

Long Covid Moonshot is a collective of patients mobilizing around the crucial need for Long Covid research funding and other issues important to the community. Our mission is to empower patients to harness their collective voice for advocacy, and work with partners across the Long Covid and chronic illness communities to advocate for change at the federal level.

## ***LONG COVID IS NOT GOING AWAY***

The crisis of Long Covid has no end in sight. Few people fully recover, with just 8% of patients estimated to do so at the two-year mark<sup>1</sup>. Meanwhile, there is little help for the millions of people suffering: nearly four years into the crisis, there remain no FDA-approved treatments for the condition.

Long Covid is a new and widely devastating illness, estimated to be affecting just over 1 in 20 American adults<sup>2</sup>. This disease does not spare children: the journal *Pediatrics* estimates that as many as 5.8 million American children have been struck by Long Covid<sup>3</sup>.

Long Covid is debilitating. The majority of Long Covid patients report impairments that limit their day-to-day activities, with nearly 1 in 4 reporting severe activity limitations<sup>4</sup>.

## ***THE SCALE + SEVERITY IS MASSIVE***

Long Covid can impact multiple organ systems—beyond a loss of sense of smell or taste, research has documented cardiovascular, gastrointestinal, respiratory, immunological, and neurological dysfunction<sup>5</sup>. Many Long Covid patients lose the ability to think, to walk, to talk, and in severe cases, to sit up or eat.

As a result, Long Covid patients are often unable to work or care for their loved ones, and for many severely impacted patients, are unable to care for themselves.

This disability burden is greater than that of heart disease and cancer<sup>6</sup>, and leaves 18% of workers with Long Covid unable to return to their jobs for more than a year<sup>7</sup>. This has removed some 700,000 Americans from the labor force<sup>8</sup> with the total economic cost of Long Covid being estimated at 3.7 trillion dollars in the first five years alone<sup>9</sup>.

**700,000**  
AMERICANS  
OUT OF WORK

**\$3.7T**  
ECONOMIC  
COST / 5 YRS

**90%**  
MILD INITIAL  
INFECTION

**2.6x**  
RISK AFTER 3+  
INFECTIONS

**8%**  
RECOVERED  
AFTER 2 YRS

Since 2020, about \$1.15b has been earmarked for Long Covid research through the RECOVER program. This flagship program has been instrumental in providing the infrastructure for large-scale longitudinal studies and in continuing to uncover Long Covid's myriad impacts on the body. However, most of this funding has already been spent, with no promise of future funds and much more work still to be done. We still do not fully understand the mechanisms of Long Covid, and no reliable biomarkers for the condition have been identified. More clinical trials are needed with great urgency; there remain no FDA-approved treatments or diagnostics for Long Covid.

Long Covid research now faces a funding cliff that will leave critical programs and projects unfunded. If this happens, the field will lose researchers to better-supported areas, and the pipeline of junior researchers will dry up. Without a guarantee of continued funding, we risk losing the momentum and knowledge developed so far—and with it the community's hope for treatments that can relieve our suffering.

## **THERE IS A SOLUTION**

The Long Covid patient community is coming together to ask that at least \$1b per year beyond the RECOVER program be allocated to the NIH for Long Covid research and clinical trials. As with the Cancer Moonshot – a \$1.8b commitment that supported more than 240 studies – a Long Covid Moonshot would establish a protected lane of world-leading research for 10 years, fast-tracking the path to treatments.

Long Covid is one of a number of related chronic conditions triggered by acute infection, such as dysautonomia and ME/CFS, collectively referred to as infection-associated chronic conditions (IACCs). The historical lack of investment in these conditions have in part contributed to the lack of preparation for the current crisis.

To ensure that further investment is used effectively to address Long Covid and to best prepare for future novel chronic diseases, we recommend the establishment of a Center for Infection-Associated Chronic Conditions Research at NIH that can coordinate research activities and direct funds to the highest priority research areas.

## **WE NEED A MOONSHOT FOR LONG COVID.**

We ask that you propose and / or support appropriations of at least \$1b annually to NIH for Long Covid research in the FY25 spending bill(s).

The solution to Long Covid is within our reach, and could be your legacy. Let us help you lead the way!

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### REFERENCES

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<sup>2</sup> CDC. (2023). *Household Pulse Survey*. <https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm>

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<sup>7</sup> New York State Insurance Fund. (2023). *Shining a Light on Long Covid: An Analysis of Workers' Compensation Data*. [https://www3.nysif.com/-/media/Files/NYSIF\\_Publications/PDF/NYSIFLongCOVIDStudy2023.ashx](https://www3.nysif.com/-/media/Files/NYSIF_Publications/PDF/NYSIFLongCOVIDStudy2023.ashx)

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