

Statement in Support of Long Covid Funding
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03/31/2023

Hello my name is Annette Tousley and at the end of February I marked being sick from covid-19 for 3 years. My acute phase of covid was severe and I sought testing for it at a local emergency room. There, the doctor I met with, made fun of me to my face, telling me he recently had an illness that also made him feel "really crummy" but that didn't make it SARS. I was sent home without covid testing, a pack of zofran, and later, a \$1,500 bill. I would say that this has been the worst, or most traumatizing part of my story, but it's only the very beginning, and to tell it all, I would also have to include a story of inappropriate sexual touching by a cardiologist, and meeting with the top pain doctor in a health system after a months long wait, only to be sent home with the instructions for how to make my own vegan cheese. To say the healthcare field on the whole is uninformed about long covid, is a pretty big understatement.

In the last 3 years, the improvements I've had have come from different places, but at least twice, they came from private practice doctors that I had to pay for out of pocket. Because I don't have access to money beyond my own savings, I've also had to delay or not do some of the tests and scans that they've recommended, because I can't afford them.

Within the healthcare system, I'm sorry to say that I'm actually taking a break from seeking care. I've had too many people attempt to tell me I'm not sick, or say that, because the standard tests are normal, there's nothing else they can do for me. The experience has been completely degrading and emotionally unsustainable. I am after all, very sick, while experiencing this open questioning of whether or not I am sick.

At the long covid clinic, I was promised tests that were never ordered, and again demeaned and belittled by the doctor. When I asked about specific research in the field and for specific tests, it was clear the doctor didn't know what I was talking about, but instead of looking it up, I was again laughed at. And not for the first time asked, "when are you going to medical school?" As if I ever wanted to know this much about blood, tissues, organs, oxygen transfer, immune system dysfunction, or any of the other research happening. In the absence of any doctor I've met with reading about the most up to date science, I've had to read about it myself and advocate for myself to that end.

My main experience and what I hope I am expressing here is this. Doctors seem to be more incentivized to tell me there's nothing wrong with me, than they do to help me. I've been told by more than one doctor to stop seeking care.

Now let me briefly tell you how sick I've been while all of this was happening. I'll cut to the third year, because the first two I was "mild" by all accounts, even though I personally knew something was drastically wrong with my health. In my third year, I had a post exertional malaise crash that left me bedbound and in severe physical distress for months. I never knew you could get so sick without dying. In fact the first couple weeks I thought I was going to die.

Post exertional malaise, or PEM, is one of the hallmarks of this illness and one of the worst experiences a person can endure. When I get PEM my blood feels like it's been poisoned. I can't move, I can't eat, I can't listen to music, I can't watch tv, I can't hold things in my hands, even. My body goes into a shutdown state and the only thing I can do is succumb to it until the "crash" has passed. Usually for me, this also involves spending the first part of my crash on my bathroom floor or near the toilet, as my body starts the process by expelling anything in it.

So that's a "normal" crash. The one I had just about a year ago, was one of the most extreme sensations I've ever experienced. In the first day of the crash I could feel my entire spine in the most painful way, every part of my body was activated and in extreme pain from the top of my head to the tips of my toes. The crash lasted more than 6 months, and unfortunately for me, brought on new symptoms that I hadn't experienced with my long covid yet. It also made my life incredibly small. I was unable to take any vacations or nights away because I couldn't ride in a car without aggravating symptoms. I couldn't drive myself places either. Last May, my big milestone was that I walked the length of my fence line outside my house. About 50 feet.

That would be my new house, as I lost my last house to this illness. I am thankful to be in a different place this year, my fourth year of illness. Though, even 1 year out, I am not back to "baseline" from that crash.

Before this, at some point, my brain came back online and I wasn't forgetting names and words for simple things anymore. As these improvements have held for me, I plan on finding a part-time job. The prospects for what's out there, are daunting, especially since most part-time jobs won't cover my expenses. I've been living off savings for 19 months. I exhausted all of the leave options at my former job and was denied a change in working hours or jobs, so I was forced to quit. I do not have social security benefits as I have not been able to prove my illness, and many of the doctors I've met with have actually made that process harder by denying my experiences altogether and denying advanced testing.

Before I got sick I was making \$165,000 a year, plus a nice bonus. I also had around \$75,000 cash in my bank account, because I was saving for a big purchase and getting pretty close to realizing that dream. I want to stress the financial aspect of my situation because I'm very concerned for what's happening financially for most long haulers like me, who have been sick for multiple years now. Had I gotten sick during any other time period of my life, I would have been facing homelessness already. I can't stress enough how expensive it has been to navigate long covid in a health system that is not incentivized to know anything about the illness, and in a state/country with no accessible safety net, unless you can come up with a burden of proof that long haulers do not have.

I see the issue as complex, I'm sure people can appreciate that. But in addition to this long covid funding, we need ongoing funding for both research and medical support of the disease, and we also need ongoing funding for long haulers so that we do not need to carry the massive financial burden of being sick, while also being sick to this extreme of degree. Disability and chronic disease are already over-represented in the unhoused population, and long haulers are joining these numbers in a way that every elected representative should feel ashamed over. Without interventions like direct payments, UBI, rent or mortgage assistance, or even easier and better access to food assistance, we will not be able to survive. To be clear, we already have negative health outcomes because of these circumstances, they're just getting more serious the longer we're sick and the longer we're denied care by the state and the major medical systems therein.

Thank you for your time.