



The COVID-19 Longhailer Advocacy Project & Long Covid Community Respond to the Absence of Long Covid Awareness & Education in President Biden's State of the Union Address.

Dear President Biden,

March 2, 2022

Last night, millions of COVID Longhailers were counting on you to acknowledge our suffering and become our champion during the State of the Union. Your address to the nation offered an unparalleled opportunity to educate the American people about the sheer devastation that Long Covid has caused and will continue to cause for decades. Although you spoke at length about the COVID-19 pandemic, you chose not to mention us. You said that no one would be left behind, yet we remained invisible.

The COVID-19 Longhailer Advocacy Project and the Long Covid community had hoped that you would continue to emphasize mitigation efforts, including continued masking, as essential in the battle against COVID-19 and Long Covid. Instead, you told Americans that they could remove their masks and move toward a "safer normal." You told Americans that vaccines and boosters would protect them from severe illness. You did not tell them that 10-35% of infections, including mild and asymptomatic cases, result in Long Covid. You did not tell them that Long Covid can lead to long-term disability.

Throughout the COVID-19 pandemic, there has been no public messaging about Long Covid, its dangers, impacts, or prevalence. For many American viewers last night, your comments would likely have been the first time they heard the term "Long Covid." Your comments could have reinforced the importance of mitigation efforts and saved people from long-term pain and disability. You could have helped people suffering, identify Long Covid as the reason for their new onslaught of health issues. Instead, you ignored this mass disabling event that has left millions of people unable to work, attend school, or participate in life as they knew it.

For COVID Longhailers, there is no return to normal. We are people. We are sons and daughters, mothers and fathers, neighbors, front line workers, and educators. We are the people who woke up one day, got sick, and never recovered. We had bright futures and families, but we are now shadows of the people we once were.

The United States urgently needs Long Covid Assistance Programs and a Long Covid Task Force, as outlined in our [Open Letter](#) dated January 10, 2022, and [again](#) a month later on February 10. Our letters included [community requests and actions](#), as well as [calculations](#) of the number of Americans afflicted with Long Covid and the associated costs. Our numbers from January have since been matched by two other reputable sources ([here](#) and [here](#)) analyzing Long Covid's impact on the labor force. NBC News recently conducted an [investigative report](#) on the economic impact of Long Covid, featuring our efforts along with their own poll, which indicated that more than one-third of Longhailers have reported applying for disability.

Our findings at the COVID-19 Longhailer Advocacy Project indicate that 44% of COVID Longhailers have been out of work completely (67% > 1 year), 51% have been reduced to part-time work (63% > 1 year), and 41% report having filed for or preparing to file for social security disability. The CDC has projected that the number of COVID-19 infections in the United States is likely four times greater than the 79 million documented cases, totalling 316 million probable cases nationwide. Using the most conservative estimate that 10% of those infected develop Long Covid, we are looking at approximately 8 to 32 million COVID Longhailers in the United States alone. With 41% of Long Covid patients filing for disability, we project, after adjusting from working age and labor force participation rates, that the social security disability system may soon be flooded with more than 5 million applications from newly disabled people as a result of Long Covid.

President Biden, the United States is facing a mass disabling event of a scale that is unprecedented. We need immediate action to assist the Long Covid community, but you cannot begin to help us until you are willing to publicly acknowledge Long Covid. Long Covid Assistance Programs and a Long Covid Task Force must be created now, in order to prevent millions of Americans from falling between the cracks: losing their homes, cars, custody of children, healthcare, and access to life saving and quality of life restoring medications.

Two years into the pandemic, many COVID Longhailers are out of options. Now is the time for the government and the patient population to work as partners to assist the millions impacted by Long Covid. President Biden, we respectfully request a meeting with you and White House officials to address the urgent needs of the Long Covid community. We look forward to a collaborative partnership and encourage swift implementation of several strategies outlined [here](#) to assist the Long Covid community now, as we simultaneously work to create long term resources and solutions.



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