

Testimony before the Select Subcommittee on the Coronavirus Crisis
Cynthia Adinig
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Good afternoon Chairman Clyburn and members of the Select Subcommittee on the Coronavirus Crisis. I am grateful for the opportunity to testify today. It is truly an honor. My name is Cynthia Adinig and I am here for a multitude of reasons, as I am known as a unique and multifaceted person. Though I expected to be before you all one day, as I have long since developed a nerdy passion for reading through hundreds of pages of legislative text. I have spent many evenings enjoying watching committee hearings on C-span or being glued to historical documentaries, upon my move here near the nation's capital, from Ohio. I didn't, however, expect to be here disabled and speaking on the behalf of a growing community of young formerly active citizens from all across the nation in the midst of the largest mass disabling event of our lifetimes.

First and foremost, I am a proud parent. I currently have a genius 7 year old son who also suffers from Long COVID. Before I got sick in March 2020 I was a multitasking supermom and entrepreneur. I ran 2 businesses from home while homeschooling. For years I was happily serving in multiple capacities at my local church, with 2 of those years, as head of the hospitality team. My church is well known for its efforts to help address and ease poverty, racism and hunger in the community, which is why it quickly became one of my favorite places to serve as a volunteer. Simultaneously, I was a volunteer at a charity that provides healthcare and other services to low income, minority women in the community while helping to fundraise for other underserved communities in Maryland.

Unfortunately, I can no longer be part of those spaces in the capacity that I used to because from time to time now my body becomes overwhelmed with nausea, dizziness, intermittent paralysis, fluctuating oxygen levels, crippling joint pain and unexpected high heart rate. To the point where I fear I'm having a heart attack or stroke.

Instead, in 2020 many nights were spent sobbing alone, in the hospital in the first wave. Isolated and restricted from having visitors as was the hospital policy at that time, even though I didn't have active COVID. There were several months where I became WHEELCHAIR bound. Thinking mournfully about the very real potential of my son growing up without a mother. After many trips to the hospital I was dying. I started thinking about my funeral arrangements. Making preparations to solidify proper education and care for my son, while I was hospitalized from a variety of life threatening complications from Long COVID. I remember emailing a psychologist who specialized in gifted IQ testing with IVs in both hands and connected to a heart monitor. Apologizing via email for being late on filing paperwork and paying the hundreds of dollars in fees, due to being hospitalized, for what at that time was an unnamed illness to the medical community and most of the world.

I stand here before you today, thrust into public policy and advocacy from a blatantly racially biased incident in September 2020 that is one of many examples of the urgency of change needed in care for Long COVID. In September 2020, while being wheelchair dependent at the time, I was threatened with arrest by Emergency Room hospital staff while seeking medical help during an episode of dangerously low oxygen and high heart rate. I had learned a few weeks prior that this same hospital had tested me for illicit drug use without my knowledge 3 times prior, in response to the Long COVID symptoms I presented with. In spite of my drug tests repeatedly coming back negative for illicit drug use, I was slated to be given Narcan for withdrawal symptoms, during one of my admissions for dehydration and starvation brought upon by Long COVID.

I was routinely met with little to no care, hostile treatment from staff, dangerous health violations such as bugs crawling on my blankets and discarded needles packages left on my floor. My blankets were left with blood stains. My arms bruised, and full of fluid from botched IV attempts by poorly trained staff. I witnessed staff speaking of my medical information amongst each other in the hearing range of other patients and myself and much more. Without apology or remorse, this hospital now touts itself as a post COVID treatment center.

Before Long COVID had a name I discovered a community of people on social media with Long COVID, called longhaulers. It began as social media support groups, but has become much more than that. Producing many well known Long COVID advocates such as, Dr Margot Gage, Hannah Davis, Liza Fisher, Karyn Bishof, Maya McNulty, Miranda Erlanson, Chimere Smith, Fiona Lowenstein, and many more.

We have spent the last 2 years working tirelessly to educate ourselves, other patients, doctors, nurses, members of congress, and government agencies. To educate those who touch the lives of those in our communities on the best way to treat and care for us. To try to do our civic duty and help ameliorate unnecessary repeat trips to the Emergency room by arming those who need it with our hard earned lived knowledge and by collaborating with researchers. To warn schools, universities and parents of the impending wave of Long COVID in children.

However, as we fight to help educate the world, our lives remain in turmoil from Long COVID. As are also, the lives of what is believed to be over 20 million within our nation, due to Long COVID. Good, HARD WORKING, Americans.

I'm standing here today, with as many media interviews under my belt as, tearful nights. Now with the help of a handful of doctors, some of whom I have found through over a year of searching. I'm here thanks to a heavy regimen of medications. But I still remain disabled and chronically ill and under treated.

My last trip to the Emergency room from Long COVID symptoms just 2 weeks ago, remains startlingly reminiscent of my treatment 2 years ago. Although I was there for several hours, it produced little more than this bruise from my I line of fluids. Though I went to the hospital with symptoms of severe allergic reaction, I wasn't administered any allergy medication, given an

immunosuppressant, nor was the protocol for my diagnosed condition that causes this illness followed. When I looked over my medical paperwork, I discovered that my main reason for the visit wasn't anywhere to be found. My symptoms of numbness and tingling in my right hand and feet were also never addressed. I wasn't given proper discharge instructions. In spite of having a reaction so severe that my mobility was affected, as is common with Long COVID flares, I was left to stiffly hobble out of the hospital, at the crack of dawn as I caught an uber home.

I sat in the car thinking about how privileged I am to have been able to afford that uber instead of having to pry my son out of bed to have alternative transportation to pick me up from home. Thankful that I had the option to move a mere 4 minutes away from to a slightly better hospital than the one that denied me care. But filled with sadness that my move was centered on the proximity of emergency care. I sat in the car, nervous that my son would discover my hospital band on my arm, re-triggering the trauma of him being unsure of my health, that in turn provokes an elevation of his Long COVID symptoms.

Long COVID touches people of all backgrounds. Mothers, teachers, veterans, nurses and even public officials from all over the country. All now having to struggle to learn to live with chronic illness, the way the MECFS community has done by the millions for decades.

We are not divided by skin color, age or class. There is nothing political about our illness. Our condition, at times, is even misunderstood by our own friends and families. Leaving many to struggle and remain dangerously close to losing the mental battle of grieving our former healthy productive lives.

There are currently no diagnostics or approved Long COVID treatments. Sadly, this contributes to also being misunderstood by doctors even today.

Financial hurdles, medical gaslighting are still often the reason why people with Long COVID do not seek medical attention. Causing permanent organ damage to some. We need to expedite financial assistance programs, expedite medicaid qualifications and expand access to those who are disabled and would like to attempt part time schooling. To provide us with transportation to and from doctor appointments that don't jeopardize our immunocompromised status and much more.

The experienced Long COVID nutrition and autoimmune specialists I need to help guide me safely to recovery are sadly not covered by insurance. Forcing me to pay out of pocket, when I can and contributing to continue a slow recovery with even more hospital visits, instead of my goal of returning to full time work and proper immersive homeschooling of my profoundly gifted child.

I am tasked with monitoring my son's vitals daily with little hope of getting him to care for his recent struggle with flares of an elevated heart rate, blurry vision, fatigue and trouble concentration. As there are very few trusted and experienced post viral pediatric specialists in the nation. The waitlists for the few that exist are months long as are post covid clinics.

Though it is clear through lived experience, unbiased studies and community consensus that race and gender plays a major part in hurdles to proper care, the care for ALL Americans who have Long COVID, including doctors and nurses continue to receive subpar care.

I know my mere mention of race in regards to Long COVID care will put many of those hearing this on the defensive. They may want to center on my mention of race as an indication that Long COVID is a social or political issue. Some who listen may even rebut that my mention of racism is a means to divide and provoke. Some may even say that I should simply be happy with the healthcare in America as is and that my privilege of standing here before you should be enough. But to quote Martin Luther King Jr., "I criticize America because I love her. I want her to stand as a moral example to the world."

While it is tempting to believe, in this racially and politically polarized time, that in a time where mass shootings have become an almost daily occurrence that Americans only know to turn against each other. I can PROUDLY say that I know we as Americans, and yourselves as members of Congress can come together. As the first Long COVID based legislation, the COVID-19 Long Haulers Act was introduced as bipartisan legislation. I can also attest that my circle of Long COVID friends are from a variety of backgrounds and even cross nations. I know first hand that in times like these, instead of fighting each other, we can fight FOR each other.

Long COVID is projected to directly affect over 20 million within our nation, and the strain it puts on our economy and working families is far greater. I am asking that our members of Congress come together to pass the Care for Long COVID Act, to create an official COVID-19 Victims and Survivors Memorial Day. To expedite educating medical staff and the general public on Long COVID. To urgently educate medical staff on bias in healthcare. To create a federal standardized disparity index scoring system for medical centers. I don't ask that you do this just for me and the future of my precocious and bright son, but in remembrance of over 1 million lives lost to COVID and for every American, business and government system that has been deeply impacted by this pandemic. Thank you.