Testimony on Long Covid
**For VT Senate **

Before 2020, I was living a good life. I had worked hard to stabilize a life with many ups and downs, and in my thirties, things were finally smoothing out. I was raising a healthy four-year-old and one-year-old, happily married, running a successful business. I rock climbed with friends, hosted dinner parties, played guitar. I took my children to enrichment programs, spent time at local farms, went hiking, did art projects. I had many friends and felt strong and light in my body.

Now I do not remember what health feels like. I have no memory of it in my body, no matter how hard I try to recall that feeling. My body is noisy nowâ€”noisy with discomfort so constant I almost accept it as normal. This is a loss that healthy people cannot possibly understand, a loss in the raging sea of loss that chronic illness patients swim in day after day. We never reach shore. We do not get a break. We are reminded of our loss every single day. In fact, as I type this, I have tubes pumping other people's blood plasma into needles in my stomachâ€”plasma that allows me to fight off infections because Covid broke my immune system.

I got sick before we knew the word Covidâ€”before anyone spoke of it publicly anywhere. I became symptomatic on January 17, 2020. A young client came in from a trip to Nepal followed by a ski trip in Washington State, and sat down in my chair coughing and sniffling. "I think it's allergies or maybe a cold from the plane ride?" she said. I was upset that I might miss a week of work between me getting this cold and then my kidsâ€”how could I afford a week off?

Little did I know I would never recover.
Six years later, I spend most of my day in bed or on the couch. The progression has been up and down but with an overall downward trajectory. I pared down my client load several times a year, only when I was willing to face the reality that it was simply too hard to continue working the way I was. I built a space to work at home to ease things on my body, only to lose that too. Eventually, illness won. In 2024, I put my tools down. The skeleton of my career constantly reminds me of one of the many freedoms I have lost.

In the first few years of my long Covid, I was able to work part-time and exercise. My main symptoms were vibrations that felt like I was plugged into a wallâ€”at times, like I had swallowed an old cell phone. I would wake up many times a night with adrenaline coursing through my veins, ready to run out of my house or fight someone. I had hallucinations. I heard voices telling me to kill myself. I had weird rashes, lost thirty pounds, had a swollen pancreas, fainting spells, and painful migraines. This isn't everythingâ€”I had over 125 symptoms in the early days.

But no one believed there was something wrong.

When I asked my doctor in April 2020 if I could have had this new virus, she laughed at me and said absolutely not. Every doctor said I needed Valium, that this was just postpartum anxiety, that I should get used to it.

A gallstone was what finally got me the information I needed. A doctor at UVM recommended removing my gallbladder, and I went for a second opinionâ€”because that's what you do before removing a whole organ. The doctor at Dartmouth told me, and I remember this clear as day: "I can take your gallbladder out if you want. But I don't think that will help you. I think you might have this new thing being referred to as long Covid. Some people get the virus and don't recover."

Allow me to walk you through a current day.

I wake to an alarm at 6am. In an attempt to maintain normalcy, I do my best to help with my kids in the morningâ€”but really, that means sitting in the room with them, pushing pain and nausea aside to ask what they're excited for in the school day ahead. Some mornings, I just can't.

It always takes at least 45 minutes for me to get out of bed because the fatigue is heavy and the nausea is unrelenting. Sleep in this illness is not refreshing; I wake up feeling no better than I did the day before, if I'm lucky. Some of my jointsâ€”a rotating selection dailyâ€—feel hot and creaky. My muscles are sore in that flu-like way.

When I make it to the kitchen, I am dizzy and feel sick to my stomach. My kids are asking questions and the noise is overwhelming to my brain. I sometimes wear earplugs; otherwise, I am asking for lower voices. My family knows to keep the lights low because the bright ones hurt.

I hug and kiss my kids as my husband Jake helps them get downstairs. I cannot do the stairs more than three times on a good day, zero times on a bad day. Stairs are energy vampires, it turns out. So are showers.

I grab coffee and swallow my fistful of pills lying on the couch while Jake cleans the kitchen and takes care of the dogs. He asks if I need anything. I start my calls to Aetna to fight for coverage of new medications and check on the status of appealed denials. Calls to doctors for appointments. Checking lab work that is likely to be in the normal range. Checking online support groups for any news. Please lets there be a cure, please let there be a cure.

I stare out the window and watch the birds, but I'm getting tired, so around 10am I head back to bed. I have weak connective tissue, so holding my head up feels like an Olympic sport. I scroll through newly published papers on my illnesses, but reading them is tiring. I close my eyes.

Around noon I can start to tolerate some foodâ€”plain toast or slices of turkey, maybe some apple. I have to be careful about what I eat and also around new medications because I now get anaphylaxis. Label reading is a must. Eating makes my blood pool in my stomach too much and I feel sick, so it's back to bed. My feet and legs turn purplish blue; they feel both numb and burning.

Jake checks on me, offers me food or refills my water bottle, tells me about his day at work. I text my good friend with more severe long Covid to commiserate, compare notes, and talk about our kids. Thank god for other sick people because being in this Groundhog Day alone would be far worse.

At 3pm, the kids get off the bus and rush into my room to hug me. We talk about their day. At 4pm, I get out of bed for my big moment: cooking dinner. I try to cook each night because I love to cook and it makes me feel like a real human being with some purpose. It doesn't happen every night. I sit at the counter and chop, move the stool to the stove and cook, then lie down on the couch to recover before we can eat. Again, eating makes me feel ill, so I eat a small portion and immediately lie down again. The kids come hang with me. Around 6:30pm, I wander back to bed or sometimes just stay on the couch until bedtime. I take my night meds and try to sleep.

Rinse and repeat.

This is an average dayâ€”far from my worst.

One of the factors in my worseningâ€”by far the most impactfulâ€—has been reinfection. My second infection put a graduation cap on my existing long Covid, sliding the tassel to the other side as it developed into ME/CFS, a disease with the lowest quality of life of any illness measured.

On my worst days, I cannot speak. I cannot walk. The muscles behind my lung function are like sleepy puppet masters. It feels like the road to death, and some days I think death would be easier than this.

But the kids. I can't leave the kids.

In these crashes, I feel like a broken machine. Where is my energy? Why is this thing not turning on? I desire a reboot or a slap on the sideâ€”something to get things going again. On these days, Jake carries me to the bathroom and reminds me to drink water because I have no drive to do the things that keep me alive.

Yet I am considered mild.

I am very emotional writing this. I want to scream, but that would take too much energy and could harm me. Imagine an illness where self-expression can hurt you. It's just cruel.

My illness doesn't just cause suffering for me. It tentacles out. It has colored our life as a family, my life as an individual, my role in my community, my marriage, my friendshipsâ€—nothing goes untouched. The pain and suffering is a daily walk through the jaws of hell.

My life, as with anyone else with chronic illness, has been heavily filtered. A few people have remained at my side, but I think for most, I am a reminder of something they don't want to look at. I was caught in the wreckage, and that's surely unfortunate, but how dare I remind them of something they don't want to remember.
Rememberâ€”the pandemic is over.

This life is deeply lonely. We miss out on so much as a family because of me. If we do anything exciting, it is Jake and the kids doing it while I stay home cheering from afar. It feels like Iâ€™ve been shot into space, like Iâ€™m not here on earth. Last Thanksgiving, I stayed on the couch with friends coming by to feed me and help me while Jake took the kids to his family's home in Connecticut. I have missed weddings, funerals, family gatherings, trips with friends. There are so many photo booth strips and family pictures, and I am not in them.

It feels like I am disappearing. You would think Jake was a single father.

An often overlooked part of chronic illness is the cost on the caregivers. The extra weight carried is enormous, yet there is no support for them. Jake works full time, cleans, does the laundry, takes me to all of my appointments, and is the primary caretaker for our children.

I have had to work hard to find supports for my children. Their little hearts ache with the fear that they could lose their mother more. I say *more* because so much of me has already been lost. They fight the battle between being taunted at school for wearing a mask and risking bringing Covid home.

Covid could disable me further. Covid could cause long Covid in my children.

My daughter already has a very mild form of long Covid. I do not want her to worsen. Her symptoms involve temperature sensitivities, trouble breathing, and new food and chemical allergies.

When I think of measures that could help, I think immediately of clean air in schools and public spaces using far-UVC light. A recent randomized control trial found that air purifiers cut school absenteeism by 12.5%. Long Covid has become the number one pediatric chronic illness, with a higher rate of incidence than asthma. We should be protecting our children.
I think of:

* Free Covid tests
* Workplace and school support that allows people to stay home when sick
* Clear messaging sent to doctors' offices on identifying long Covid

RTHM, a virtual care clinic focused on infection-associated chronic conditions, has published a long Covid guide for patients and doctors alike. Many people are waiting around when they could be trying some over-the-counter medications and getting some level of benefit. The CoRE team at Mt Sinai is holding teachings for doctors so that they learn the condition is real and not psychosomatic.

I am not a doctor, but I have been able to help countless people figure out where to focus on their illness, what to read about, what over-the-counter medications they could discuss with their doctor, and what testing to request. I cannot tell you how often I receive messages expressing gratitude for helping to light the way for them and their doctor.

Although I am always happy to help, this should not fall to a disabled hairstylist to do.

I wish we had a long Covid clinic in Vermontâ€”a place where people can receive a diagnosis, access basic treatments, and be referred to specialists. A place where doctors can gain knowledge around neuroimmune diseases. I know UVM had a version, but I am talking about a legitimate clinic. Why clinics have closed when this illness is trending upward, not down, makes no sense.

All in all, we are lonely. We have been mostly forgotten. I still meet people who don't know what long Covid is. I still hear of many doctors who don't believe in it at all.

We are craving support and visibility. We are a group of people full of ambitions and dreams, stuck in bodies that don't work. We want nothing more than to be amongst the living.

I thank you for hearing us and only hope this helps to breed understanding and support for our community.

Thank you very much for your time and energy today.