

My name is Angela Meriquez Vazquez and today I am here to speak as a disabled former athlete, Long COVID patient, and former President of [Body Politic](#), the grassroots patient-led virtual community health organization that was at the forefront of Long COVID advocacy. Before we had to close due to a lack of funding, we connected and supported over 15,000 Long COVID patients worldwide, the vast majority of whom were from the U.S.

Before getting COVID19 in Los Angeles in March 2020, I was a runner for nearly two decades. What started as a mild illness progressed over weeks with 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, extreme confusion, and numbness in my face, hands, and legs that progressed to an inability to walk for several days, and new onset of allergic anaphylaxis after every meal. I had many clinical signs that something was wrong within weeks - high markers for an autoimmune disease, labs that showed my blood was severely clotted, markers of an exhausted immune system. All were dismissed by doctors as anxiety, but now are being verified by overdue and still underfunded [research](#) as clear evidence of Long COVID and infection-related pathology.

I was left to fend for myself from bed that first year, because I did not fit the profile of who was considered high-risk. There wasn't even acknowledgement that infections could trigger chronic disease - something I knew when I first got sick since I have a friend who has lived with Chronic Lyme for years. I was a young person of color, not elderly and white. Now, even the CDC's [data](#) shows that Latiné and LGBTQ+ communities are currently experiencing the highest levels of Long COVID in the US, and there is strong evidence that people of color are [not prescribed antivirals](#) like Paxlovid at the same rate as white people. The medical neglect and discrimination I faced contributed to my current level of disability and continues to harm patients like me.

With Long COVID, I have several chronic diseases, including myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome or ME/CFS. It is a neuroimmune disease whose hallmark symptom is post exertional symptom exacerbation or post-exertion malaise, 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'm on 12 different prescription medications, including weekly IV treatments at the hospital. I have a strict pacing regimen that allows me to work from home, but not do much else. I do not socialize, or enjoy my old hobbies, and I don't really leave my home, especially now that I am now considered high-risk. Though we were recently vaccinated, my spouse and I were reinfected with COVID over Christmas - I am here today despite my Long COVID and new autoimmune disease flaring, and I am risking permanent worsening of my MECFS from the exertion.

I am on the mild end of disability and now have access to a lot of medical support. Patients who have had MECFS for decades guided me to the right specialists familiar with the historic research on infection triggered diseases like [Postural Orthostatic Tachycardia Syndrome](#) (POTS), [Mast Cell Activation Syndrome \(MCAS\)](#), and [ME/CFS](#) and how to manage them. Patients of color's access to benefits, and diagnostic and supportive healthcare, is nonexistent because Long COVID was not even a diagnosable condition until [nearly two years into the pandemic](#), despite the medical research that has existed, though limited, to guide clinicians in managing infection-triggered diseases. Low-income, immigrant, and

patients of color who are more likely to get COVID-19, Long COVID, and have the least access to healthcare, are likely experiencing the greatest levels of disability and medical neglect and largely remain unidentified or unsupported with their new disabilities by the healthcare system, employers, and schools.

Unlike me, at least half to nearly two-thirds of surveyed Long COVID patients could not work full-time, according to [research](#) conducted by the Patient Led Research Collaborative, a group of patients with Long COVID that started their peer-reviewed research through our Body Politic support group. Many patients like me 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 Institution [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.

As we speak, the [return of Medicaid eligibility redetermination](#) as a result of the federal Public Health Emergency unwinding is creating an escalating health crisis for Long COVID patients. Having to prove that you are still poor is a [time-consuming, stressful, and bureaucratic process](#) that contributes to millions of otherwise eligible households losing their health insurance because of application errors or missed notifications. This process was wisely stopped during the first three years of the crisis in the interest of preserving healthcare access for vulnerable groups. Hundreds of thousands of disabled Long COVID patients are likely to be new Medicaid recipients who are unfamiliar with the process. They may have moved due to their shifting financial situation and employment and thus may have missed notices sent by mail. Or, they may be simply too ill, like I have been during relapses, to understand and complete the process on their own. If they lose their health insurance, they will inevitably become sicker and almost certainly become poorer.

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 inequitable structures that bring exceptional 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 diseases and are compounded for marginalized communities by social drivers of health. With enough political will, we can fund a Long COVID moonshot that transforms clinical and community care for all of us.