

To: Dr. Richard Pan, Chair, Senate Health Committee

And

Hon. Josh Newman, Chair, Senate Special Committee on Pandemic Emergency Response

From: Angela M. Vázquez, MSW, President, Body Politic; Long COVID Patient

Re: Written testimony for Senate Joint Informational Hearing on Long-Term Costs and Consequences of COVID-19 on Californians

Date: March 9, 2022

My name is Angela Meriquez Vazquez and today I am here to speak as a disabled former athlete, Long COVID patient, and President of Body Politic, the grassroots patient-led organization at the forefront of Long COVID advocacy, fueled by our support group of over 10,000 patients worldwide. Thank you members of the committees and staff for inviting me today.

Best estimates show that at least thirty percent of individuals who had COVID-19 reported at least one persistent symptom up to six months after initially being infected. That means a conservative estimate of 2.6 Million surviving COVID patients in California are experiencing symptoms of Long COVID in the US alone, which are varied and ongoing, including neurological challenges, cognitive difficulties, shortness of breath, severe fatigue, cardiovascular complications, pain, mobility issues, and symptoms that are greatly exacerbated by even minimal levels of exertion.

Before getting COVID19 here in Los Angeles in March 2020, I was a runner for nearly two decades. In fact, the morning of the day I first started feeling sick I had gone for a great 3 mile run. It's been nearly two years of COVID19 symptoms and I have not run since - I'm not sure when I'll be able to. I experienced an increasingly scary set of symptoms, including severe levels of blood clots, a series of mini strokes, brain swelling, seizures, painful heart palpitations, severe shortness of breath, and extreme confusion, and numbness in my face, hands, and legs that progressed to an inability to walk for several days, and new onset of anaphylaxis after every meal.

With Long COVID, I now have several ongoing chronic conditions, including likely a mild form of myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome or ME/CFS. It is a neuroimmune condition whose hallmark symptom is post exertional symptom exacerbation, which means when I push myself past a dynamic threshold, I

will experience a relapse of my worst symptoms like insomnia, brain fog and confusion, sleep apnea, heart palpitations, fevers, and severe migraines. I have developed a strict pacing regimen that allows me to work from home more than full-time, but not do much else. I do not socialize, or enjoy my old hobbies, and I don't leave my home, especially now that I am now considered high-risk for complications from a subsequent breakthrough infection.

Unlike me, at least half to nearly  $\frac{2}{3}$  of surveyed Long COVID patients could not work full-time. The vast majority of patients experience deep fatigue along with neurological and cognitive symptoms that make it difficult to drive, make decisions, remember instructions, follow conversations, and plan ahead. The Brookings Institute recently estimated that 1.6 million workers are out of the workforce due to Long COVID, which represents an astounding majority of the estimated 2.2 million people that the labor force is missing from its pre-pandemic size.

Even before COVID, ME/CFS, which is extremely debilitating and has significant overlap with Long COVID, affected 180,000 Californians and cost our economy \$5 billion annually in lost wages and medical expenses. There are only about six ME/CFS specialists practicing in California, which means that Californians like me afflicted with ME/CFS often wait up to two years to be examined by a specialist; many never get to see a specialist at all. This trend is now occurring with Long COVID.

I am on the mild end in the spectrum of disability of Long COVID patients. I have been part of support groups, listening sessions, and news reports with patients who are unable to work at all, who are homebound like me, or bedbound, who are unable to care for themselves because the act of making a meal leaves them with fevers and pain so severe they are completely taken out for the rest of the day. These patients have families, and they are often parents and breadwinners. Their access to benefits is nonexistent because Long COVID was not even a diagnosable condition until October, nearly two years into the pandemic, despite the medical research on post-viral conditions like ME/CFS, Chronic Lyme, and even AIDS, has existed to guide clinicians in caring for patients with infection-triggered sequelae. We must build on this existing research and not continue to frame Long COVID as an entirely new phenomenon. My friend and colleague Hannah Davis from the Patient Led Research Collaborative who are studying Long COVID, has said "all my tests came up normal, until I went to an ME/CFS doctor - then none of my labs were normal." That was true for me as well - I waited a year to see a specialist who could diagnose and treat my conditions because she has worked with patients with post viral illness for years and has a waitlist a mile long.

We also know that the virus has disproportionately impacted communities of color both economically and in terms of their health. This means that there are likely millions of Long COVID patients who because of income or immigration status remain unidentified or unsupported with their new disabilities by the healthcare system, employers, and schools.

We are living through what is likely to be the largest mass disabling event in modern history. Not since the emergence of the AIDS pandemic has there been such an imperative for large-scale change in healthcare, public health, and unjust structures that bring inequitable risks of illness, suffering, disability, and mortality. COVID-19 is but the most recent driver of a known phenomenon of post-viral illnesses that often cluster around a set of understudied complex chronic conditions.

Together with the disability and chronic illness communities, Long COVID patients need California to do the following:

1. To address the clinical care crisis in Long COVID and related post-viral illnesses like ME/CFS, California Centers of Excellence must be created. These Centers should be located throughout the state, and should provide adequate care, conduct research, and engage in education, training, and outreach.
2. Policies that ensure that all patients with complex, chronic illnesses have access to the best possible primary and specialist care, fully covered by private insurance and Medi-Cal, and in the case of COVID19, regardless of having a positive test due to testing issues throughout the pandemic, especially in poor Black and brown communities.
3. Ensure that Long Covid patients are able to access State Disability Insurance benefits, even if they do not have a positive test, given the persistent testing issues, especially in marginalized communities.
4. Require commercial and public health plans, with guidance from the CA Department of Public Health and CalHHS, to conduct extensive outreach and education to providers and beneficiaries about the symptoms of Long COVID and guidance on how to access care.
5. Create incentives for providers and medical students, including Medi-Cal providers, to receive ongoing clinical education on complex chronic and infection-initiated illnesses, including diagnosis, symptom management, and where appropriate, evidence-based treatment, to ensure patients receive proper care as well as support should they need to apply for disability benefits or request school or work accommodations.
6. Stronger enforcement of employer and school accommodations for Long COVID and other chronically ill patients who may be able to work or go to school if they have access to telework or distance learning, can have adaptive schedules, are

provided with reasonable accommodations including masking requirements for their colleagues with whom they share indoor space, and have the opportunity to restructure their assignments or jobs.

7. Fund health insurance navigators and legal aid organizations to help people with Long COVID apply for disability benefits.
8. Provide a state-funded long-term care benefit that works for episodic disabilities like Long COVID.