Policy Experts, Scientists, Disability Groups Urge Biden to Address Long COVID Crisis

The authors demand Biden outline the actions his administration is taking to address it in his State of the Union address.

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A wide breadth of policy experts, scientists, and disability groups are calling on President Biden to urgently address the long COVID crisis with annual funding in the billions.

In the open letter published on Monday [December 18], health policy experts, leading long COVID researchers, clinicians, journalists, chronic illness and health advocacy groups, and many others demand that Biden demonstrate support for the millions of Americans with long COVID and infection-associated chronic conditions (IACCs). The authors demand Biden acknowledge this crisis and outline the actions his administration is taking to address it in his State of the Union address.

"Failure to address this problem," the letter's authors write, "will result in significant economic, health, quality of life, and societal costs, in the trillions of dollars. Moreover, every dollar invested in long COVID and IACC research will prepare our country for future pandemics and emerging infection-associated conditions."

The Biden administration developed the HHS Office of Long COVID in 2022, but advocates and scientists have criticized it for failing to move more urgently on the long COVID crisis and make meaningful changes in the everyday lives of people with this disease and related infection-associated illnesses.

Many citizens have also pointed out Biden's unfulfilled campaign promises of containing the spread of COVID-19. Since he took office in 2021, over 750,000 Americans have died from Covid and millions have developed long COVID, but Biden continues to deny the reality of the ongoing pandemic. Current data — which are not comprehensive estimates, thanks to the dismantling of COVID-19 surveillance systems — suggest hundreds of thousands of Americans are getting infected and more than one thousand are dying each week of COVID-19. We know that around 10% of daily cases will go on develop long COVID, meaning many thousands of Americans will become debilitated by long COVID in the coming months.

The letter serves as a call to not only support people with long COVID and IACCs financially with safety nets, but to also take steps to prevent millions more Americans from getting COVID-19 and developing long COVID. The authors call for the Biden administration to implement common sense prevention efforts such as "improved ventilation and air filtration in commercial, educational, and work environments to reduce the spread of COVID, thereby ensuring more people do not develop long COVID."

To support people with long COVID and IACCs, the letter demands that federal agencies fund social safety net programs, biomedical research, clinical trials, healthcare provider education, healthcare delivery research and equitable access to high-quality care, public health education, and home- and community-based care.

The letter echoes a recent Nature op-ed that called for investing at least one billion dollars a year in long COVID research for the next ten years in a "moonshot" that could help improve the lives of people with long COVID (pwLC) and save the U.S. trillions in economic costs. The Nature article later inspired a telethon advocacy effort in November by pwLC and their allies that made hundreds of calls to representatives across the country. The long COVID moonshot effort continues this month with an "Unhappy Holidays" letter-writing campaign.

"We recognize that long COVID is a public health crisis and an economic and social challenge of immense proportions, but this has not been reflected in the President's budget to date," said Lisa McCorkell, one of the authors of the letter and a co-founder of the Patient Led Research Collaborative. "When the President is considering his priorities for FY25, he must show that he values the over 20 million Americans with long COVID and the millions more at risk."

So far, over 60 prominent researchers, clinicians, and others have signed on. They include Ezekiel Emanuel, a health policy expert, former Obama advisor, and Biden Transition COVID Task Force member, and Bob Wachter, chair of the department of medicine at the University of California, San Francisco. Other signatories include Akiko Iwasaki, Ziyad Al-Aly, Ed Yong, Eric Topol, Anthony Komaroff, David Putrino, Resia Pretorius, Michael Peluso, and many principal investigators of the National Institute of Health's RECOVER initiative.

Also signed onto the letter are over twenty health advocacy and disability organizations, including Center for Economic and Policy Research, Long COVID Justice, LONG Covid Families, BIPOC Equity Agency, Black COVID-19 Survivors Alliance, Inc., The Black Long Covid Experience, Disability Rights California, COVID-19 Longhauler Advocacy Project, Dysautonomia International, #MEAction, and Patient-Led Research Collaborative.

"My experience is a stark reminder of the systemic inadequacies in healthcare that many face, particularly in marginalized communities," Cynthia Adnig, co-founder of BIPOC Equity Agency, wrote to The Sick Times when we reached out to ask about why her organization signed the letter. "As a caregiver, I also see the ripple effects of long COVID on families and the looming threat it poses to our nation's future generations and economic health." Adinig testified in Congress in July 2022, detailing her and her son's experience with long COVID before the Select

Subcommittee on the Coronavirus Crisis.

“We implore the Biden Administration to take the recommendations in this letter to heart,” Adnig wrote. “The health of our nation, the well-being of our communities, and the economic stability of our country hinge on the actions we take now to address the challenges of long COVID and related conditions.”

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