

An Open Letter to President Biden, Cabinet and Congressional Leadership,
and Key Governmental Agencies.

COVID-19 Longhaulers & Their Families Call for the Immediate Formation of Long COVID Assistance Programs and a Long COVID Task Force.

People with Long COVID also respectfully ask President Biden to address this burgeoning crisis with the American people during the upcoming State of the Union address. Strong leadership in this moment can help prevent irreversible economic devastation for millions of Americans that will impact the national economy for decades to come and overwhelm the medical system beyond repair. We urge President Biden, Cabinet and Congressional Leaders and Key Government Agencies to [#CountLongCOVID](#), create [#LongCOVIDPolicy](#), and take [#LongCOVIDActionNow](#)



The COVID-19 Longhailer Advocacy Project ([C-19 LAP](#)) was formed in June 2020 to raise awareness and advocate for the staggering and growing number of COVID Longhaulers in the United States. C-19 LAP, in partnership with the Long Covid and chronic illness communities, is calling for the **immediate formation of Long Covid Assistance Programs (LCAP) and a Long Covid Task Force (LCTF)** to address the neglected needs of this population. COVID-19 has brought financial devastation to millions of COVID Longhaulers in the United States (and around the world), creating a crisis that will have decades-long consequences for individuals and the nation alike if not addressed immediately.

What is Long Covid?

COVID-19 has infected, at minimum, 52 million adults and children in the United States. The CDC [estimates](#) that more than 146 million have actually been infected with COVID-19, citing that only one in four cases has been reported. Ten to thirty percent of those infected have become COVID Longhaulers, suffering from post-viral symptoms for months, even [years, following COVID-19](#). “Long Covid” is the patient-preferred term for this phenomenon, officially identified as Post Acute Sequela of COVID-19 (PASC). It is important to note that 85% of Long Covid patients had [mild cases of acute COVID-19 and were never hospitalized](#), and some were even [asymptomatic](#). After their initial infections, many were mistakenly considered recovered.

However, the majority of Long Covid patients have developed [debilitating, often chronic conditions](#) commonly seen after other viral infections, conditions including Dysautonomia ([57%](#), most

commonly Postural Orthostatic Tachycardia Syndrome); ME/CFS ([46%](#), Myalgic Encephalomyelitis); MCAS (Mast Cell Activation Syndrome); Autoimmune Diseases (Lupus, Sjogren's Syndrome, Rheumatoid Arthritis); Peripheral Neuropathies; Chronic Migraines and Headaches; Hypermobility Spectrum Disorder; Fibromyalgia & other chronic pain conditions including but not limited to Ehlers-Danlos Syndrome and others caused by Connective Tissue Diseases.

It is time to debunk the popular but dangerous [misconceptions about Long Covid's purportedly mild impact](#). Millions of Americans have developed post-viral conditions that have no cure, no effective restorative treatments, and not enough research focused on finding solutions. A large and growing number of Americans may remain sick for the rest of their lives, yet the American public and our elected leaders are neither discussing nor preparing for the immediate and [long-term medical and financial needs](#) of COVID Longhaulers.

The Devastating Financial Impact

[The Labor Department announced](#) in early January 2022 that hiring in the United States slowed in December 2021 at a rate higher than economists had expected, even as job seekers were able to find employment. Leaders seem perplexed by this, but as we approach the second anniversary of the COVID-19 pandemic, the Long Covid community has reached the point of financial crisis. Millions of people have been unable to work for varying lengths of time, many for nearly two years, due to this illness.

Using the lowest estimate that [10%](#) of those infected experience long-term health problems, the U.S. has, at minimum, 5.2 million COVID Longhaulers. Based on our calculations using Labor Force Participation Rates and the percentage of COVID Longhaulers of working age, we extrapolated out to the community as a whole, indicating that there are potentially 2.3 million people who were in the workforce at the time of COVID-19 infection. We then utilized this data, along with data from polls within the COVID-19 Longhailer Advocacy Project, to compute all other estimates provided in this letter. In one self-selected survey of Longhailers (496) in the group from December 2021, [44%](#) of respondents indicated they are unable to work at all ([67%](#) for more than a year) and [51%](#) have been reduced to working part time ([63%](#) for more than a year), which has significantly impacted their finances and ability to provide for themselves and their families. Only [5%](#) of Longhailer respondents report being able to work at 100% capacity. Even taking into account that those COVID Longhailers who have joined support and advocacy communities are likely more severely ill than others, these findings are alarming.

From 2019-2021, the [increase in the number of people who were unemployed](#) was approximately [6.3 million](#); the conservative estimate of 52 million total COVID-19 infections in the United States indicates that COVID Longhailers may comprise 16% of these workers, due to changes in reporting implemented during the pandemic. That percentage shoots up to [46%](#) and [47%](#) respectively, however, if one uses the CDC's or Johns Hopkins' estimates. Further, at minimum, 9% of the 11 million current job openings in the United States may have been held by COVID Longhailers.

With [sixty-nine percent](#) of Americans having less than \$1,000 in savings, the majority of surveyed COVID Longhaulers have not been able to [sustain](#) themselves financially through their illnesses. Most Long Covid patients unable to work, or with limited work capacity, have depleted whatever savings they had, accumulating unprecedented debt and becoming unable to cover basic needs. As a result, people are losing their homes, automobiles, and businesses. They are forced to decide between paying for their medication, the utility bill, or groceries. Adding to this devastation, many COVID Longhaulers lost their employment-based health insurance along with their jobs, leaving them unable to cover their medical expenses or even to seek the care that may save their lives or help restore quality of life.

In the COVID-19 Longhailer Advocacy Project Facebook group's poll of 496 COVID Longhaulers on the financial impacts of Long Covid, 48% reported that they were experiencing financial ruin from which, without assistance, they would not recover from. Forty-two percent reported having accrued over \$5,000 in medical bills and 21% have had to sell furniture, collectibles and other valuables in order to pay bills. Twenty percent said they were completely out of resources, 14% have multiple members of the household whose income had been impacted by Long Covid, and 9% were single parents who are Longhaulers or caring for another Longhailer in the home. Seven percent of Longhailers had lost or were about to lose their homes or cars. Seven percent also reported that their relationship or marriage had ended due to Long Covid, which has had a compounding negative impact on the Longhailer's finances. Of the respondents, 28% were health care workers, first responders, members of the military, or educators, comprising four of the largest essential fields that keep the United States running.

Based on our calculations using the limited data available and that which we have compiled, the current estimated total income lost by COVID Longhailers is approximately [\\$88.8 billion](#), with an average cost per Longhailer of [\\$17,763](#). Additionally, the estimated average annual cost of healthcare per COVID Longhailer is [\\$18,645](#), based on the average cost of care for [Dysautonomia](#) (using comparative conditions like COPD and CHF) and [Myalgic Encephalomyelitis](#). The average income lost per COVID Longhailer in combination with the estimated yearly health care cost of the condition is totaled at \$36,408 per Longhailer, per year. As staggering as that number is, it is an average; healthcare expenses increase with the severity of illness and the number of post-viral conditions a patient is facing. Many COVID Longhailers have several and will require long-term care.

The total estimated cost of 5.2 million Longhailers is already in excess of [\\$189 billion per year](#). But with the [Omicron variant surging](#), we know that the pandemic is not yet over. With more than 500,000 daily infections in the United States, we can expect at least 50,000 new Long Covid patients each day, at a total added national price tag of more than \$1.8 billion per day. The financial devastation faced by millions of Long Covid patients will [impact families](#) for generations, and the economy may not recover for decades if this crisis is not addressed now.

Roadblocks to Assistance

Although [federal action](#) was recently taken to [identify Long Covid as a disabling event](#), help is coming too slowly and millions need immediate assistance. COVID Longhaulers have been unable to qualify for existing assistance programs like Social Security Disability, Short and Long-Term Disability, Workers Compensation, Medicaid, Food Assistance, Temporary Cash Assistance, Housing Assistance and Unemployment. Many of these programs require that recipients work, look for work, attend training, or be classified as disabled, a designation that COVID Longhaulers are often denied; others have a low household income cap. These barriers are prohibitive for those who need assistance. Federal Pandemic Unemployment Programs and state-sponsored assistance provided temporary lifelines for many, but when work search requirements were reinstated, COVID Longhaulers with disabling illnesses became ineligible.

In the United States, from 2019-2021, [Medicaid](#) enrollment [increased](#) by 12,162,763 recipients and [food](#) assistance by [5,797,635](#). While no data is available yet for the increase in Social Security Disability claims, 41% of survey respondents whose employment has been impacted by Long Covid and its associated conditions have reported that they have applied or will soon apply for SSD. The current system cannot handle such a dramatic increase. The United States thus needs a swift yet comprehensive overhaul of the disability system in order to accommodate the influx of millions of newly disabled Americans, a group that grows larger every day.

The Unemployment roster increased from [11.8 million to 13.8 million](#) people from November 2019 to November 2021. From March 2019 to March 2021, there was an [increase](#) for those unemployed longer than 27 weeks (6 months) by just under 2 million, coincidentally, at the same time that our poll indicated that approximately [1.4 million](#) COVID Longhaulers may have been out of work over 6 months. This indicates that Longhaulers may **comprise 10%** of the total number of people unemployed and **71%** of those unemployed for more than 27 weeks. A current estimate by the Mayo Clinic has a similar finding, calculating that approximately [1.3 million Americans](#) are out of work due to Long COVID.

However, despite these alarming preliminary calculations and the number of unfilled jobs in the United States, there has been no investigation into the financial devastation of Long Covid on millions of Americans who have lost their livelihoods. The failure to recognize Long Covid as a mass disabling event, with long-term impacts on the national economy means that critical discussions and planning are not taking place. Millions of uncounted people are suffering from Long Covid right now, and their financial and medical needs must no longer remain invisible. Americans with Long Covid cannot wait any longer.

What COVID Longhaulers Need

The United States cannot afford to ignore the gravity of Long Covid and the long-term consequences our nation faces. **Therefore, we are requesting an Interim Long Covid Assistance Program (LCAP) and a Long Covid Task Force (LCTF) that will, in real time, measure the impacts of Long Covid on Americans and develop long-term plans and resources for this population.** More information on LCAP and LCTF is laid out [here](#).)

For nearly two years, Long Covid patients have struggled to find interested and informed medical providers, facing significant delays in care, diagnostics, treatments, and access to financial assistance programs. The patient community has worked tirelessly to dispel the misconception that most COVID Longhaulers have recovered or will soon do so. The failure to recognize the severity of Long Covid means two things: first, that there will be no answers or treatments for Longhaulers for years or potentially decades; and, second, that long-term support programs have not been established for people affected by Long Covid or their families, thus setting up a large swath of the American public for economic failure and devastation on a scale not seen in this country in nearly a century. Every day that COVID-19 continues to spread, the number of future disabled COVID Longhaulers increases, which will result in even higher workforce deficits, financial ruin for families, and long-term economic disaster for the nation.

It is time to **create [Long Covid Assistance Programs](#) and to designate a [Long Covid Task Force](#)**, composed of patient experts, post-viral disease specialists, labor economists, public health advisors, and other relevant experts, to address the needs of our nation's growing Long Covid community. The often-repeated saying, "We have survived, but we are not living" rings true for most COVID Longhaulers. Millions of these patients have indeed [lost most](#) of [who they were](#), what they had, and the futures they had planned to live. The U.S. has lost a significant percentage of its workforce, with concentrated losses in healthcare, education, and essential workers. These impacts are high cost and need to be treated as such.

While the calculations here are conservatively based on 10% of the documented 52 million cases of COVID-19 leading to Long Covid, estimates by the CDC and Johns Hopkins triple our estimates to [15 million](#) Longhaulers. We are in the midst of a clear and urgent public health emergency.

President Biden, on behalf of the Long Covid community and their families, we respectfully ask that your administration [take action now](#) and address this burgeoning crisis with the American people in your upcoming State of the Union address. Your strong leadership in this moment can help prevent irreversible economic devastation for millions of Americans that will impact the national economy for decades to come and overwhelm the medical system beyond repair.

We invite you all, as our nation's leaders, to partner with us in this effort so that, collectively, we can improve the lives of millions of disabled COVID Longhaulers and their families. We look forward to your response and partnership.



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