy me hiking sticks for my birthday [b6] mostly because I was just still not feeling great, and was trying to do more exercise and get stronger. After stationary biking in [b6] light amount, for 10 min, later that night I would start to cause shooting nerve pains up and down my leg, keeping me up at night for a few days. I never had that before. So, I did not use a stationary bike for a month, then tried it again, the same thing happened, so I never biked again, and did not have that since the nerve stuff.

I never fully recovered from the [b6] sequelae and issues, but pushed through [b6] [b6] and would come home and collapse, barely able to bathe and then rest, then cook dinner and go to bed, so I was not exactly "recovered" before I got my COVID vaccines, but was managing, and still had the fatigue, brain fog and such, but did not expect this. I have never had vertigo in my life until now.

[b6]

[b6]

[b6] and had a significant systemic inflammatory, mostly neuro and respiratory inflammatory phase from 5 weeks onwards that involved a relapse of severe deep lung pain, pallor, cracked lips, severe headache for over 6 weeks, [b6] [b6] with progressive neuro issues with the constant headache that involved bilateral numb fingers and toes, that led to progressive hand and leg weakness, and not being able to support his weight on his legs, and weakness to above his knees bilaterally, and having some very odd absence-seizure-like issues with all of this, which thankfully the leg weakness started to reverse, and the issues calmed down but he had a few relapses over the summer, but not as severe as this. So, he saw a neurologist for that, and had lots of tests.

He also has an unusual history and [b6] [b6] past history of triggered flaring of joint, GI, lung, headache, sometimes odd rashes, sometimes elevated inflammatory markers triggered after infections, and can be very prolonged, but he had been doing well prior to getting sick in [b6]

[b6]

He has had one dose of the Pfizer vaccine, and did have a headache, chills and fatigue, pain at the vaccine site for a few days, but nothing serious. He is due for dose #2 on [b6]

I have been trying to get help from the CDC CISA program, and submitted a request a few months ago. I also have asked my Dr to try to help on that too, as the CISA location for the west

is at the [b6] I am not sure who he has contacted, outside his neuro colleagues, but he is open to suggestions.

This is the person that I think is over the west coast CISA, that I have asked my Dr to contact, and I have tried to reach, but I have not yet emailed. I will try again, but have not dared email, as I had hoped that my Dr would reach out, as [b6] I have tried to call a few times. I called the CDC and emailed in a request for a referral too, with no luck for this program. I know they are busy, but I had hoped they would help me.

b6

b6

b6

I also asked my neurologist to submit my case to this registry for COVID vaccine neuro events too, but I am not sure that he has, but I think it makes sense to collaborate:

<https://www.liverpool.ac.uk/covid-neuro-network/>. Do you work with this group too?

Note that I am 100% pro-vaccine, and have kept my story private, and most of my family, outside my kids and my mom who has been sworn to secrecy have not heard, and I have hidden this from colleagues at work too, but they do know something happened, and about the vertigo and R side weakness, but I think "through the grapevine" as I have tried to keep it quiet, and have not gone to the media, etc.

But I need help, and also we are trying to figure out what to do for

b6

b6

b6

After what happened [b6] with our bad illness and prolonged issues for me about what could happen to [b6] so he really wants to get the vaccine, but has concerns about that too, with his history, and now what has happened to me.

Sorry for the novel. If you are able to help, that would be amazing, but if not, please share any suggestions, and feel free to contact my Dr, [b6] or anyone.

Thank you,

[b6]

On Mon, May 31, 2021 at 7:07 AM Goldbach-Mansky, Raphaela (NIH/NIAID) [E] [b6]
[b6] wrote:

Dear [b6]

I received an e-mail back from Dr Nath, a neurologist and his colleagues who are suggesting that you contact them for further advice and possibly consultation. Please go ahead. I highlighted the e-mail addresses.

Raphaela

Raphaela Goldbach-Mansky, M.D., MHS

TADS/LCIM/NIAID

phone: [b6]

fax: 301 480 4953

REL0000231173

e-mail: [b6]

From: "Nath, Avindra (NIH/NINDS) [E]" [b6]
Date: Monday, May 31, 2021 at 9:03 AM
To: "Goldbach-Mansky, Raphaela (NIH/NIAID) [E]" [b6]
Cc: "Smith, Bryan (NIH/NINDS) [E]" [b6] "Safavi, Farinaz (NIH/NINDS) [E]" [b6]
Subject: Re: Post COVID vaccine study

We do not have a specific protocol but have seen a number of them. Sounds like [b6]
[b6] We can talk to the patient to see what we can do to help. You can share our contact information with her

Avi

Avindra Nath MD

Dear Avi,

I hope you are enjoying the long weekend. Mike Sneller told me about you protocol assessing neurologic complications post COVID vaccine.

[b6] developed severe neck pain and headaches, dizziness, vertigo and nausea with in 48 hours after the first COVID shot which got better and then she developed [b6] after the second shot.

She is not getting much better after [b6] Would she qualify for your protocol and if so who should she contact?

Kind regards,

Raphaella

Raphaella Goldbach-Mansky, M.D., MHS

Senior Investigator

Chief, Translational Autoinflammatory Diseases Section (TADS)

Laboratory of Clinical Immunology and Microbiology, LCIM

NIAID/NIH

Bldg.10 room 11C205, MSC1960

10 Center Dr.

Bethesda, MD 20892

phone: b6

fax: 301 480 4953

e-mail: b6

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b6

From: Wiebold, Amanda (NIH/NINDS) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=4491EE2AE9804610899C741100150540] b6
Sent: 6/10/2021 4:54:14 PM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246] b6 Gustafson, Lindsey (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=5bcc895932d544e4a2f36eb6f9388adb] b6
CC: b6
Subject: RE: List of labs for post COVID vaccine patient

Excellent! Thank you!
Amanda

From: Safavi, Farinaz (NIH/NINDS) [E] b6
Sent: Thursday, June 10, 2021 12:50 PM
To: Gustafson, Lindsey (NIH/NINDS) [E] b6 Wiebold, Amanda (NIH/NINDS) [E] b6
Cc: b6
Subject: Re: List of labs for post COVID vaccine patient

Here is the list

- o Serum:
- § Hematology:
 - CBC with differential (daily)
- § Coagulation Studies:
 - PT, PTT (admission)
 - Lupus Anticoagulant (admission)
- § Chemistry:
 - ESR (admission)
 - Acute Care Panel (daily)
 - Mineral Panel (admission)
 - Hepatic Panel (admission)
 - Aldosterone, Serum (admission)
 - CK-MB Immunoassay (admission)
 - CRP, high sensitivity comprehensive (admission)
 - Cryoglobulins (admission)
 - Ferritin (admission)
 - Gamma Glutamyl Transferase (admission)
 - Thyroglobulin Panel (admission)
 - Thyroid Stimulating Hormone (admission)
 - Vitamin B12, Serum Level (admission)
 - Vitamin D, 1,25-Dihydroxy (admission)
 - IgG subclass Serum (Send out Mayo contract test not in CRIS)
- o Mayo Test Name: IgG subclass Serum, Mayo Test ID: IGGS, Red top, refrigerate
 - IgE (Send out Mayo contract test not in CRIS)
- o Mayo Test Name: IgE, Mayo Test ID: IgE, Red top, refrigerate
 - SARS cov2 spike Ab semi quantitative serum (Send out Mayo contract test not in CRIS)
- o Mayo Test Name: SAR cov2 spike Ab semi quantitative serum, Mayo Test ID: COVSQ, red top, refrigerate
 - SARS-COV2 Nucleocapsid Total Ab (Send out Mayo contract test not in CRIS)
- o Mayo Test Name: SARS-COV2 Nucleocapsid Total Ab, Mayo Test ID: COVTA, red top, refrigerate
 - Cytokine Panel 13 (Send out Mayo contract test not in CRIS)

- o Mayo Test Name: Cytokine Panel 13, Mayo Test ID: FCYTP, red top tube, spin down within 2hrs and send in frozen plastic vial
 - Cytokine panel plasma (Send out Mayo contract test not in CRIS)
- o Mayo Test Name: Cytokine panel plasma, Mayo Test ID: CYPAN, Lavender top, spin down and freeze in 30min and place in plastic
 - Encephalopathy autoimmune evaluation serum (Send out Mayo contract test not in CRIS)
- o Mayo Test Name: encephalopathy autoimmune evaluation serum, Mayo Test ID: ens2, red top, serum gel
- § Immunology
 - Anti-CCP AB x1
 - C3/4 x1
 - IgA Serum (Send out Mayo contract test not in CRIS) x1 before IVIG
- o Mayo ID: IGA, Red top
 - IgG Index CSF and serum x1
 - Lyme Disease Ab, Serum x1
 - Rheumatoid Factor x1
 - Antibody to extractable nuclear antigen eval, serum (Send out Mayo contract test not in CRIS) x1
- o Mayo Test Name: Antibody to extractable nuclear antigen eval, serum, Mayo Test ID: ENAE, Red top, refrigerate
 - dsDNA antibodies by crithidia lucilae IFA, IgG serum (Send out Mayo contract test not in CRIS) x1
- o Mayo Test Name: dsDNA antibodies by crithidia lucilae IFA, IgG serum, Test ID: CRITH, Red top tube, refrigerated
 - Antinuclear Antibodies, Hep2 Substrate, IgG serum (Send out Mayo contract test not in CRIS) x1
- o Mayo Test Name: Antinuclear Antibodies, Hep2 Substrate, IgG serum, Mayo ID: NAIFA, Red Top, refrigerate
- § Microbiology (Misc):
 - Carbapenemase Surveillance Cultures (admission)
 - SARS-CoV-2 PCR, Surveillance, NP Swab (admission)

She may already got some of them done but this is a complete list.

Farinaz

From: Wiebold, Amanda (NIH/NINDS) [E] [b6]
Sent: Thursday, June 10, 2021 9:16:21 PM
To: Gustafson, Lindsey (NIH/NINDS) [E] [b6] Safavi, Farinaz (NIH/NINDS) [E]
 [b6]
Cc: [b6]
Subject: List of labs for post COVID vaccine patient

Dr. Safavi and Lee,

Dr. Safavi in your email below to [b6] there was mention that a list of labs will be sent to her. Labs that you have been recommending for post vaccine patients having complications. I want to close the loop because I am not sure if Lee was actually copied on that email or not but [b6] has not received the list of labs yet. She is scheduled for [b6]

Thanks,
 Amanda

On Tue, Jun 8, 2021, 6:20 PM Safavi, Farinaz (NIH/NINDS) [E] [b6] wrote:

b6

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

I cc our NP Lee to send you the list.

Lee, Can you please send the list of labs we usually send for post vaccine complications to b6 however based on your symptoms you may not need all of them and require others that I defer to your neurologist.

Unfortunately I can not provide further information until ai return and speak with you and b6 most likely affect many tests if we dont run them beforehand.

Can you send us some serum before b6 (red top or SST, spun down and frozen serum)?

Thanks

Farinaz

From: b6

Sent: Tuesday, June 8, 2021 11:27:43 PM

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

b6

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

b6

Smith, Bryan (NIH/NINDS) [E]

b6

Wiebold, Amanda (NIH/NINDS) [E]

b6

Subject: Re: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

Dear Dr Safavi,

I have done the consent with Ms Wiebold RN, and have submitted the forms, and consent to review my medical records.

I also have requested that my medical records, and b6 be sent to you from b6 and will follow up on that, but I gave you most of the essential documents for 2021 in the past attachment.

Dr Safavi said in a prior email: "I can send you the list of labworks we usually send for post vaccine adverse events before b6 Hope it helps."

b6 is still scheduled for b6 Mr neurologist is willing to order any labs that are wanted, but he would need a list to do that in the next few days.

I am not sure if you contacted him, but if you make a list, or a letter with a list, I can get that to him to order for me. He has nothing planned for pre-labs at this time. b6 is my neurologist, and his office number is b6

I will also be working on getting my lab drawn at Quest for your study lab, and will try to set up an appointment to get that done before b6

I can even get labs drawn on a Sunday with b6 but the sample would not be able to be shipped out until Monday, and I am not sure if that is acceptable for your study, but b6 lab is open on weekends, and I know them well.

Thanks,

b6

b6

b6

b6

b6

On Sun, Jun 6, 2021 at 5:00 PM [b6] wrote:

Dear Dr Farinaz and Dr Nath,

Thanks so much for your help, even on a weekend! Sorry for more info coming your way. Hopefully this will help to get things going, and your nurse can call me at [b6] or my cell at [b6] to consent anytime tomorrow (Pacific time zone, but I will answer anytime.)

To answer your questions:

b6

My neurologist is willing to do anything recommended. Here are the only labs done on me since my fFizer vaccine reactions

My [b6] dates are for Mon and Tues, June 14-15. I could not get anything sooner.

I have attached a full document of all [b6] and also some info from the past 14 months on anything of relevance.

I did not include much on my resolved issues, but focused more on the neuro-related stuff, but I can send you much more if you want on more details of my complex, prolonged, relapsing post viral issues since [b6] that I had most of the common COVID-19 type symptoms, including the loss of taste and smell,, diarrhea around day 6 onwards, when my lung issues and shortness of breath got worse, fever, brain fog, weird red tips of the fingers for weeks, cardiac arrhythmias, tachycardia, deep lung pain but no wheezing, dry cough, severe headaches, and so much more.

Note also past issues with [b6] in the document, and past issues with [b6]
[b6] is in the document.

LABS DONE in 2021:

b6

Current medications:

b6

b6

Are you working. with the COVID-Neuro Network - Vaccine neurological adverse events following immunisation (AEFI)?

<https://www.liverpool.ac.uk/covid-vaccine-neuro-ac/>

I asked my Dr to submit, but I don't think he has, but I think it would be good.

I really appreciate your help, and caring. Sorry for the info overload, but I thought it would help to decide on what you wanted to do.

Thanks so much. It really means a lot to have your willingness to help in any way possible. And I hope my info can help your research to benefit others too.

Best regards,

b6

On Sun, Jun 6, 2021, 12:36 AM Safavi, Farinaz (NIH/NINDS) [E] **b6** wrote:

Dear **b6**

Thank you for your comprehensive history.

I havr afew questions.

b6

I cc our research nurse Amanda to send you paperworks for medical release form and sample only consent. I can send you the list of labworks we usually send for post vaccine adverse events before **b6** Hope it helps. Thank you!

Farinaz

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

Sent: Saturday, June 5, 2021 6:57:21 PM

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

Subject: Re: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

Dear [b6]

Thanks for all the information below. We will review the information and then get back to you.

Avi

Avindra Nath MD

Chief, Section of Infections of the Nervous System

Clinical Director,

National Institute of Neurological Disorders and Stroke

National Institutes of Health, Bethesda, MD

[b6]

From: [b6]

Date: Friday, June 4, 2021 at 1:36 AM

To: Nath, Avindra (NIH/NINDS) [E] [b6] Smith, Bryan (NIH/NINDS) [E]
[b6] Safavi, Farinaz (NIH/NINDS) [E] [b6]

Subject: Hi! I am the patient that Dr Goldbach-Mansky asked about re: neuro issues post Pfizer COVID vaccine

Dear Doctors,

I tried to call and leave a message, but I know you all must be so busy, especially after the holiday weekend. My cell phone is [b6] and my land line is [b6] Sorry if the details below are more than expected.

I have my story below, and give you permission to use it as needed. I have shared a lot of this in the VAERS report too. No one ever has followed up with me from the CDC.

I also [b6] I was [b6]
[b6] until after I had my bad and persistent issues after dose #2 of the Pfizer COVID vaccine, but I had reactions to both doses that were intense and unusual. My vaccines were [b6]
[b6] and I have had issues ever since!

My WES is at the NIH NIAID, along with [b6]
[b6] You are welcome to look at that too.

I could send you more info, imaging, labs, etc.

Currently: I am still currently dealing with the issues of vertigo, R cranial neuropathy, R facial droop, R outer leg weakness and neurologic changes, R arm and hand still weaker, and have had [b6] on my face (both sides last week), leg, R arm, R wrist.

I use walking sticks due to my R leg issues, and vertigo that makes me unstable, and to be able to walk around more, when not at home. At home, I can grab at narrow hallway walls, chairs etc as needed. I am still on [b6] for the vertigo, and [b6] for the headache, [b6]
[b6] and have not dared stop the [b6] I have used a R wrist splint but am getting stronger but at half strength (left handed, thank goodness), and also [b6] and trying my best to be overcoming this, and got my R leg to half strength too.

My neurologist is willing to do any suggested testing, treatments, anything. He wants me to have [b6] but it has been difficult to [b6]
[b6] so if you want labs, let me know.

b6

b6

Pfizer dose #1 **b6**

Onset of symptoms **b6** around 1.5 hrs post vaccine: severe headache, stiff neck ache, dizziness, nausea, chills, extreme fatigue, feverish but below 100.4, severe muscle aches, loss of taste and smell. Loose bowels at times, slept all the rest of the day and night, drank lots of fluids and electrolytes (low sugar). Felt more weak and dizzy the next day, and when walking felt veering right more, more issues with extended activity after the next dose on **b6** onwards, and it has never gone away fully.

R arm pain and raised, tender area at vaccine site continued to hurt for weeks, even into the next dose on **b6** onwards, and has never gone away fully.

b6 I woke up at 5:30 am: sudden-onset shortness of breath, deep lung pain in the center of the chest. I felt like my R lung blocked, and started to cough up large amounts of clear mucus, and vomiting mucus due to my R side middle airway feeling blocked. I did **b6** to try to open my airway, but I was not wheezing, and did not have any respiratory symptoms or illness at the time before this started. (I have **b6** and have not needed it in over a year) I had been having continued less lung capacity for many months prior due to having been very sick in **b6** onwards, including loss of sense of smell and taste, shortness of breath, deep lung pain, fever, No wheezing, not sick.

Pfizer dose #2 **b6** after work. Onset of symptoms by 5:30 pm with headache, dizziness, nausea, extreme fatigue, increased R arm pain at the vaccine site, but it was still hurting at the site from the **b6** shot too, before this dose. Drank fluids and went to bed. Loss of smell and taste returned **b6** Had continued bad headache from **b6** onwards, with nausea and feeling more dizzy at times, and on **b6** I was at work with increased headache, dizziness and nausea, and went home early from my shift **b6** due to symptoms. Went to bed early, due to continued nausea and headache and dizziness at times **b6** continued bad headache, then in the afternoon around 3 pm, GI felt bloated, bad nausea, and then felt shortness of breath around 4 pm and faster heart rate **b6** lasting for minutes, despite laying down in bed, so I too used my oximeter (I Have photos) and the sats were **b6** **b6** and had shortness of breath and return of deep internal mid lung pain, and this lasted for over 10 min. I used **b6** to try to recover, and the sats **b6** No wheezing. Not sick. I had a bad headache and nausea, and was not feeling good and went to bed.

On **b6** I woke up at 5:30 with severe vertigo and dizziness, nausea and a bad headache and could not walk due to the vertigo, and vomited when I was trying to have my head up. I had to crawl to the bathroom on my hands and knees. I called out sick for work due to this and contacted my Dr. I was started **b6** for vertigo, and was taking **b6** to help.

b6 noted my Re upper eyelid was doing a lot of spastic twitching at times, that would stop and start, but did not think about it much. The vertigo was unrelenting and then I started to have Right arm and hand weakness noted on b6 and was still very dizzy, nauseated and had a constant headache since I got dose #2 of the COVID vaccine on b6 I was using a walking stick for the dizziness to be stable, and also felt weaker on the R side, and drifting to the right when walking. On b6 and noticed I could not fully shut my Right eye b6 and by b6 my face was drooping. I still had the constant headache, nausea and dizziness, and increased R hand, arm and R leg weakness and R hip weakness. I could not lift my R leg up to walk well, cannot grip well with the R hand, and uncoordinated, and cannot walk straight, and am unstable when trying to walk heel to toe, or even stand still with my eyes shut, and have had some double vision with the R eye. I was started on b6 for the vertigo on b6 after seeing my neurologist. I took b6 and did not have improvement with the R facial droop or R side weakness and the headaches have persisted, along with some dizziness and nausea. On b6 I had increased shortness of breath and R lung felt like it was not inflating much, and got b6 and went onto b6 which did help my lungs to improve, and I was able to breathe better, and got my Right lung capacity back.

I stopped the b6 to manage through the symptoms without it, and have been doing b6 (but the Dr does not think it is that sort of issue, but that b6 would help). I had b6 after an in-person neurology appointment, and was having some improvement with the vertigo, so I b6 b6 but I was still having the constant headache, nausea, and some dizziness, R face droop, R hand weakness, R leg weakness and walk with a walking stick, and have increased issues with exertion, but have been walking and doing therapies to get stronger.3 I started to have increased R facial droop. b6 of my R arm. Worse headache, nausea, dizziness at the desk, and fatigue, but R side weakness issues increased, so I started back onto b6 b6 but had increasingly bad headache, nausea and increasing R facial droop, and much worse R hand weakness, R arm weakness and pain, and R hip pain and weakness, worse walking, cannot lift my R leg or foot as high as the L, again, and am struggling to walk, and get worse with exertion with R side walking and weakness. I also had shooting pains in my R jaw start on b6 along with R jaw and face pain and increased numbness, more face droop shooting pains in my R hip, and arm and body pain and a worse headache making it hard to even sleep, and some increased issues with my R eye that I need to have checked. R hip jerking and awakening me multiple times a night the last few days on b6 b6 after a video visit with the neurologist. Increased R leg weakness, R weak hip vs left, R foot drag/drop, with increased issues to maintain walking with progressive walking, still using walking stick to try to walk, but now for stability and to keep from drifting, R facial droop increasing and now some R eye blurring b6 onwards, that is new. R eye found to have some tear film issues, so I have b6 for that.

History from last year.

I also was sick from very early in b6 (but I had what I thought was allergies 6 days prior which I now question) with significant respiratory cough but no wheezing, deep pain in the low center of my chest, fever, headache, increasing shortness of breath by day 6, diarrhea, was getting worse and my Drs had me on b6 which halted my lung issue progression enough, plus b6 I had the loss of taste and smell, then red tips of my fingers and weaker grip on the fingers bilaterally with cardiac arrhythmias, tachycardia, dizziness b6 constant headaches, heart rate issues, skipped beats

[b6] continued low lung capacity and [b6] brain fog, and relapses of all these issues, including my sense of taste and smell going away with each relapse. I also lost hair in clumps in [b6] after being so sick.

I have weird patches of rash that reappear in the same places, that never existed before this illness, that started in [b6] on my back of my neck, chest, wrists and arms. I shared photos to my Drs, and they prescribed [b6]

I was [b6] until the cardiac issues resolved, and [b6] but still was dealing with headaches, brain fog, fatigue, and feeling less stable after more exertion, so I asked for my husband to buy me hiking sticks for my birthday [b6] mostly because I was just still not feeling great, and was trying to do more exercise and get stronger. After stationary biking in [b6] light amount, for 10 min, later that night I would start to cause shooting nerve pains up and down my leg, keeping me up at night for a few days. I never had that before. So, I did not use a stationary bike for a month, then tried it again, the same thing happened, so I never biked again, and did not have that since the nerve stuff.

I never fully recovered from the [b6] sequelae and issues, but pushed through [b6] [b6] and would come home and collapse, barely able to bathe and then rest, then cook dinner and go to bed, so I was not exactly "recovered" before I got my COVID vaccines, but was managing, and still had the fatigue, brain fog and such, but did not expect this. I have never had vertigo in my life until now.

[b6]

[b6]

[b6] and had a significant systemic inflammatory, mostly neuro and respiratory inflammatory phase from 5 weeks onwards that involved a relapse of severe deep lung pain, pallor, cracked lips, severe headache for over 6 weeks, [b6]

[b6] with progressive neuro issues with the constant headache that involved bilateral numb fingers and toes, that led to progressive hand and leg weakness, and not being able to support his weight on his legs, and weakness to above his knees bilaterally, and having some very odd absence-seizure-like issues with all of this, which thankfully the leg weakness started to reverse, and the issues calmed down but he had a few relapses over the summer, but not as severe as this. So, he saw a neurologist for that, and had lots of tests.

He also has an unusual history and [b6] past history of triggered flaring of joint, GI, lung, headache, sometimes odd rashes, sometimes elevated inflammatory markers triggered after infections, and can be very prolonged, but he had been doing well prior to getting sick in [b6]

b6

He has had one dose of the Pfizer vaccine, and did have a headache, chills and fatigue, pain at the vaccine site for a few days, but nothing serious. He is due for dose #2 on [b6]

I have been trying to get help from the CDC CISA program, and submitted a request a few months ago. I also have asked my Dr to try to help on that too, as the CISA location for the west is at the [b6] I am not sure who he has contacted, outside his neuro colleagues, but he is open to suggestions.

This is the person that I think is over the west coast CISA, that I have asked my Dr to contact, and I have tried to reach, but I have not yet emailed. I will try again, but have not dared email, as I had hoped that my Dr would reach out, as [b6] I have tried to call a few times. I called the CDC and emailed in a request for a referral too, with no luck for this program. I know they are busy, but I had hoped they would help me.

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I also asked my neurologist to submit my case to this registry for COVID vaccine neuro events too, but I am not sure that he has, but I think it makes sense to collaborate:

<https://www.liverpool.ac.uk/covid-neuro-network/>. Do you work with this group too?

Note that I am 100% pro-vaccine, and have kept my story private, and most of my family, outside my kids and my mom who has been sworn to secrecy have not heard, and I have hidden this from colleagues at work too, but they do know something happened, and about the vertigo and R side weakness, but I think "through the grapevine" as I have tried to keep it quiet, and have not gone to the media, etc.

But I need help, and also we are trying to figure out what to do for

b6

b6

After what happened **b6** with our bad illness and prolonged issues for me about what could happen to **b6** so he really wants to get the vaccine, but has concerns about that too, with his history, and now what has happened to me.

Sorry for the novel. If you are able to help, that would be amazing, but if not, please share any suggestions, and feel free to contact my Dr, **b6** or anyone.

Thank you,

b6

On Mon, May 31, 2021 at 7:07 AM Goldbach-Mansky, Raphaela (NIH/NIAID) [E]

b6

b6 wrote:

Dear **b6**

I received an e-mail back from Dr Nath, a neurologist and his colleagues who are suggesting that you contact them for further advice and possibly consultation. Please go ahead. I highlighted the e-mail addresses.

Raphaela

Raphaela Goldbach-Mansky, M.D., MHS

TADS/LCIM/NIAID

phone: [b6]

fax: 301 480 4953

e-mail: [b6]

From: "Nath, Avindra (NIH/NINDS) [E]" [b6]
Date: Monday, May 31, 2021 at 9:03 AM
To: "Goldbach-Mansky, Raphaela (NIH/NIAID) [E]" [b6]
Cc: "Smith, Bryan (NIH/NINDS) [E]" [b6] "Safavi, Farinaz (NIH/NINDS) [E]" [b6]
Subject: Re: Post COVID vaccine study

We do not have a specific protocol but have seen a number of them. Sounds like [b6]
[b6] We can talk to the patient to see what we can do to help. You can share our contact information with her

Avi

Avindra Nath MD

Dear Avi,

I hope you are enjoying the long weekend. Mike Sneller told me about your protocol assessing neurologic complications post COVID vaccine.

[b6] developed severe neck pain and headaches, dizziness, vertigo and nausea within 48 hours after the first COVID shot which got better and then she developed [b6] after the second shot.

She is not getting much better after [b6] Would she qualify for your protocol and if so who should she contact?

Kind regards,

Raphaella

Raphaella Goldbach-Mansky, M.D., MHS

Senior Investigator

Chief, Translational Autoinflammatory Diseases Section (TADS)

Laboratory of Clinical Immunology and Microbiology, LCIM

NIAID/NIH

Bldg. 10 room 11C205, MSC1960

10 Center Dr.

Bethesda, MD 20892

phone: [b6]

fax: 301 480 4953

e-mail: [b6]

From: [REDACTED] b6
Sent: 3/9/2021 8:26:33 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group
(FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [REDACTED] b6
Subject: Re: 1 Year Covid Long Hauler

Attachments cont.

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

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> Dr. Safavi,

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

>

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

>

> [b6]

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

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From: [REDACTED] b6
Sent: 3/9/2021 8:27:58 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246] b6
Subject: Re: 1 Year Covid Long Hauler

Attachments cont.

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> [b6]

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

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From: [b6]
Sent: 3/9/2021 8:56:17 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group
(FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: 1 Year Covid Long Hauler

Attachments cont.

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From: [REDACTED] b6
Sent: 3/9/2021 8:28:33 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246- b6
Subject: Re: 1 Year Covid Long Hauler

Attachments cont.

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

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> [b6]

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

>>

From: [REDACTED] b6
Sent: 3/9/2021 8:01:21 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246] b6
Subject: Re: 1 Year Covid Long Hauler

Attachments cont.

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> On Mar 6, 2021, at 9:08 PM, b6 wrote:
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From: [b6]
Sent: 3/9/2021 7:50:02 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=94807ce146e045d4b61655da26a0c246 [b6]
Subject: Re: 1 Year Covid Long Hauler

Attachments cont.

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