



Responding to Long COVID Responsibly

To effectively address the unique challenges presented by Long COVID, the Global Virus Network recommends a unified and integrated approach involving the public, policymakers, and those involved in the research enterprise and in healthcare systems to create and implement policy changes, support continuing research, foster awareness, and advocate for—and initiate—multi-specialty care.

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The COVID-19 pandemic has created both immediate, acute health challenges, and a condition called Long COVID, which can last months or even years following the initial infection. Also known as Post-Acute Sequelae of COVID-19 (PASC), Long COVID includes more than two-hundred diverse symptoms, such as fatigue, shortness of breath, chest pain, difficulty concentrating, and muscle pain. Beyond persistent symptoms, Long COVID is also associated with an increased risk for significant medical events, including major adverse cardiovascular events and new-onset diabetes mellitus.(1) For many people, Long COVID has a significant impact on their ability to work, study, take care of their families, and participate in other activities of daily living. For these reasons, Long COVID is often described as a “mass disabling event.”(2) Long COVID can also lead to financial hardship, social isolation, and mental health challenges.

As medical, virology, and public health experts delve deeper into understanding Long COVID, it is evident that a comprehensive and collaborative approach to Long COVID is needed. In particular, the cause or causes of Long COVID are still not fully understood. Long COVID is thought to be due to a combination of factors, including inflammation, damage to the lungs and other major organs, immunopathology, autoimmunity, viral persistence, microclots, mitochondrial dysfunction, and dysautonomia.(3,4)

Importantly, Long COVID patients exhibit symptoms similar to those of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). This condition—possibly also a post-viral syndrome—has frustrated scientists and clinicians for decades, especially in their attempts to diagnose and treat it.(5) Much like how ME/CFS came to be characterized and recognized, it has taken more than a year for providers, insurers, investigators, and policymakers to recognize that Long COVID is not only real, but also a disabling condition requiring urgent prioritization for scientific inquiry, service provision, resource allocation, and patient support.(6)

After months of delay, in December 2020 the U.S. Congress authorized over one billion dollars to the U.S. National Institutes of Health (NIH) to be spent over four years for “research and clinical trials related to long-term studies of COVID-19.”(7) That enabled the NIH to start a large observational study—called the Researching COVID to Enhance Recovery (RECOVER) Initiative—to define Long COVID and to determine its underlying pathophysiology.(8) Many patients suffering from Long COVID had high expectations of rapid relief from their symptoms. But the RECOVER Initiative was never intended to do that, which has led to widespread frustration and ongoing disappointment.(9)

The eventual outcomes of the RECOVER Initiative and those of other ongoing studies and clinical trials (e.g., PHOSP-COVID) may not be enough to respond to the challenges presented by Long COVID. That is despite



significant investment in these initiatives, including by thousands of adult, pregnant, and child participants across multiple sites(10), numerous findings published(11) with many more to come, and several large clinical trials underway to test various Long COVID treatments targeted at specific etiologies and symptoms(12).

Indeed, Long COVID presents a unique set of challenges. The GVN believes addressing them requires a more united effort, coordinated centrally and involving caregivers, patients, policymakers, the public, and all other stakeholders. By fostering awareness, advocating for multi-specialty care, supporting research, and implementing policy changes, we can address—collectively—the impacts of Long COVID on people’s health and well-being.

To advance this important agenda, the GVN recommends the following:

- **Enhance healthcare infrastructure** to provide specialized care for Long COVID patients. Establish clinics and/or centers of excellence dedicated to diagnosing, treating, and researching this condition.
- Engage in both **comprehensive and collaborative research** on Long COVID. Understanding the biological mechanisms which underpin its development, risk factors, and treatment options is vital for offering effective care. In our opinion, this effort will require an unprecedented collaboration between healthcare providers, basic and translational scientists, patients and others in order to achieve deep characterization of Long COVID from multiple angles, including research on samples from intervention trials.
- **Launch public health campaigns** to increase awareness of Long COVID among the general population. Highlight the importance of preventive measures, vaccination, and early intervention.
- Implement workplace policies that **accommodate individuals with Long COVID**. Flexible work arrangements and disability accommodations can aid in recovery while helping to maintain livelihoods.
- **Establish comprehensive data collection systems** to track Long COVID cases. This data will aid in identifying trends, risk factors, and potential interventions.
- **Develop guidelines, dissemination methods and programs** for healthcare professionals to diagnose, treat, and manage Long COVID patients. Encourage interdisciplinary collaboration for a holistic approach.
- Recognize the psychological impact of Long COVID and **integrate mental health support** into patient care. Addressing anxiety, depression, and other mental health challenges is integral to overall recovery.

The GVN (GVN.org) is a worldwide network of virologists and physicians committed to solving viral challenges facing humanity. As we navigate COVID-19’s evolving landscape, our strongest allies in the fight against Long COVID remain solidarity, collaboration, and compassion. But responding to Long COVID responsibly will take significant funding, too.

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