

7/2/2021

I am a previously healthy 39 year old, preschool teacher, hiking and mountaineering on the weekends. Prior history of contracting West Nile at 27, but had recovered. No other major medical history worthy of note. I am pro-science and pro-vaccine, and was thrilled at the opportunity to do my part in ending the pandemic. I received my COVID vaccine 11/4/20 as part of a phase 3 trial with Astra Zeneca.

My initial reaction that occurred within an hour was tingling down my arm. Later that evening I experienced blurred/double vision, and sound sensitivity. The first night I had a more typical reaction including a high fever that had resolved by morning. When I got out of bed to get ready for work, I noticed my left foot did not work correctly and I would easily walk into the left of doorways. The sensitivity to sound and blurred vision was still there, accompanied by a strong tinnitus.

Within 48 hours it had progressed to sensitivity of light and touch. The clinic told me I likely had MS and told me to get a neurologist to verify this. The neurologist recommended I go to the ER, one of many visits that would happen over the ensuing months.

The ER ruled out MS, transverse myelitis and sent me home. I could only spend time in a completely dark and quiet room. Even touch was painful. Brushing my teeth was also extremely painful. My condition deteriorated over the next 2.5 weeks, to the point where my legs began to have trouble and I experienced severe motor dysfunction of my legs and feet, and became incontinent. I had lost over 20 lbs from extreme nausea and diarrhea, dizziness, and experienced a strange painful vibrating sensation that would move through my brain and body. I also developed autonomic dysfunction including heart rate fluctuations and blood pressure disfunction. The painful pins and needles also progressed from my arm to my other arm and face, I experienced a strange overwhelming brain fog, uncontrollable tremors, low fevers and even developed the COVID cough. My symptoms lined up so well with acute COVID that I was tested 13 times over 3 weeks between four facilities, all negative. I also have had 3 negative nucleocapsid tests.

I was admitted to the hospital just before Thanksgiving when I struggled to walk, where they treated me for a severe migraine which unfortunately did not improve my symptoms. I was then told it must be anxiety. I must note that have never had an issue with anxiety in my life. I have never taken an anti-depressant or other psychiatric medication.

My husband, armed with scientific research stood at my bedside every day begging my physicians to run a test or do any sort of treatment that would help. His pleas went unheeded I went home with PT and OT to help me learn how to walk correctly again, and try to work on the cognitive impairments. Every single day for months, my focus was just to survive, countless hours trying to just remind myself to breathe, and just hang on for my kids and hope that it would pass. The sensations were unrelenting 24/7, no rest or reprieve...It was the scariest 3+ months of my life.

When I was admitted to the hospital I was unblinded from the trial, dropped from the study and thus deemed an Adverse Event. I have no idea what happened to my data after being dropped from the study. I was removed from their tracking software, however I continued to send all of my medical records to the study clinic.

We began seeing multiple news releases from the drug company stating the vaccine was proving to be safe and effective. After several weeks of reporting my severe reaction to the drug company, the CDC, FDA and VAERS and not receiving any reply, we reached out to the NIH in January. They responded right away, and setup a call to review what was happening. They also reviewed a 2nd similar case from Astra Zeneca. They took this reaction seriously and started research. Some time after that, the US government declined an EUA for Astra Zeneca.

I repeatedly called my physicians and the test clinic in tears, begging someone to help me as these horribly painful sensations overtook my body, brain and life. My physicians would ask, what is Astra Zeneca saying? And the test clinic would ask what my physicians were saying. With no help whatsoever, and no answers, I had no choice but to hang on and hope that I survived.

Finally, after a consult with lead researchers, my home neuro team decided to take this seriously and looked further into my condition. They visited with me in January, then scheduled a followup in March, citing a vacation. I held on every single day until that appointment in March. At the March visit, the neurologist performed a lumbar puncture that resulted in a CSF leak. 2 blood patches were administered in the ER with temporary relief. After the 2nd failed blood patch, the neurologist deemed me "too fragile to treat" and declined any further care. I was left on my own and after 6 long and painful weeks of being bedridden, my internist ordered a 3rd blood patch that resolved my severe CSF leak symptoms. To this day, I still have not recovered from the de-conditioning I experienced during this time.

Like the majority of us who present with these strange GBS or MS like symptoms post vaccine, my tests were unremarkable. My neutrophil to lymphocyte ratio was high and slowly went back to normal over 6 months. My TSH fluctuated. My aldosterone also was zero. One type two oligoclonal band was found in my CSF.

I went 7 months without appropriate diagnoses.

Finally after months of being lost and dismissed, I had the privilege of visiting a highly respected research institution in June. Several simple tests were redone and I was given the diagnoses of sensory neuropathy of my hands, short term memory loss, non-length dependent neuropathy in my arms and legs, and severe postural orthostatic tachycardia syndrome with a possibility of auto-immune dysautonomia. After months of suffering and trying to squeak by on my own, these physicians quickly picked up on some very simple findings that paved the way for treatment options.

The treatment they administered was the same treatment my husband had been pushing for me to receive from the beginning. Now I am left with the question of how much of this neurological decline could have been prevented, had I just had the

appropriate treatment to begin with. I was told that this is treatable and also that early intervention is important. Obviously this is very concerning as this is leading many many more like me, to experience this same cascade of neurological decline over weeks following vaccination, which possibly could be halted or slowed.

Some of my symptoms have since resolved, no more fevers, no more sensitivities to light or sound, no more extreme nausea, and paresthesia appears to be improving. Heavy brain fog and derealization has also improved. My most debilitating symptoms are improving, including strange weakness in my legs, tremors similar to parkinsons, and inability to walk very far, horrific vibrations in my brain. Very painful electrical sensation through my body, tinnitus, and fatigue.

This has severely impacted my life and my family's life. I have had to hire substitutes to teach my preschool classes. We have also had to refinance our home so we can pay for after-school childcare. My husband now has to work from home so he can help take care of me. The test clinic and study sponsor agreed to pay for my medical bills and considered compensating for my lost wages. After repeated dialogue for months, I have yet to see any payment from them, neglecting any consideration that a sick person cannot advocate for their own needs.

We have been trying to right this sinking ship for months. My small children now know me as "sick mom" and have really struggled with this emotionally. I have missed out on 8+ months of their lives now and I have no idea when it will end.

-Brienne Dressen