



**LONG COVID RESEARCH FY2025 APPROPRIATIONS  
Recommendations for Consideration  
May 21, 2024**

**LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES**

**RECOMMENDATION #1: AT LEAST \$1 BILLION IN FY25 NIH FUNDING FOR LONG COVID RESEARCH**  
Under section: NIH "OFFICE OF THE DIRECTOR"

**Proposed language: Research on Long COVID.**— The Committee continues to be concerned about the lack of diagnostics and treatments available for those continuing to suffer from the long-term effects of COVID-19, known as Long COVID. While longitudinal studies – the focus of the NIH’s RECOVER Initiative – are useful for a novel condition, the Committee believes that non-behavioral interventional trials to develop treatments are urgently needed to augment other public or private sector research initiatives. In addition to other funds appropriated for the Office of the Director, the Committee provides no less than \$1,000,000,000 to fund grants for new Long COVID research, outside of the NIH RECOVER Initiative, with a focus on interventional drug trials, accelerating the discovery of Long COVID biomarkers and therapeutics, and research across infection-associated chronic conditions, with input on how funding is spent from the Federal Advisory Committee on Long COVID.

**RECOMMENDATION #2: \$200 MILLION IN FY25 ARPA-H FUNDING FOR LONG COVID RESEARCH**  
Under section: "ADVANCED RESEARCH PROJECTS AGENCY FOR HEALTH [ARPA-H]"

**Proposed language: Research on Long COVID.**— The Committee continues to be concerned about the lack of diagnostics and treatments available for those continuing to suffer from the long-term effects of COVID-19, known as Long COVID. While longitudinal studies – the focus of the NIH’s RECOVER Initiative – are useful for a novel condition, the Committee believes that rapidly deployed non-behavioral interventional trials to develop treatments are urgently needed to augment other public or private sector research initiatives. In addition to other funds appropriated to ARPA-H, the Committee includes \$200,000,000 for new Long COVID research, with a focus on non-behavioral interventional trials, accelerating the development of Long COVID biomarkers and therapeutics, and research across infection-associated chronic conditions.

**RECOMMENDATION #3: PROPOSED FY25 REPORT LANGUAGE ON LONG COVID RESEARCH**  
Under section: NIH "OFFICE OF THE DIRECTOR"

**Proposed Language:** Long COVID.—The Committee continues to be concerned about the lack of diagnostics and treatments available for those continuing to suffer from the long-term effects of

COVID-19, known as Long COVID or Post-Acute Sequelae of SARS-CoV-2 (PASC). While longitudinal studies – the focus of the NIH’s RECOVER Initiative – are useful for a novel condition, the Committee believes that interventional drug trials are urgently needed to develop treatments, which should be built on expertise in other infection-associated chronic conditions as well as insights from patient lived experience. The Committee directs NIH to describe in its fiscal year 2026 and future budget justifications its plans for accelerating the development of treatments for Long COVID through non-behavioral interventional studies and research across infection-associated chronic conditions, and how these plans augment other public or private sector research initiatives.

In addition, the Committee directs the NIH to provide a report to the Committee within 60 days of enactment that includes a detailed accounting of funds spent to date for research on Long COVID/PASC, including but not limited to the RECOVER Initiative. The report should also include anticipated future research goals and funding requirements by fiscal year, timelines for current and planned study milestones, and how projects will be selected for future research, including what mechanisms will be deployed to engage input from Long Covid patients and experts in other infection-associated chronic conditions throughout the research process. The report shall be made available to the public every year no later than 90 days after the fiscal year ends. Further, the Committee commends the NIH for the dedicated website for RECOVER, and directs them to expand the website to include in the information provided in the report.

#### **RECOMMENDATION #4: LONG COVID INCLUSION IN NIH FY CONGRESSIONAL JUSTIFICATIONS**

Under section: “NATIONAL INSTITUTES OF HEALTH”

**Proposed Language:** The Committee directs NIH to include updates on the following research, projects, and programs in the fiscal year 2026 Congressional Justification: ...**Long COVID/Post-Acute Sequelae of SARS-CoV-2 [PASC]**.

#### **RECOMMENDATION #5: \$20 MILLION IN FY25 FUNDING HHS OFFICE OF LONG COVID RESEARCH & PRACTICE**

Under section: “OFFICE OF THE SECRETARY GENERAL DEPARTMENTAL MANAGEMENT”

**Proposed Language: *Office of Long COVID Research and Practice.***—The Committee recommends \$20,000,000 for the Office of Long COVID Research and Practice [OLCRP], located within OASH, to ensure effective coordination across agencies, conduct public-private sector convenings, issue reports on Long COVID, conduct widespread clinician education, hold workshops, and accelerate the U.S. Government response to the growing public health crisis of Long COVID. The OLCRP works across the U.S. Government to coordinate the whole-of-government response to the longer-term impacts of COVID-19, including Long COVID. The OLCRP helps facilitate the Long COVID Coordination Council and meets regularly to share information across 14 federal agencies and with patient organizations. The Council supports topic-specific workgroups that meet monthly to promote collaboration and communication to tackle tough cross-cutting Long COVID issues.

**AGRICULTURE, RURAL DEVELOPMENT, FOOD AND DRUG ADMINISTRATION, AND RELATED AGENCIES**

**RECOMMENDATION #1: PROPOSED FY25 REPORT LANGUAGE FOR CONTINUED OPERATION OF FDA CURE ID TO EXPLORE EFFICACY OF REPURPOSED PHARMACEUTICALS FOR LONG COVID**

Under section: "FOOD AND DRUG ADMINISTRATION"

**Proposed Language: FDA CURE ID.**— The Committee is very supportive of efforts at the FDA that focus on the potential efficacy of repurposed pharmaceuticals as treatments for Long COVID. In particular, the Committee directs the FDA to continue supporting the CURE ID platform and urges other HHS organizations to support this important initiative. The platform provides a robust and highly effective mechanism for gathering information from patients and healthcare providers on their real-world experiences treating Long COVID with repurposed drugs.

**RECOMMENDATION #2: PROPOSED FY25 REPORT LANGUAGE DIRECTING THE FDA TO ISSUE LONG COVID GUIDANCE AND PRIORITIZE PATIENT ENGAGEMENT**

Under section: "FOOD AND DRUG ADMINISTRATION"

**Proposed Language: Long COVID FDA Guidance and Patient Engagement.**— The Committee understands the challenges of constructing clinical trials for conditions that cross scientific disciplines, however the wide variety of endpoints currently being used for drug trials hampers the efforts of clinicians to make prescribing decisions. The Committee urges the FDA to issue guidance on Long COVID trials that bring cohesion to the field. Such guidance should be informed by meaningful engagement of relevant stakeholders including Long COVID and infection-associated chronic conditions patient organizations, researchers, and treating physicians. Additionally, the Committee recommends that Long COVID be a priority area of recruitment for the FDA Patient Representative Program.

**DEPARTMENT OF DEFENSE**

**RECOMMENDATION #1: ADD LONG COVID TO LIST OF TOPIC AREAS FOR CDMRP PRMRP**

**Proposed Language in appropriations letter:** As you begin work on the Fiscal Year 2025 Defense Appropriations bill, we respectfully request that you include language to add Post-Acute Sequelae of SARS CoV-2 infection (PASC), commonly referred to as Long COVID, to the list of Topic Areas for the Congressionally Directed Medical Research Program's Peer Reviewed Medical Research Program (PRMRP).