



Solve M.E.

Dear Honorable Members of the Committee,

I am writing to you on behalf of [Solve M.E.](#) and the millions of Americans deeply affected by post-infection diseases. The Solve ME/CFS Initiative (Solve M.E.) is a non-profit organization that serves as a catalyst for critical research into diagnostics, treatments, and cures for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), Long COVID and other post-infection diseases. Our work with the scientific, medical, and pharmaceutical communities, advocacy with government agencies, and alliances with patient groups worldwide is laying the foundation for breakthroughs that can improve the lives of millions who suffer from various post-infection diseases.

Post-Infection Diseases: A Growing Public Health Concern

Post-infection diseases, such as ME/CFS and Long COVID, represent the most significant and growing public health concern of today due to the size of the impacted population, the decreased quality of life, the lack of treatments, burdens on caretakers, increased healthcare costs, and ongoing economic and productivity losses. The impact is far-reaching, with up to 32 million Americans currently debilitated by [ME/CFS](#) and [Long COVID](#). Additionally, [as many as 4 million individuals are unable to work](#) due to Long COVID. The economic implications are profound; Long COVID alone is projected to [cost the U.S. economy a staggering \\$3.7 trillion](#), as reported in a recent Harvard study.

The most prevalent Long COVID symptoms — crippling fatigue worsened by exertion (post-exertional malaise), autonomic, and cognitive dysfunction — mirror those of ME/CFS, and other related infection-associated chronic illnesses. Learning more about Long COVID can deepen our understanding of ME/CFS — and what we know about ME/CFS can shed light on Long COVID, ultimately accelerating treatments and cures for both, as well as other long-haul infection-associated chronic illnesses that share similar characteristics. Studies indicate that [COVID-19 triggered ME/CFS in as many as 46% of Long COVID patients](#). The urgency for congressional responsiveness to address this debilitating disease is paramount, especially as the number of those impacted continues to grow.

The severity of these conditions is compounded by the lack of available treatments, placing an immense strain on healthcare systems, caregivers, and the broader economy. Despite their high disease burden, these illnesses receive a distressingly low amount of funding per capita. This emerging wave of chronic illness and long-term disability disproportionately impacts women, communities of color, and members of our military.

The Federal Government's Role in Addressing this Crisis

To effectively support those suffering from Long COVID and related infection-associated chronic illnesses, we urge the federal government to undertake the following actions:

1. **Enhanced Research and Community Support Funding:** We strongly recommend an annual allocation of at least \$10 billion from the National Institutes of Health (NIH) for dedicated Long COVID

www.SolveCFS.org

Mailing address: 350 N Glendale Ave Suite B#368
Glendale, CA 91206

Street address: 611 N Brand Blvd Suite 13-120
Glendale, CA 91203



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and ME/CFS research. This funding is essential to achieve parity with the investments made in cancer and HIV research. Additionally, this budget should also include provisions for symptom relief for patients, as both Long COVID and ME/CFS currently lack FDA-approved diagnostics or treatments.

- 2. Establishment of an NIH Office on Infection-Associated Chronic Illness:** We propose the creation of a dedicated NIH Office to address the complexities of infection-associated chronic illnesses specifically. This office would play a pivotal role in coordinating research efforts, ensuring efficient use of resources, avoiding duplication of efforts, and speeding up the process of clinical trials and treatment development.
- 3. Expansion of Clinical Care through Centers of Excellence:** We urge the establishment of specialized Centers of Excellence to provide focused care for Long COVID and ME/CFS, among other related infection-associated illnesses. These centers would serve as hubs for advanced treatment and research. Additionally, we advocate for significant investment in medical education and training for primary care physicians and specialists to improve disease recognition, diagnosis, and treatment access. A model for this is the Long COVID & Fatiguing Illness Recovery Program, which is an existing model that offers valuable insights and best practices for healthcare providers treating these conditions.
- 4. Improvement of Quality of Care Through Insurance Coverage:** It is crucial to ensure comprehensive coverage for Long COVID, ME/CFS, and other infection-associated chronic conditions under commercial plans as well as Medicare and Medicaid. This coverage should extend to treatments that, while not yet proven, show promising potential benefits that outweigh the potential risks. Additionally, ensuring continued access to treatment through telehealth is vital due to both the energy limitations of the patient population, and for the purposes of ensuring access for patients in rural areas. Ensuring access to a wide range of potential treatments and ongoing physician support is key to managing these complex conditions effectively.

Understanding the Connection Between Acute Infections and Chronic Illnesses

There is a significant and concerning link between acute viral or bacterial infections and the development of chronic illnesses. Approximately 10% of individuals contracting an infection, such as with the Epstein-Barr virus, experience persistent symptoms. This persistence of symptoms can lead to a diagnosis of Myalgic Encephalomyelitis (ME or ME/CFS). Before the COVID-19 pandemic, it was estimated by the CDC that around 2.5 million people in the United States had ME/CFS.

The pandemic has exacerbated this situation. [About 10%](#) of those who have contracted COVID-19 continue to suffer from prolonged symptoms, known as Long COVID. This has dramatically increased the number of individuals who now meet the diagnostic criteria for ME/CFS, Postural Orthostatic Tachycardia Syndrome (POTS), and other forms of dysautonomia. Notably, nearly half of those with Long COVID may qualify for a diagnosis of ME/CFS. Additionally, at least 28% of Long COVID patients demonstrated POTS or other

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dysautonomic symptoms in NASA Lean Test and Active Stand Test studies. Additionally, there is a growing number of people suffering from chronic conditions following other infections, such as "long Lyme," "long flu," and "long RSV."

Beyond ME/CFS and Long COVID, some of the other chronic illnesses linked to infections include Gulf War Illness, POTS and other dysautonomias, Mast Cell Activation Syndrome, Chronic Lyme Disease, and Guillain-Barré Syndrome. Research and attention in these areas are essential, as breakthroughs could potentially benefit a wide range of related conditions.

It is crucial that our response to Long COVID includes those suffering from other infection-associated chronic illnesses. These conditions not only burden individuals but also impact military readiness and the national economy. Your attention and action in addressing this public health crisis is vital.

Thank you for your consideration and for taking action on this crucial issue.

Sincerely,

Emily Taylor
Vice President of Advocacy & Engagement
Solve M.E.

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