



January 15, 2025

Dear Colleagues, Clinicians, Researchers, and Health Policy Experts:

Thank you for your thoughtful letter to President Biden: *Address the Crisis of Long COVID and Other Infection-Associated Chronic Conditions in FY25 Budget*.

The Administration is fully committed to identifying strategies to prevent, diagnose, and treat Long COVID and its associated conditions. We also remain dedicated to continuing to raise awareness of Long COVID and supporting solutions for those affected by these conditions.

We have mobilized a team in the Office of Long COVID Research and Practice, in the Department of Health and Human Services' (HHS) Office of the Assistant Secretary for Health, and we collaborate with hundreds of federal colleagues across the U.S. Government and hundreds more external partners, including many of you. As you noted, some large investments have been made through the National Institutes of Health (NIH), including a total of \$1.8 billion to date for the Researching COVID to Enhance Recovery (RECOVER) Initiative, of which \$662 million is dedicated to the next phase of clinical trials. Allocated over Fiscal Years 2025-2029, these funds will also support additional pathobiology studies to examine how Long COVID affects different parts of the body and broader access to data and biospecimens. The Agency for Healthcare Research and Quality has also invested \$67.5 million to fund multidisciplinary clinics to improve access to care and quality of care for people with Long COVID and increase primary care capacity for managing Long COVID. In addition, we are focused on leveraging existing personnel and programs to start to address barriers to care and services. For example,

- HHS engaged the National Academies of Science, Engineering, and Medicine to examine the definition for Long COVID.
- The Centers for Disease Control and Prevention (CDC) is partnering with organizations to assist state and local health departments in meeting the needs of people with Long COVID in their jurisdictions and to help educate primary care clinicians on Long COVID care.

- The Equal Employment Opportunity Commission filed a lawsuit against an employer for disability discrimination related to Long COVID.
- The Department of Labor created resources for employers and employees about workplace accommodations related to Long COVID.
- The Social Security Administration published information for health professionals to provide evidence for Social Security Disability Claims related to Long COVID.
- The Department of Justice and HHS published guidance on Long COVID as a disability under the Americans with Disabilities Act.
- The Department of Veterans Affairs (VA) and the Department of Defense are conducting research and examining clinical outcomes of Long COVID treatment.

While Long COVID is new, the occurrence of infection-associated chronic conditions (IACC) is not. Inasmuch as Long COVID presents with more than 200 symptoms and affects multiple organ systems, a team science approach is warranted. Involving leaders and experts from across several of the NIH institutes, including intramural scientists, is foundational to NIH's RECOVER Initiative. The Administration is leveraging the expertise of experts both in and outside of government who have been working on associated conditions, including myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), especially professionals at the CDC, NIH, and the VA. For example, through the RECOVER Initiative, NIH is building on the extensive expertise and knowledge in ME/CFS and other IACCs to facilitate research progress in Long COVID. This NIH-wide effort is a patient-centered, adaptive nationwide research program to help understand, treat, and prevent these conditions.

NIH is beginning to plan for the next phase of RECOVER clinical trials. They are applying lessons learned from initial RECOVER studies and trials to develop a new clinical trials program called RECOVER-Treating Long COVID (RECOVER-TLC). As the current RECOVER clinical trials and studies continue, the emerging data will inform the ongoing work of RECOVER-TLC. The new program will be led by the National Institute of Allergy and Infectious Diseases, leveraging expertise in infectious and immunologic diseases and conditions and extensive experience in conducting COVID-19 clinical trials. As the current RECOVER clinical trials and studies continue, the emerging data will inform the activities of RECOVER-TLC.

RECOVER-TLC will provide a clear path for ongoing scientific and community engagement to assess new ideas, identify potential therapeutics and biologics, and execute innovative study designs. Importantly, it will provide additional clinical trials capacity, building on existing and new RECOVER clinical trial sites to maintain the involvement of investigators and study participants who are deeply invested in Long COVID research and clinical care.

The forthcoming HHS Secretary's Advisory Committee on Long COVID will be another important mechanism to bring perspectives from outside the government to help inform action on Long COVID and associated conditions. We view the current investments and emerging partnerships in Long COVID research and the broader response as important opportunities to increase our overall understanding of IACCs.

Your advocacy, expertise, and experience are vital to these ongoing efforts. Thank you for everything you do.

Sincerely,

A handwritten signature in black ink that reads "Ian Simon". The signature is written in a cursive, flowing style.

Ian D. Simon, PhD.
Director
Office of Long COVID Research and Practice
Office of the Assistant Secretary for Health
Department of Health and Human Services