

Contact Our Nation's Leaders

Background: Long COVID remains a major public health emergency, with one in five people infected with COVID-19 developing Long COVID. According to the April 2024 U.S. Census Bureau Household Pulse Survey, an estimated 23% (62 million) of U.S. adults have experienced Long COVID, with 15.6 million facing severe daily impairment. This condition is also severely underreported in children, with current research indicating at least 6 million pediatric cases in the U.S. Children with Long COVID often face chronic absenteeism, academic punishment, and long-term health consequences similar to adults, and go undiagnosed as children struggle to verbalize their experiences and depend on an adult to recognize the issue and seek care.

Despite the overwhelming need, recent federal actions have dismantled critical support systems, making it even harder for Long COVID patients to access care, legal protections, and research advancements. These rollbacks are not just failing patients—they are actively harming the economy, weakening the workforce, and increasing healthcare costs, all while undermining America's long-term ability to recover from the pandemic.

Direct Outreach from Constituents Drives Change. Use Your Voice to Make a Difference for Tens of Millions of People in the U.S. and Hundreds of Millions Globally for #LongCOVIDAwareness2025

Instructions:

1. Complete our easy, 30 second action providing background, data, and needs to President Trump, Vice President Vance, your members of congress, your governor, and your state legislators, [here](#).
2. Having read that letter, write a personalized letter to these individuals you will send by mail or through their websites. Speak about your experience as a person with Long COVID, as a caregiver, as a clinician who cares for people with Long COVID, or as someone genuinely concerned about public health. Describe the impacts COVID-19 and Long COVID have had on you personally, in your home, in your community, etc. Describe how your health has been impacted, or your employment, housing, or food security. Explain how actions they can take will support you, and the tens of millions of people in the U.S. with Long COVID. Be real. Be vulnerable. Be stern.
3. Post to social media letting others know you participated in this action.
 - a. Sample post: Today I wrote ____ to advocate for millions of people with #LongCOVID & #PublicHealth. You can do the same for #LongCOVIDAwareness2025 or any day here: <https://bit.ly/LCA25AN>

President Trump	The White House 1600 Pennsylvania Avenue NW	Contact Us – The White	202-456-1111
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	Washington, DC 20500	House	TTY/TTD 202-456-6213
V.P. Vance	The White House 1600 Pennsylvania Avenue NW Washington, DC 20500	Contact Us – The White House	202-456-1111 TTY/TTD 202-456-6213
Congress	Find your members and their contact information at the link to the right.	Contact Us Congress.gov Library of Congress	
Governor	Find your governor and their contact information on their website at the link to the right.	State governors USAGov	
State Legislators	Find your state legislators and their contact information on their website at the link to the right.	State Legislature Websites Congress.gov Library of Congress	

How Each Entity Can Help

Personalizing your letters to your elected officials' roles makes your advocacy more impactful.

Focus on:

- The President's role in national policy and funding decisions
- Congress's ability to legislate and allocate funding
- Governors' power to implement statewide healthcare and public health measures
- State legislators' ability to pass laws that directly affect communities

President Trump – Federal Leadership and National Strategy

- Restore and Expand Long COVID Programs: Ensure continued NIH and CDC research funding, and direct HHS to prioritize Long COVID in federal health initiatives.
- Strengthen Public Health Infrastructure: Implement national air quality standards, expand access to high-filtration masks, testing, and treatments, and improve COVID-19 prevention policies.

- Address Workforce and Economic Impact: Direct the Department of Labor and Social Security Administration (SSA) to develop stronger protections for disabled workers and Long COVID patients.
- Expand Disability and Healthcare Protections: Reverse cuts to Medicaid, Medicare, and DEIA programs, ensuring access to care and employment accommodations.
- Prevent Future Public Health Crises: Rebuild pandemic preparedness strategies to prevent COVID-19 reinfections and worsening chronic disease burdens.

Members of Congress – Federal Funding and Legislation

- Restore and Increase Long COVID Research Funding: Ensure dedicated funding in the NIH, CDC, and AHRQ budgets to advance treatment development.
- Legislate Stronger Public Health Protections: Support bills enforcing air quality regulations, mask access, and workplace safety measures to reduce COVID-19 transmission.
- Expand Medicaid, Medicare, and Social Security Protections: Oppose cuts to federal health programs that millions of Long COVID patients rely on for care.
- Ensure Clinician Education on Long COVID: Require funding for medical school curricula and continuing education (CME) programs on post-viral conditions.
- Pass Workforce and Disability Protection Laws: Strengthen Americans with Disabilities Act (ADA) compliance to protect employees with Long COVID.

Governors – Statewide Public Health and Economic Policies

- Invest in Long COVID Research and Treatment Centers: Establish state-funded Long COVID specialty clinics and regional treatment hubs.
- Improve Air Quality and Prevention Measures: Enforce indoor air filtration standards in schools, businesses, and healthcare settings.
- Ensure Medicaid and State Insurance Coverage: Expand state Medicaid eligibility and require private insurers to cover Long COVID treatments.
- Enhance Workplace Protections: Implement state-level disability and employment rights policies to support workers with Long COVID.
- Fund Public Health Awareness Campaigns: Ensure the public receives clear, science-based messaging about COVID-19 risks and prevention.

State Legislators – Community-Level Protections and Funding

- **Pass State-Level Air Quality and Masking Laws:** Require air filtration improvements in schools, workplaces, and public transit.
- **Expand Medicaid and Disability Rights:** Support state bills that improve healthcare access for Long COVID patients.
- **Fund Local Long COVID Research:** Allocate state funding to universities and hospitals studying Long COVID's impact.
- **Improve Schools' Response to Long COVID:** Ensure students with Long COVID receive educational accommodations under IEP and 504 plans.
- **Support Clinician Education Mandates:** Require state medical boards to include Long COVID training for licensing.

Original Messaging to Pull Data & Facts From

Did you know for many, COVID-19 is a gateway to lifelong disability?

I am writing to you as a constituent deeply concerned about the ongoing Long COVID crisis and the critical need for immediate federal and state action. March is Long COVID Awareness Month, and March 15th marks Long COVID Awareness Day—a time to recognize the millions affected and address this worsening public health emergency now five years later. Despite the lifting of COVID-19 emergency declarations, Long COVID has not disappeared. Instead, it continues to devastate lives, strain our healthcare system, and destabilize our economy. Without urgent investment in research, clinical care, and public health protections, this crisis will only grow.

Long COVID: A National Crisis Affecting Millions

Long COVID remains a major public health emergency, with one in five people infected with COVID-19 developing Long COVID. According to the April 2024 U.S. Census Bureau Household Pulse Survey, an estimated 23% (62 million) of U.S. adults have experienced Long COVID, with 15.6 million facing severe daily impairment. This condition is also severely underreported in children, with current research indicating at least 6 million pediatric cases in the U.S. Children with Long COVID often face chronic absenteeism, academic punishment, and long-term health consequences similar to adults, and go undiagnosed as children struggle to verbalize their experiences and depend on an adult to recognize the issue and seek care.

The only way to prevent Long COVID is to prevent COVID-19 infections. Public health mitigation strategies—which are essential tools in reducing transmission—include improving indoor air quality, increasing access to high-filtration masks, widespread availability of testing and treatments, clear public health messaging, and data-driven policies that protect vulnerable populations.

Yet, federal policies continue to abandon these efforts, removing critical protections that helped reduce the spread of COVID-19. Indoor air quality standards remain unregulated, masking in high-risk settings has been eliminated, free testing programs have been discontinued, and public health messaging on transmission risks has been silenced. These rollbacks not only

increase the risk of COVID-19 reinfections—each of which heightens the likelihood of Long COVID—but also leave millions of immunocompromised and disabled individuals without safe access to healthcare, workplaces, or education.

Mitigation strategies must be restored and expanded to protect public health, reduce the burden of chronic disease, and prevent further disability. This includes enforcing indoor air filtration and ventilation standards, reinstating mask availability in healthcare and public spaces, improving access to antivirals and preventative treatments, and prioritizing research into long-term immune system impacts. COVID-19 is not just an acute illness—it has long-term consequences that public health policies must account for to prevent further harm.

Long COVID's Economic & Workforce Impact is Unprecedented

Long COVID is not just a health crisis; it is also an economic and social catastrophe. Studies estimate that Long COVID costs the U.S. at least \$1 trillion annually, including lost wages, disability benefits, and healthcare expenses. The number of disabled Americans has increased by nearly 35% in just four years, with Long COVID being a primary driver of this rise. This has led to massive workforce losses, reduced productivity, and increased strain on social services, all while funding and resources for Long COVID research and care are being slashed.

The answer is not to abandon public health and dismantle the very programs needed to address this crisis, as though these issues don't exist. The answer is to confront them head-on—with strategic investment, research, and policy action that protects public health, strengthens the workforce, and ensures that those affected are not left behind.

Ignoring this crisis will not make it disappear. Without robust federal and state-level intervention, Long COVID will continue to drain the economy, push millions into financial and medical hardship, and increase the prevalence of chronic disease and disability. The time to act is now—before the damage becomes irreversible.

Federal Rollbacks Are Undermining Long COVID Programs and Hurting America's Health & Economy

Despite the overwhelming need, recent federal actions have dismantled critical support systems, making it even harder for Long COVID patients to access care, legal protections, and research advancements. These rollbacks are not just failing patients—they are actively harming

the economy, weakening the workforce, and increasing healthcare costs, all while undermining America's long-term ability to recover from the pandemic. The notion that cutting funding and programs will "save money" is both short-sighted and counterproductive—failing to invest in public health now will cost exponentially more in the long run.

Here's how these harmful rollbacks are worsening the crisis:

- The termination of the Secretary's Advisory Committee on Long COVID eliminated an essential policy voice that guided federal agencies on research, disability rights, and healthcare strategies. Without this committee, there is no centralized leadership driving Long COVID solutions at the national level.
- The CMS Health Equity Advisory Committee disbandment threatens Medicaid and Medicare protections, putting millions of disabled and low-income Americans at risk of losing coverage. Cutting these safety nets increases emergency room visits and uncompensated care costs, which ultimately drive up national healthcare spending.
- NIH research funding cuts have disrupted critical studies on Long COVID and Infection-Associated Chronic Conditions (IACCs), delaying treatment discoveries that could help millions return to work and reduce disability claims. Investing in research now would not only improve health outcomes but also save billions in disability and healthcare costs over time.
- Disability rights investigations have been halted, leaving children with disabilities unprotected in schools. Without enforcement of these rights, children with Long COVID and other post-viral disabilities face educational discrimination, school pushout, and long-term socioeconomic harm—creating higher future dependency on social services and lost economic potential.
- Government websites have removed Long COVID resources, erasing essential public awareness tools that helped patients, caregivers, and clinicians navigate this complex condition. Lack of access to accurate, science-based information leads to misdiagnosis, ineffective treatment, and increased long-term healthcare costs.
- Diversity, Equity, Inclusion, and Accessibility (DEIA) programs have been gutted, further limiting healthcare and employment protections for people with Long COVID and disabilities. These programs were designed to ensure equal access to medical care, workplace accommodations, and social services—without them, more Americans will be forced out of the workforce and into poverty.

- Public comment opportunities at HHS have been eliminated, silencing patient voices in decision-making. This move further alienates the very people who need these policies the most and prevents lawmakers and agencies from crafting effective, evidence-based solutions that address real-world challenges.

Cutting these programs may seem like a budget-saving measure, but in reality, these rollbacks will cost America far more in the long run. A sick, disabled, and unsupported workforce leads to lower productivity, increased healthcare spending, and greater dependence on government assistance. Instead of reducing costs, these cuts are pushing more people onto disability programs, overburdening hospitals, and worsening an already strained labor market.

The bottom line is simple: a nation cannot be strong, competitive, or economically sound if its workforce is chronically ill and unsupported. Investing in Long COVID research, care, and prevention is not just about compassion—it's about protecting the long-term health and economic stability of the United States. These rollbacks are not just harming patients; they are actively undermining America's recovery. It's time for policymakers to stop ignoring the crisis and start taking action.

Rather than abandoning public health, federal and state governments should be investing in solutions that strengthen the economy, protect the workforce, and improve long-term health outcomes. As my representative, I urge you to:

- 1. Enhance, not dismantle, public health infrastructure by restoring and expanding programs that support infection prevention, air quality improvements, and equitable healthcare access. Public health must be prioritized, not defunded.**

Strengthening public health infrastructure requires investment at every level. Local governments can implement air quality regulations in schools, workplaces, and public buildings to reduce airborne disease transmission, while states should allocate funding to improve indoor air filtration in high-risk settings like hospitals and long-term care facilities. Federally, Congress must restore pandemic preparedness programs, enforce stronger workplace health protections, and ensure public health agencies have the resources they need to respond to ongoing and future health crises. Without these investments, communities will continue to face unnecessary disease spread, disability, and economic strain.

- 2. Invest in Long COVID and post-viral research by ensuring dedicated funding in both state and federal budgets for scientific studies, clinical trials, and the development of treatments.** To develop effective treatments for Long COVID, research must be prioritized across all levels of government. Local and state health departments should partner with universities and research institutions to study Long COVID's impact and develop regional treatment models. States must allocate dedicated funding in their health budgets for post-viral condition research, while the federal government, through the NIH and CDC, must increase national investment in clinical trials and biomedical innovation. Cutting research funding now will only lead to greater healthcare costs, workforce losses, and disability claims in the long run.
- 3. Fund clinician education initiatives to ensure current and future healthcare professionals are adequately trained in Long COVID. Medical education must evolve to meet the growing needs of millions with chronic conditions.** Medical training at all levels must be modernized to address the reality of Long COVID. Medical schools and local hospitals must incorporate Long COVID education into their curriculum and continuing medical education (CME) programs. States should require healthcare professionals to complete post-viral disease training as part of licensing and certification processes. Federally, the Department of Health and Human Services (HHS) and the Centers for Medicare & Medicaid Services (CMS) must provide funding incentives to healthcare institutions that prioritize Long COVID education. Without proper training, misdiagnoses and ineffective treatment approaches will persist, leading to worse health outcomes and greater healthcare system strain.
- 4. Protect Medicaid and Medicare from funding cuts that would strip essential healthcare access from vulnerable populations, including those disabled by Long COVID. These programs must be strengthened, not weakened.** Access to healthcare is a fundamental necessity, and cuts to Medicaid and Medicare would devastate millions, particularly those with Long COVID who rely on these programs for ongoing care. Cities and counties must ensure their residents are informed about Medicaid and Medicare enrollment, while states should strengthen rather than restrict eligibility criteria for these programs. At the federal level, lawmakers must ensure full funding for Medicaid and Medicare while expanding coverage for Long COVID treatments, specialist visits, and disability-related services. Weakening these programs will only drive up long-term costs, as untreated conditions lead to more emergency care and disability claims.

- 5. Allocate funding for clinical care coordination and enhancement, ensuring that Long COVID patients have access to multidisciplinary, patient-centered care that addresses the complexities of the disease.** Effective care for Long COVID requires a coordinated, multidisciplinary approach. Local healthcare providers must develop community-based care models that integrate primary care, neurology, cardiology, and rehabilitation services. States should establish Long COVID specialty clinics and regional healthcare networks to connect patients with the right providers, while federal agencies must fund Long COVID Centers of Excellence and improve insurance reimbursement models for coordinated care. Without these investments, millions will continue to face fragmented, ineffective healthcare, resulting in worsening conditions and increased disability rates.
- 6. Promote the prevention of COVID-19 by restoring public health measures, including indoor air quality standards, equitable access to masks and antivirals, and improved public awareness campaigns. Preventing infections is the most effective way to prevent Long COVID.** Preventing COVID-19 infections is the most cost-effective strategy for reducing Long COVID cases. Local governments can implement air filtration standards in public spaces, schools, and workplaces, ensuring safer indoor environments. States should distribute free high-quality masks, expand access to antivirals, and launch public awareness campaigns to educate communities on the risks of reinfection. At the federal level, stronger workplace safety protections, free testing programs, and increased funding for COVID-19 prevention measures are essential. Ignoring prevention now will only lead to higher healthcare costs, workforce disruptions, and long-term disability burdens.
- 7. Restore and expand federal Long COVID programs, including dedicated research funding, disability protections, and public health initiatives that provide direct support to affected individuals and communities.** Long COVID is a national crisis that requires coordinated action across all levels of government. Cities and counties must work with community organizations to provide Long COVID support services, including patient advocacy, disability assistance, and access to healthcare resources. State governments should establish Long COVID task forces to develop evidence-based policies and ensure state budgets allocate funding for Long COVID care and research. Federally, Congress must reinstate funding for national Long COVID programs, reestablish the Secretary's Advisory Committee on Long COVID, and strengthen

disability protections to ensure those affected receive necessary support and accommodations.

Long COVID is a Public Health and Disability Emergency

COVID-19 does not just cause acute illness—it permanently alters the immune system, increasing susceptibility to reinfections, autoimmune disorders, and life-threatening conditions. Studies show that it reactivates viruses like Epstein-Barr (EBV), disrupts immune regulation, and leaves people vulnerable to secondary infections and progressive disability.

For many, COVID-19 is a gateway to lifelong disability. Millions who once led active lives can no longer work, attend school, or care for themselves—yet our disability systems fail to recognize COVID-induced disabilities, forcing patients into financial and medical hardship.

At the same time, the U.S. remains dangerously unprepared for future pandemics. The H5N1 avian influenza virus is adapting to mammalian hosts, increasing the risk of human-to-human transmission. The erosion of public health protections and the rise of misinformation have left the nation at risk of another devastating pandemic—worsening the crisis for those already living with Long COVID and other chronic conditions.

I urge you to take immediate action and champion policies that invest in research, education, prevention, and care. I look forward to your response on how you plan to address this urgent issue. Please do not hesitate to reach out if you need further information or resources.

Long COVID is not going away, and ignoring it will only deepen the crisis. I urge you to take a leadership role in addressing this public health emergency by advocating for stronger federal support, research funding, and disability protections. Your action now can make a lasting impact on millions of Americans and the future of public health.

I look forward to your response on how you plan to address this urgent issue. Please do not hesitate to reach out if you need further information or resources.

Here are some additional resources:

1. **COVID-19 Longhailer Advocacy Project (C19LAP) Comprehensive Guide to Long COVID:** Developed by the COVID-19 Longhailer Advocacy Project, this extensive guide equips patients, caregivers, healthcare professionals and various other stakeholders with vital information on Long COVID. It covers a wide range of topics that can be found within its table of contents. The guide aims to empower stakeholders with the knowledge and tools necessary to navigate and respond to the challenges associated with Long COVID effectively. <https://www.longhailer-advocacy.org/2024cgic>
2. **COVID-19 Longhailer Advocacy Project Website:**
<https://www.longhailer-advocacy.org/>
3. **National Academies of Sciences, Engineering, and Medicine (NASEM) Long COVID Definition Report:** This comprehensive report, titled "A Long COVID Definition: A Chronic, Systemic Disease State with Profound Consequences," offers a standardized consensus, and U.S. Government adopted definition of Long COVID to aid in diagnosis, management, and research. It provides insights into the multifaceted nature of Long COVID, emphasizing its chronic and systemic impacts. The report serves as a foundational document for healthcare providers, researchers, and policymakers aiming to understand and address the complexities of Long COVID.
<https://nap.nationalacademies.org/read/27768/chapter/1>
4. **New York City Department of Health Letter to Clinicians:** In this letter, the New York City Department of Health and Mental Hygiene addresses healthcare providers, emphasizing the importance of recognizing and managing Long COVID. The letter discusses current knowledge about Long COVID, including its pathophysiology and clinical considerations for evaluation. It also provides strategies for prevention and offers patient resources, urging clinicians to stay informed and adopt standardized definitions to ensure consistent and effective patient care.
<https://www.nyc.gov/assets/doh/downloads/pdf/covid/providers/long-covid-dear-colleagu-e-09102024.pdf>
5. **Social Security Administration (SSA) Guidance on Long COVID as a Disability:** The SSA has issued guidance for healthcare professionals on evaluating disability claims related to Long COVID. This document outlines the criteria for determining when Long COVID qualifies as a disability under the Social Security Act. It provides insights into the medical evidence required, the evaluation process, and considerations for assessing the functional impacts of Long COVID on individuals' ability to work.
<https://www.ssa.gov/disability/professionals/documents/EN-64-128.pdf>

Sincerely,

[Your Name]

[Your Address]

[Your Email]

[Your Phone Number]

For more information or to collaborate on a Long COVID initiative, please contact the COVID-19 Longhailer Advocacy Project at <https://www.longhailer-advocacy.org/contact> or contact@longhailer-advocacy.org.