

**Congress of the United States**  
**Washington, DC 20515**

March 24, 2023

The Honorable Robert Aderholt  
Chair

Appropriations Subcommittee on Labor, Health and Human Services, and Education  
2358-B Rayburn House Office Building  
Washington, DC 20515

The Honorable Rosa DeLauro  
Ranking Member

Appropriations Subcommittee on Labor, Health and Human Services, and Education  
2358-B Rayburn House Office Building  
Washington, DC 20515

Dear Chairwoman Granger and Ranking Member DeLauro,

As you begin work on the Fiscal Year 2024 Labor, Health and Human Services, and Education Appropriations bill, we respectfully request that you provide \$20 million in additional resources to address the growing crisis of post-viral illness. It is critical that our response to the pandemic include steps to prevent and control lasting repercussions from COVID, along with efforts to stem the spread of the disease. This funding will increase resources for research, reduce redundancies at the NIH and expand successful programs at the CDC.

We respectfully request \$10 million to create an Office of Infection-Associated Chronic Illnesses (IACIs) at the National Institutes of Health (NIH). An office is critically important to streamline and coordinate multifaceted research across multiple institutes and specialties at the NIH. Specifically, the Office of Infection-Associated Chronic Illnesses, located within the Office of Research on Women's Health, will prioritize research applicable across the spectrum of infection-triggered chronic conditions. We include the attached report language to complement this work.

We also respectfully request that you provide an additional \$10 million to study the intersection of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and post-acute sequelae of COVID-19 infection (Long COVID) at the Chronic Fatigue Syndrome Programs at the Centers for Disease Control and Prevention (CDC), and to include the attached report language to complement this work.

Most Americans have had COVID-19 and a substantial number experience long-term symptoms called "Long COVID".<sup>i</sup> In July of 2022, the CDC published an analysis showing 1 in 5 American adult COVID survivors under the age of 65 are experiencing symptoms consistent with long COVID<sup>ii</sup>, forcing an estimated 4 million people out of the labor force and many more to work with debility at any given time.<sup>iii</sup> The broader economic impact has been estimated at \$3.7 trillion, due to reduced quality of life, lost earnings, and medical costs.<sup>iv</sup> While there is less

research available on long COVID in children and adolescents, a review of 20 studies suggests 1 in 4 could be suffering from the condition.<sup>v</sup>

COVID-19 is associated with the development of other infection-associated chronic conditions, such as: ME/CFS, fibromyalgia, postural orthostatic tachycardia (POTS) and other forms of dysautonomia, mast cell activation syndrome (MCAS), and Guillain-Barré. In fact, many people with Long COVID meet diagnostic criteria for one or more of these complex, chronic illnesses.<sup>vi,vii</sup> For example, population-based studies in the United States and Germany have found between 43-46% of Long COVID patients fulfill diagnostic criteria for ME/CFS.<sup>viii,ix,x</sup> It has been estimated that the number of Americans with ME/CFS has increased sixfold since the pandemic began as a result of COVID.<sup>xi</sup> People with ME/CFS report substantial impairment<sup>xii</sup> and an estimated 25% are confined to their homes or completely bed bound.<sup>xiii</sup> For many, it is a lifelong illness. The cost to families and larger society is profound: current ME/CFS prevalence estimates translate to \$149 to \$362 billion in medical expenses and lost income, exclusive of other costs, such as disability benefits, social services, and lost wages of caretakers.

SARS-CoV-2 is the most recent, but certainly not unique, in its ability to cause post-acute symptoms. Other pathogens have long been associated with an unexplained, persistent symptoms in a subset of patients, including herpesviruses (HHV-6a/7b, Epstein-Barr)<sup>xiv,xv</sup>, Ebola<sup>xvi</sup>, SARS-CoV-1 (the cause of severe acute respiratory syndrome (SARS))<sup>xvii</sup>, West Nile virus<sup>xviii</sup>, dengue<sup>xix</sup>, and Ross River virus<sup>xx</sup>. There is also growing evidence that microbial infections are a risk factor for multiple sclerosis (MS) and other neurodegenerative diseases.<sup>xxi</sup>

Because post-acute conditions have been neglected for years, we lack understanding of the underlying mechanisms and are lagging far behind in the development of effective treatments.

However, available research findings highlight overlapping characteristics of infection-associated chronic illnesses, including:

- Risk Factors
  - female sex<sup>xxii,xxiii,xxiv,xxv,xxvi</sup>
  - pre-existing infection with certain pathogens<sup>xxvii,xxviii</sup>
- Pathophysiological Observations:
  - immune system disturbances (e.g., chronic immune activation/inflammation<sup>xxix</sup>, autoimmunity<sup>xxx</sup>, reduced immune defenses<sup>xxxii</sup>, latent pathogen reactivation<sup>xxxiii</sup>)
  - chronic, multi-system inflammation<sup>xxxiii,xxxiv,xxxv</sup>
  - nervous system abnormalities<sup>xxxvi,xxxvii,xxxviii,xxxix</sup>
  - hormone imbalances<sup>xl,xli</sup>
  - cardiovascular perturbations<sup>xlii,xliii,xliv</sup>
  - metabolic dysfunction<sup>xlv,xlvi,xlvii</sup>
- Symptoms and Disease Course<sup>xlviii,xlix</sup>
  - fatigue and exertional intolerance
  - dysautonomia symptoms
  - neurological manifestations and cognitive dysfunction
  - unpredictable disease course (e.g., persistent, fluctuating, relapsing-remitting)
  - limited functional status and poor quality of life

The requested funds include level funding for existing CDC programs addressing ME/CFS, such as the Multisite Clinical Assessment of ME/CFS (MCAM) study and medical education efforts, and the NIH NINDS Common Data Elements project. The additional \$10 million is requested to conduct a nationwide epidemiological study to understand and identify:

- The natural history of ME/CFS, Long COVID, and related post-viral illnesses;
- The prevalence of Long COVID, ME/CFS, and related post-viral illnesses in COVID-19 patients;
- Potential risk, resiliency, and disparity through socioeconomic data on Long COVID; and
- The accessibility of quality care for increased ME/CFS cases as a result of the COVID-19 pandemic.

Furthermore, a coordinating office at NIH holds the potential to be a convening force for researchers from across multiple specialties, synergize research across multiple institutes, streamline the use of funding resources, and facilitate patient and stakeholder engagement in research prioritization. Much needed funding, focused research, and improved medical education will strengthen support for and improve the lives of ME/CFS and Long COVID patients across the country.

Again, we urge you to support \$10 million for an Office of Infection Associated Chronic Illnesses FY24 appropriations bill to fund the appropriate research and to develop strategies for effective treatment and prevention of these complex chronic illnesses. And, an additional \$10

million to expand on the successful activities of the Chronic Fatigue Syndrome program at the CDC.

We appreciate your leadership on this issue and thank you for your consideration of these requests.

Sincerely,



Zoe Lofgren  
Member of Congress



Anna G. Eshoo  
Member of Congress

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