

December 18, 2023

President Biden
1600 Pennsylvania Avenue, N.W.
Washington, DC 20500

Subject: Address the Crisis of Long COVID and Other Infection-Associated Chronic Conditions in FY25 Budget

Dear President Biden,

As a collection of clinicians, researchers, health policy experts, NIH RECOVER PIs, journalists, patient and disability organizations, community organizations, and research organizations, we write to **urge you to address the crisis of Long COVID and other infection-associated chronic conditions¹ as you establish priorities in the FY25 budget.**

Long COVID is an infection-associated chronic condition (IACC) that can develop following a COVID-19 infection, and has devastating impacts - on people's individual health and quality of life, on caregivers and families, and on communities. According to the Centers for Disease Control and Prevention (CDC), at least [5.3% of American adults](#) were experiencing Long COVID as of October 2023 and at least [1.3% of American children](#) ever had Long COVID as of 2022.² While Long COVID can affect anyone (including people who are [vaccinated](#) against COVID), transgender people, women, Hispanics/Latinos, and people with a pre-existing disability are [disproportionately impacted](#). Recovery rates are dismal: [of patients sick at 2 months](#), only 15% were recovered at one year, and of those, one-third subsequently relapsed. [Estimates](#) place the disease burden of Long COVID [higher](#) than that of heart disease and cancer, and there are significant impacts to people's [ability to work](#), with Brookings estimating in January 2022 that the disease could account for [upwards of 15% of unfilled jobs](#).

[Harvard economist David Cutler](#) and others have estimated that the economic cost of Long COVID approaches \$3.7 trillion in the first five years alone in terms of diminished quality of life, lost earnings, and medical care costs, which is equivalent to 17% of pre-pandemic US GDP. Meanwhile, the [de Beaumont Foundation](#) reports that while the vast

¹ Infection-associated chronic conditions (IACCs) are conditions that develop following an infection, and include Long COVID, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), postural orthostatic tachycardia syndrome (POTS) and other forms of dysautonomia, chronic Lyme disease, and mast cell activation disorders.

² These prevalence rates of Long COVID underestimate the true number of people impacted due to survey respondent bias, lack of public knowledge about Long COVID, inaccuracy of testing, and lack of access to healthcare and testing, particularly amongst Black and Indigenous communities who are underrepresented or not included in the Household Pulse Survey. Of note, meta-analyses show that [about 25%](#) of children who have COVID develop Long COVID.

majority of physicians understand that Long COVID is a problem, only 7% are very confident diagnosing it and 4% are very confident treating it. This follows the historical neglect and [underfunding](#) of other infection-associated chronic conditions, like myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), postural orthostatic tachycardia syndrome (POTS) and other forms of dysautonomia, chronic Lyme disease, and mast cell activation disorders.

The current steps the Administration is taking, such as establishing the Office of Long COVID Research and Practice and creating a Federal Advisory Committee on Long COVID, are encouraging but insufficient to mitigate the devastating public health and economic impact of Long COVID and other IACCs. The \$1.15 billion in NIH research funding for Long COVID that was allocated in 2021 and used to create the RECOVER Initiative [is running out](#), and NIH budgets have been silent on future funding for Long COVID research, despite [calls for an investment of at least \\$1 billion/year](#). We need a much more robust and sustained investment to ensure that we build upon the momentum of the [scientific progress](#) made over the last four years. Additionally, while patients with Long COVID await FDA-approved treatments, many do not have [access to high-quality care](#) and fall through cracks in the [social safety net](#), which has long [neglected](#) disabled people.

This crisis is not going away. With COVID continuing to spread and [reinfections](#) leading [to higher risk](#) of developing Long COVID, millions more will develop Long COVID over the next several years. Additionally, the people who have Long COVID and other infection-associated chronic conditions are suffering now - in terms of pain, loss of quality of life, stigma, and [material hardship](#).

Mr. President, [your father Joseph Biden Sr. has said](#), “Don’t tell me what you value. Show me your budget, and I’ll tell you what you value.” The FY25 budget proposal reflects the Administration’s values and priorities. We ask you to prioritize the health of the millions of Americans with Long COVID and other infection-associated chronic conditions, as well as those at higher risk of developing these conditions, as you prepare the FY25 budget. This includes:

1. **Establishing an NIH Center or an Office under the NIH Director with an annual budget in the billions of dollars** to coordinate and fund research on Long COVID and other infection-associated chronic conditions across NIH Institutes.
2. **Directing federal agencies (e.g. SSA, HHS, DOD, VA, DOE, USDA, DOL) to include a response to Long COVID and other infection-associated chronic conditions in their budgets, to fund:**
 - **Improving access to social safety net programs** to ensure people can easily apply for benefits, receive adequate assistive workplace and school accommodations, and do not wait longer than needed to receive benefits.

- **Addressing social determinants of health** to ensure people's basic needs are met before they develop Long COVID/IACCs and while they have Long COVID/ IACCs.
- **Biomedical research** on mechanisms and risk factors with meaningful patient engagement to ensure we build on the momentum of the last four years and pursue opportunities identified at the [National Academies'](#) workshop on IACCs. This includes research on the relationships between these conditions.
- **Clinical trials** with meaningful patient engagement to ensure we begin trialing repurposed drugs that can both improve quality of life and provide insight on disease mechanisms.
- **Healthcare provider education** with meaningful patient engagement, including expanding the Project ECHO Long COVID and Fatiguing Illness Recovery Program, to ensure providers understand the condition and research to date so they can provide adequate treatment options.
- **Healthcare delivery research and equitable access to high-quality care** to ensure that all adults and children, particularly those in marginalized communities, can easily access providers, including community health workers, who are knowledgeable about these conditions (e.g. through a Ryan White HIV/AIDS Program for IACCs).
- **Public health education** to ensure the public understands Long COVID and other IACCs and the severity of their impact. These efforts should also include recommendations for prevention and information about patient rights for those who do contract IACCs.
- **Home- and community-based care (HCBS)** to ensure individuals with Long COVID and other IACCs have the support and care they need to remain in their communities.
- **Prevention efforts like 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.

We also ask that you demonstrate your support for people with Long COVID and IACCs by **acknowledging this crisis and outlining the actions your Administration is taking to address it in your State of the Union address**. In addition to showing your values through the budget, please show your values through your words and actions.

Failure to address this problem 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.

As you have said, "[budgets are statements of values](#)." Please value the lives of the tens of millions of people with Long COVID and IACCs, as well as those at higher risk of

developing these conditions, by including their needs in your budget priorities for FY25 and draft your State of the Union address.

Sincerely,

Clinicians, Researchers, and Health Policy Experts

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Patient, Disability, and Community Organizations

Access Living	Marked By COVID
BIPOC Equity Agency	MassME (Massachusetts ME/CFS & FM Association)
Black COVID-19 Survivors Alliance, Inc.	MEAction
COVID-19 Longhauler Advocacy Project	National Pain Advocacy Center
Disability Rights California	New Disabled South
Disability Visibility Project	Patient-Led Research Collaborative
Dysautonomia International	Roots Community Health Center
Illinois Unidos	Solve ME
Long COVID Alliance	Strategies for High Impact
Long Covid Families	The Black Long Covid Experience
Long COVID Justice	Utah Covid-19 Long Haulers
Long Covid Kids	
LymeDisease.org	

Research Organizations, Professional Organizations, and Universities

Bateman Horne Center of Excellence	Long Covid Physio
Bay Area Lyme Foundation	Mass General Brigham
Center for Economic and Policy Research	Workwell Health
Global Pandemic Coalition	Workwell Foundation

Individual and organization sign ons are continuing to be collected. For a full list that will be updated weekly, [please click here](#).

For questions about this letter, please email Patient-Led Research Collaborative at team@patientledresearch.com