

PANDEMIC PATIENTS

December 15, 2023

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

FY 2025 President's Budget

Dear President Biden,

Pandemic Patients is a 501(c)(3) patient advocacy organization that works directly with disabled long COVID patients to educate them about their rights in the workplace and to help them obtain accommodations from their employers.¹ For long COVID patients who are unable to work, Pandemic Patients helps them navigate the process of applying for disability benefits and appealing wrongful denials. When long COVID patients become the victims of disability discrimination in the workplace, Pandemic Patients connects them with pro bono legal assistance to enforce their rights.

We write to you on behalf of the millions of Americans who have been impacted by COVID-19, including those who have been disabled by long COVID.² By working directly with this population, we have learned first-hand how the lives and livelihoods of countless Americans have been upended by devastating long COVID symptoms.

Long COVID characterized by damage to the heart, lungs, brain, kidneys, immune system, and other vital organs.³ The symptoms of long COVID range from mild to severe, and they can significantly impair a person's ability to work.⁴ The impacts of long COVID are being felt across the country, with millions of Americans being unable to work due to their long COVID symptoms and struggling to afford basic necessities. The consequences are dire, potentially costing the American economy hundreds of billions of dollars each year in lost earnings.⁵

We respectfully request that you develop a coordinated plan to address long COVID in your FY 2025 President's Budget. This plan should build upon *The National Research Action Plan on Long COVID and The Services and Supports for Longer-Term Impacts of COVID-19* reports issued in 2022.⁶ We urge you to lead the American government toward implementing bold policy solutions that can reduce the occurrence of long COVID and provide meaningful relief for

¹ <https://pandemicpatients.org>.

² <https://cepr.net/the-extent-and-demographics-of-long-covid-disability-in-united-states/>.

³ <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html>.

⁴ <https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/guidance-long-covid-disability/index.html>.

⁵ <https://www.brookings.edu/articles/new-data-shows-long-covid-is-keeping-as-many-as-4-million-people-out-of-work/>.

⁶ <https://www.hhs.gov/about/news/2022/08/03/biden-harris-administration-releases-two-new-reports-long-covid-support-patients-further-research.html>.

the millions of Americans experiencing this life-shattering condition. Including thoughtful and strategic policy approaches to long COVID and targeted funding allocations in your forthcoming Budget Request will represent the necessary continuation of your administration’s “whole of government” response to long COVID.⁷

We encourage you to consider including the following policy measures in your plan to address long COVID:

- Allocation of significant long COVID research funding through the National Institutes of Health (NIH). This funding should be substantial enough to fully leverage existing research capacity to fund promising research proposals and to attract additional researchers to the field of long COVID research. We believe that the funding levels for long COVID research through the NIH should be commensurate with the overall prevalence of long COVID among the American population and the cumulative disease burden caused by this condition. Providing sustained funding through the NIH is necessary to foster the development of diagnostics for long COVID and clinical trials for safe and effective long COVID treatments. To ensure this funding is effectively managed, we support the establishment of an NIH office specifically focused on long COVID research.
- Allocation of funding through the U.S. Social Security Administration (SSA) to ensure timely review of Supplemental Security Income and Social Security Disability Insurance (SSI/SSDI) applications. We believe funding should also be allocated to streamline the application process, reduce barriers to benefit eligibility, and reduce administrative burden for applicants.
- Allocation of funding through the U.S. Department of Labor (DOL) to establish grant programs to facilitate engagement with employers to heighten their understanding of the rights of people with disabilities and how employers can support the needs of long COVID patients in the workplace. We also believe funding should be allocated to facilitate full enforcement of the Employee Retirement Income Security Act (ERISA) against disability insurance administrators who wrongfully deny benefits to claimants and those who unreasonably delay the timely adjudication of claims.
- Allocation of funding through the U.S. Department of Health and Human Services (HHS) to establish grant programs to provide educational curricula for healthcare providers on the diagnosis and management of long COVID. We believe funding should also be allocated to identify and implement further policy measures to coordinate care for long COVID patients, ensure equitable access to providers who are competent in long COVID, and increase the capacity of the healthcare workforce to deliver care to long COVID patients. We also believe funding should be allocated to study the mental health impacts of long COVID and the development of policy measures to ensure timely access to resources for Americans experiencing a mental health crisis.
- Allocation of funding through the U.S. Department of Justice (DOJ) to increase the availability of civil legal aid for people with legal issues related to long COVID, such as applications for disability benefits and other safety net resources, workers’ compensation benefits, and disability discrimination.

⁷ <https://www.hhs.gov/about/news/2023/04/05/fact-sheet-biden-harris-administration-makes-progress-whole-government-response-long-covid.html>.

- Allocation of funding through the U.S. Food and Drug Administration (FDA) to promote patient-focused drug development for long COVID and to ensure meaningful patient engagement in the drug development process.
- Allocation of funding through the U.S. Centers for Disease Control & Prevention (CDC) to conduct public health education campaigns to heighten the public's understanding of long COVID.
- Directing the Occupational Safety & Health Administration to develop and implement workplace safety rules to protect workers against occupational exposure to COVID-19. We also believe the agency should be directed to develop and implement workplace safety rules for healthcare facilities that will protect patients against exposure to COVID-19 in these settings.
- Directing the Centers for Medicare & Medicaid Services (CMS) to work collaboratively with states to establish demonstration projects under Sec. 1115 of the Social Security Act focused on improving health outcomes for long COVID patients covered by Medicaid. These demonstration projects could include the expansion of services tailored for long COVID patients, care coordination programs, expansion of telehealth services, community-based programs and services to address social determinants of health, research and data collection to better understand long COVID and to improve care strategies, and training and education for healthcare professionals to enhance their understanding of this condition.
- Directing CMS to work collaboratively with states to establish State Innovation Waivers under Sec. 1332 of the Patient Protection & Affordable Care Act (ACA) focused on improving health outcomes for long COVID patients covered by traditional health insurance. Through these waivers, states could expand health coverage options to ensure long COVID patients have access to necessary services and treatments, implement care coordination initiatives to enhance collaboration between healthcare providers, expand the availability of telehealth services, establish specialized clinics focused on the diagnosis and ongoing care management of long COVID patients, ensure coverage for rehabilitation services to support the recovery and well-being of long COVID patients, implement programs to educate long COVID patients about the resources available to them, and explore alternative payment models that would incentivize improved health outcomes for long COVID patients and encourage efficient and effective care delivery.

We are hopeful that these policy measures will help lay the foundation for a strong and sustained plan to address the needs of Americans who have been affected by long COVID.

In addition to these funding priorities, we request that you consider mentioning the importance of addressing long COVID in your upcoming State of the Union Address. By acknowledging the millions of Americans who are facing extreme hardship because of long COVID, you will give them confidence that the American government sees their suffering and is handling this issue with the urgency it demands.

We sincerely appreciate your consideration of our request, and we stand ready to partner with you to develop comprehensive and equitable solutions for Americans affected by long COVID.

Thank you for your leadership during these challenging and uncertain times. Please contact me at a.wylam@pandemicpatients.org if you have any questions or comments about our request.

Sincerely,

A handwritten signature in black ink, appearing to read "AW".

Andrew Wylam, Esq.
President
Pandemic Patients