

Testimony of Dr. Alexis N. Misko, OTD, OTR
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In Support of Maryland SB0392 (FAV)
February 10, 2026

I worked full-time as an occupational therapist in a hospital in the state of Ohio for eight and a half years, including throughout the pandemic. I regularly worked directly with Covid-19 patients, including in the ICU. I contracted Covid-19 at work in October of 2020 at age 33, before vaccines were made available to healthcare workers or the general public. I have never recovered, and I want to express my support of Maryland SB0392.

Before Covid, I could hike hundreds of miles at steep mountain elevation. I could kayak, jog, or do strenuous yard work after working a hospital shift where I performed hours of detailed electronic medical charting, engaged in constant multitasking. My husband and I traveled all over and had a vibrant social life. I had no pre-existing conditions and was never hospitalized. I was told I was “young and healthy,” and would get better without any of the antiviral medications or monoclonal antibody treatments that were being given to the elderly and immunocompromised at the time.

I went to the ER twice at the beginning of my illness, the second time with chest pain, shortness of breath, confirmed double pneumonia and a heart rate of 192. I was given a bag of IV saline and discharged. My nurse would not allow me to walk to the exit and insisted I use a wheelchair, yet I was discharged nonetheless with a heart rate of 150, one that I normally would not have reached even while running on a treadmill. In the weeks that followed I was offered only antidepressants and a steroid inhaler as my health continued to spiral downward.

Doctors repeatedly disbelieved how ill I was. At first I was able to shower, walk up and down the stairs, move around my home, but the more I tried to gradually and slowly increase my activity levels, the worse I became. My health worsened dramatically after what used to be basic daily occurrences: a trip to the grocery store, driving a car, a doctor’s appointment, a 45-minute Zoom call, menstruating. I became unable to climb the stairs at all. I lay on the floor of the bathroom for 30 minutes after vomiting, just to muster the energy for the 25-foot walk back to bed. There were times I could not lift my head or arms, send a text message, or use a spoon. Chewing and digesting were physically draining, the room around me a hazy blur. My skin felt like someone had lit it on fire. Receiving a hug was painful, as were sound and light. I spent months feeling like I had been poisoned. Insomnia raged. I would attempt to sleep when my husband was awake in case I stopped breathing, but instead I repeatedly woke up choking and gasping. My doctor reacted by running basic blood tests and then giving me the phone number of a psychiatric facility.

I was totally bedridden for seven months, in constant physical suffering and unable to tolerate much stimulation, including reading or using a computer or a cell phone in any capacity. All my energy went to using the bathroom and feeding myself food brought to me by my husband. I could not even look out the window. Speaking was done in short phrases and soft tones. Crying or even laughing resulted in days of increased excruciating symptoms. I was unable to shower or

bathe, even with help, for over four months. I did not watch television for over two years, or listen to music for over three years, all due to neurological symptoms.

In 2021, along with Long Covid, I was diagnosed with myalgic encephalomyelitis (ME/CFS), dysautonomia and postural orthostatic tachycardia syndrome (POTS) as a direct result of my Covid infection. These are typically lifelong illnesses with extremely low recovery rates and very poor quality of life scores. I received these diagnoses via telehealth from a specialist in the state of New York, as there were no specialists in the state of Ohio knowledgeable or experienced enough to provide care and I was too ill to travel. There are currently zero FDA-approved treatments for any of these illnesses, and while any treatment given focuses merely on temporary symptom management, most doctors are highly reluctant to prescribe off label medications they are personally unfamiliar with. Long Covid clinics offer little assistance either, providing only basic advice about pacing, energy conservation and sleep hygiene that almost anyone can easily find online.

Today, I still require assistance from my husband with all aspects of daily life and would be unable to live independently at age 38. I spend my time mostly alone in a dimly lit, quiet room listening to audiobooks or occasionally watching television. I get about two to three total hours per day, not consecutively, to function at 10-15% of my previous capacity, and have to spend the rest of the time lying down or sitting reclined with legs elevated to prevent episodes of disabling post exertional malaise that can last days to months. Every morning I wake up with the motivation and desire to do hundreds of different tasks, but I physically cannot. It has taken me several days, in small increments, to write this testimony.

Though I have made small improvements since 2020, my life is still focused entirely on managing my illness. I am not able to socialize with family or friends, and I rarely leave my house for anything other than an appointment with a doctor. I shower only sporadically, as it takes a full day to recover each time. I can walk only short distances and have to use a power wheelchair for any mobility done outside my home. In 2023 my husband and I had to sell our old home to move into a one-story house due to my level of disability. Exercise in any capacity causes a disabling exacerbation of all of my symptoms. Because I am forced by Long Covid and ME/CFS to be so sedentary, I am also at an increased risk for diabetes, stroke, heart disease, obesity, osteoporosis, cancer, etc, risks once easily mitigated by how functional and active I was. Now, placing a load of laundry into the washing machine consumes my entire energy capacity for the day, meaning if I do this I am then incapable of making a basic meal for dinner. I must rest after microwaving food or playing with my cat for a few minutes. I must rest after cognitive activity, like having a conversation with another person. Because of these illnesses, I will never have children, not only because it would worsen my conditions but also because I would be physically unable to care for them properly. There has been an overwhelming amount of loss and grief due to Long Covid. There is very little room for hobbies or activities that feel like I am contributing something to my household, let alone to the outside community or economy.

When I initially became ill with Covid, I was given the federally sponsored two weeks off work to recover before having to apply for short-term disability/FMLA. I likely had three decades worth of work left in me, but I have never been able to return to work in any capacity, instead forced to apply for SSDI, which I was granted after a battle that included hiring a disability attorney. I am

still, almost five years later, battling a worker's compensation claim.

Like veterans who return from war and receive inadequate care, essential workers with Long Covid were discarded and forgotten. Many struggle to pay off their medical debt, or to even be believed. Some are ridiculed for a devastating illness that some members of both the healthcare field and general public still insist is a minor inconvenience, exaggerated, or a political scheme. Yet according to *Yale Medicine*, as of March 2024, 17% of people who contract Covid will go on to develop Long Covid. The majority will never recover.

It is critical that Long Covid and infection-associated illnesses such as myalgic encephalomyelitis (ME/CFS), dysautonomia and postural orthostatic tachycardia syndrome (POTS), which people are experiencing in high numbers after Covid infections, are funded and studied at a rate that is comparable to other chronic illnesses based on population affected. The focus must be on ambitious clinical trials, including trials of already existing drugs that show promise with infection-associated illnesses. As both a former medical professional and a patient with Long Covid, I have been devastated watching the current federal administration remove so much funding and resources from the NIH and from public health in general. Many of us have lost hope. We need experienced experts to study serious drugs, as soon as possible, with the goal of rapid availability and wide accessibility to patients who are suffering terribly. We deserve the same treatment that other serious chronic illnesses receive: knowledgeable doctors, medications to try, and meaningful healthcare plans of care that will improve functionality and quality of life.

Thank you to Delegate Greg Wims and all other committee members. Your consideration of this horrific problem and potential solutions is not only very much appreciated, but absolutely necessary. Thank you for your time.