

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

Begin forwarded message:

From: "Nath, Avindra (NIH/NINDS) [E]" <[REDACTED]>
Date: May 26, 2021 at 9:35:36 PM EDT
To: Stephanie de Garay <[REDACTED]>
Cc: "Safavi, Farinaz (NIH/NINDS) [E]" <[REDACTED]>, Patrick de Garay <[REDACTED]>, "Wiebold, Amanda (NIH/NINDS) [E]" <[REDACTED]>
Subject: Re: Severe Covid Vaccine Reaction from 12 year old girl in Pfizer Trial for 12-15 year old children

Thanks for the additional information. Due to HIPPA your daughter would need to give consent to her physicians to talk to me about her. Then the physicians would need to contact me. Sorry, I am not allowed to contact the physicians directly. OK to share my contact information below with them.
Avi

From: Stephanie de Garay <[REDACTED]>
Date: Wednesday, May 26, 2021 at 10:57 AM
To: Nath, Avindra (NIH/NINDS) [E] <[REDACTED]>
Cc: Safavi, Farinaz (NIH/NINDS) [E] <[REDACTED]>, Patrick de Garay <pdegaray@gmail.com>, Wiebold, Amanda (NIH/NINDS) [E] <[REDACTED]>
Subject: Re: Severe Covid Vaccine Reaction from 12 year old girl in Pfizer Trial for 12-15 year old children

Hi Dr. Nath,

Thank you for the quick response, I know you are very busy. Thank you for offering to talk to her neurologist. I am going to email him your contact information, his name is Dr. Kristen Robert Wesselkamper (Primary Physician, Neurology). Right now she is inpatient rehabilitation for walking and her doctors are Dr. Jeremy Brian Shapiro (Resident, Physical Medicine Rehab) and Dr. Mary Anne McMahon, M.D. (Attending Provider).

She was diagnosed with Functional Neurologic Disorder shortly after she started having her symptoms. They have done an MRI of her spine but not her head. They have not done an EMG or any testing for auto immune or allergy except IgA which was normal. If she can't walk today without a walker (her PT goal then they are discharging her). She still has an NG tube because she is unable to swallow food without regurgitating it, she is given miralax, senna and suppositories daily to be able to go to the bathroom and pees 800-1200cc of urine twice a day by sitting in the toilet (previously had to do a

straight cath and she has no urge to pee just a horrible pain which is her signal. She also has numbness from her waist down but does have some feeling coming back.

I am sharing a summary of her test results, ER visits and hospitalizations. I also have a document that gives more details of her symptoms as they progressed that is a work in progress. My concern is she was tagged with FND early on and there has been an unconscious bias from that point forward by specialists she has seen and the ER doctors. Additionally all of the doctors are from the hospital that she participated in the Pfizer trial and from the beginning no one was even willing to talk about the vaccine as the trigger for this.

From what I have read, the peripheral immune response and psychiatric disease can produce the same type of Neurologic symptoms. My concern is they are treating her symptoms and not the underlying cause.

I am extremely concerned about her health and the discharge plan they have for her which is sending her for inpatient treatment for an eating disorder which she does not have. I am not fully confident they will reach out to you but my plan is to refuse to let her be discharged until they do.

I appreciate your help, we are desperate to get our daughter better. She has developed extreme anxiety and a mistrust of all medical professionals due to her experience.

Maddie de Garay Lucy summary up to 5/22/21

[REDACTED]

Maddie de Garay symptom timeline details

[REDACTED]

Kind regards,

Stephanie de Garay

[REDACTED]

Sent from my iPhone

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

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

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
[REDACTED] (Office)
[REDACTED]

From: Stephanie de Garay <[REDACTED]>
Date: Monday, May 24, 2021 at 12:36 AM
To: Safavi, Farinaz (NIH/NINDS) [E] [REDACTED] >, Nath, Avindra (NIH/NINDS) [E] [REDACTED] >
Cc: Patrick de Garay <[REDACTED]>, Wiebold, Amanda (NIH/NINDS) [E] [REDACTED] >
Subject: Severe Covid Vaccine Reaction from 12 year old girl in Pfizer Trial for 12-15 year old children

Hello Dr. Nath and Dr. Safavi,

[REDACTED] shared your contact information and recommended reaching out to you for help. Our 12-year-old daughter, Maddie, was a healthy 7th grader with no major medical issues, the only things on her medical chart were ADHD and dermatographia. She participated in the Pfizer vaccine trial for 12-15-year-olds at Cincinnati Children's Hospital and was confirmed that she got the vaccine on Monday by Dr. Frenke. She received her first dose in the trial on 12/30/20. The next day she had a fever of 101, felt tired, and had swelling at the injection site but all of these resolved within a couple of days. She received her second dose on 1/20/21. She had immediate pain at the injection site which didn't happen with the first dose. About 18 hours after receiving the vaccine, she developed the following: severe muscle/nerve pain, painful electrical shocks down her neck and spine which caused her to walk hunched over, severe chest pain that felt like her heart was being pulled out, numbness, and swelling in her vaccine arm (left), her fingers and toes turned white and were ice cold to the touch, the pain in her toes was so bad she walked on her heels, severe abdominal pain (especially on the lower right side) and a fever of 101.4. We were instructed to take her to the ER at Cincinnati Children's Hospital where they did an ultrasound to check for appendicitis. The results showed there wasn't any sign of appendicitis even though the appendix could not be visualized or the right kidney, her bladder appeared normal, and a note that there was a diffuse gaseous-filled bowel seen throughout the right lower quadrant. They did a renal profile that showed her potassium was slightly low (3.2) and her glucose was slightly high (110), they did not do any other blood tests. Her urine

test showed a moderate amount of blood in her urine. She was given an IV, Tylenol, and Zofran, then sent home.

Over the next 2.5 months her severe abdominal pain along with the muscle and nerve pain persisted plus she new symptoms including fatigue, nausea, vomiting, abdominal distension, regurgitation of food, and eventually the inability to swallow food or liquids, itchy rash on her arms, peeling skin on her feet, unexplained painful cysts on her vagina and then her head, tinnitus, vision problems, headaches, dizziness, erratic blood pressure, and heart rate, memory loss, brain fog, verbal and motor tics, fainting/seizures (10+ a day), loss of feeling from the waist down then paralysis of her legs, inability to walk, muscle weakness, abnormal gait, gastroparesis, urinary retention, anxiety, and medical PTSD. Additionally, she started her first menstrual cycle on 2/5/21 which continued off and on for over a month with clumps of blood and then off and on spotting until 4/13/21 and nothing since then. Between 1/21/21 and 4/9/21 we had to take her to the ER nine (9) times and she was admitted to the hospital 3 times. In between hospital visits she has seen multiple specialists at Cincinnati Children's Hospital and had Physical Therapy and Cognitive Behavioral Therapy with no improvement, instead she continued to decline.

After several desperate calls to multiple doctors expressing our concern for her declining health and more ER trips we finally got help from our new Care Coordinator to have neurology guarantee, she would be admitted if we went to the ER on 4/9/21. When she got to the ER on 4/9/21 she could not walk, was unable to feel or move below her waist, had tachycardia and her blood sugar was at 47. Once she was stable they admitted her to neurology and then transferred her to Inpatient Rehabilitation on 4/13/21. As of today, 5/24/21, she is finally close to being able to walk without a walker but she still has an abnormal gait. She also still has an NG tube for nutrition and continued problems with urination and gastroparesis, not to mention the PTSD from this experience with doctors, especially in the ER and Pfizer Vaccine Trial, doubting her and treating her like a mental patient. Right now every Wednesday and Friday, she has to meet specific PT goals. *If she is unable to reach these goals, she will be discharged to follow-up outpatient primarily with Pain, GI, Adolescent, and psychology. If she is to be discharged, outpatient will focus much more on mental health.* NOTE: the words in italics are directly from her medical chart.

My daughter has gone from being a typical healthy 12-year-old girl who worried about doing well in school and loved hanging out with friends to being so ill she had to miss 4 months of school. She has been in the hospital for almost 2 months total where she celebrated her 13th

birthday. She is the strongest person I know and I am so proud of her for pushing through this nightmare and never giving up. There is no doubt in my mind that the vaccine caused this. All of these medical problems started less than 24 hours after the second dose of the Pfizer covid vaccine and did not just go away within 72 hours like they say. She was not forced to do the vaccine trial, she asked to do it along with her 2 brothers so she could help get our world back to normal. The only diagnosis we have been given is Functional Neurological Symptom Disorder with mixed presentation, acute episode in which the vaccine was likely the trigger, no explanation as to why the vaccine triggered it. They have dismissed her having repetitive abnormal blood work and that she has had blood in her urine countless times over the past 4 months, even with a catheter.

Once she was given the Functional Neurological Disorder diagnosis they stopped any further testing that could and should have been done. We have had issues with doctors avoiding vaccine conversations and the immunologist/allergist who saw her for 15 minutes is the doctor who "told" Dr. Frenke her symptoms were likely not due to the vaccine. She is not even close to being functional and that is with over a month of top-notch inpatient rehabilitation which has included PT/OT/Recreational Therapy/Music Therapy, Speech Therapy, and Cognitive Behavioral Therapy. And no one can explain or improve her urinary and GI issues. We have a family meeting today to discuss her discharge on Friday, May 28th. We are desperate to get her treatment that will help her get back to the healthy 12 (now 13) year old girl she was before she got the Pfizer vaccine. I was told her case was included in Pfizer's final report on the trial for 12-15-year-old children but they did not share the end diagnosis and all of her symptoms. They summed it up as functional abdominal pain with ongoing investigation, it was MUCH more than that! We do not want this to happen to more innocent people, especially children!

Kind regards,

Stephanie de Garay (Maddie's mom)

