



**PATIENT-LED
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Long COVID and ME/CFS Organizations Call on Congress to Establish COVID-19 Task Force

Organizations led by people living with Long COVID and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) are joining the call for Congress to pass [bipartisan legislation](#) (S.1489) to establish a task force that would investigate the COVID-19 outbreak, and identify lessons regarding preparedness, response, and recovery.

[Long COVID Justice](#), [Patient-Led Research Collaborative](#), [#MEAction](#) and [Strategies for High Impact](#) endorse this legislation, and have signed onto [Marked By Covid's open letter](#) to Congress calling for the bill's passage, endorsed by 50 non-profit organizations and almost 100 public health and national security experts.

We believe a national task force is crucial not only for investigating the impact of acute COVID-19, but also for examining the many devastating costs of Long COVID on individuals and society. We urge Congress to include Long COVID in the task force mandate. **We cannot tell the story of COVID-19 without talking about Long COVID and associated diseases, like ME/CFS.**

"Pandemics are chronic. As the COVID-19 pandemic continues, our world is significantly more disabled and chronically-ill," said JD Davids, Co-Founder of [Long COVID Justice](#). "As we saw with HIV/AIDS, disease outbreaks expose the need for large-scale change in healthcare, public health, and other unjust structures."

Long COVID is a complex and frequently disabling disease that affects children, youth, adults and seniors. The condition already affects about [6% of American adults](#), as well as children, leaving an estimated [4 million people unable to work](#), and costing our economy an estimated \$170 billion a year. And, this number will only continue to grow as SARS-CoV-2 continues to spread and cause Long COVID, even after mild infections or reinfections, asymptomatic cases and in vaccinated people.

"At the beginning of the pandemic, the government provided no warning or resources about how chronic conditions could follow COVID-19, leaving those of us who developed Long COVID with

little information or help,” said Lisa McCorkell, Co-Founder of the [Patient-Led Research Collaborative](#). “Long COVID and all infection-associated chronic conditions must be considered in evaluating the COVID-19 pandemic and preparing for the next one, otherwise we will repeat our mistakes all over again.”

Long COVID was a Preventable Tragedy

Virally-triggered chronic illness is not new, and the ME/CFS community has been [calling](#) on our government to invest in research and medical education into infection-associated disease for decades. Up to 80 percent of ME/CFS cases are triggered by infections, and there’s ample evidence from past [viral outbreaks](#) showing viruses cause complex, chronic illness. But, our government ignored all of that. As a result, the pandemic has more than [quadrupled](#) the size of the ME/CFS community to an estimated 9 million in the U.S. alone. An estimated 50 percent of the Long COVID community [meets the criteria](#) for ME/CFS, which is a highly debilitating and complex disease, leaving 75 percent unable to work and 25 percent bedbound.

We urge Congress to hold our federal health and research agencies accountable for their abject failure to be prepared for the Long COVID and ME/CFS crisis our country now faces.

“The problem isn’t that Long COVID is new,” said Ben HsuBorger, [#MEAction](#) U.S. Advocacy Director. “The problem is that such illnesses have been ignored and stigmatized for decades. This year, NIH spent just \$15 million on ME/CFS out of a total budget of \$47.5 billion. Historically, they spent far less. No money, a lack of strategic commitment, and the disease stigma have predictably resulted in very few researchers and little progress.”

Long COVID’s Disproportionate Impact on Marginalized Communities

Long COVID has also disproportionately impacted minoritized and marginalized communities, leaving behind a devastating trail of chronic illness and disability in Black, Brown, Indigenous, and transgender people.

Our organizations call on the federal government to end practices and policies that have ignored and further marginalize disabled and chronically-ill people, and to center our voices in any government investigation and preparations for the future.

“To be as effective as possible, we need to spell out what did and didn’t happen in the first years of COVID-19,” said Chimère Smith, a consultant for [Strategies for High Impact](#). “And that means not just preparing better ahead of time to combat the health disparities that took a heavier toll on our Black and Brown communities, it also means not leaving us behind when we have these chronic impacts!”