

Beth Israel Deaconess Medical Center



Winter 2025

Hello BIDMC Long COVID Community,

As we look back on 2024, it's clear that strides were made in the fight against Long COVID. Researchers made significant progress, uncovering key insights into the underlying mechanisms, potential treatments, and long-term effects of the condition. Studies confirmed that factors like viral persistence, immune dysfunction, and clotting abnormalities play a major role in prolonged symptoms. At the same time, clinical trials explored a range of treatments, from existing medications to antiviral and immunemodulating therapies, offering new hope for those struggling with Long COVID.

Currently, Long COVID treatment remains focused on symptom management, rehabilitation, and supporting the mental health of patients. While no single treatment is universally effective, a personalized approach involving multiple healthcare disciplines

remains the best way to address the complex nature of Long COVID. We stay hopeful, as research is ongoing, and new treatment options are expected to emerge over time. We hope that this newletter helps to keep you informed about ways to prioritize yourself, stay connected with current information, and be a place to find information as you navigate your own path to recovery.

Best,

Amberly Ticotsky, RN

The Boston COVID Recovery Cohort (BCRC): Working Together for Long COVID Recovery

The Boston COVID Recovery Cohort (BCRC) is a key part of the NIH-funded RECOVER research initiative, which is focused on understanding, treating, and preventing Long COVID. BCRC brings together six Boston-based research sites, community partners, healthcare leaders, and policymakers, all working toward a common goal: to center community voices and promote social justice in the recovery process, ensuring equity for all.

BCRC has four main goals:

- 1. Recruiting a diverse group of participants
- 2. Supporting education and engagement

- 3. Providing equitable care and social support
- 4. Advocating for policy changes to improve recovery for everyone

In 2025, BCRC will collaborate with Massachusetts legislators, the Department of Public Health, and other important partners to better meet the needs of Long COVID patients and enhance our healthcare system. To help guide this work, BCRC will hold various meetings with Long COVID support groups and caregivers to hear directly from you. Your experiences and priorities will play a key role in shaping future efforts to improve Long COVID care and recovery. Check out the work that the BCRC is doing!

How to Prepare for Your Doctor's Visit: Long COVID Edition

We know that managing healthcare appointments can feel overwhelming, especially when you're already coping with the symptoms of Long COVID. Juggling appointment reminders, travel to healthcare providers, and the emotional toll of discussing a complex health history can add significant stress. We hope that some of these tips can help decrease the burden:

Track Your Symptoms: Keep a detailed record of your symptoms, including any changes or new issues you're experiencing. Note the frequency, duration, and intensity of symptoms like fatigue, brain fog, or difficulty breathing.

List Your Medications: Bring a list of all medications, supplements, and treatments you are currently using, including over-the-counter options.

Prepare Your Questions: Write down any questions or concerns you have. This can include questions about treatment options, symptom management, or recommendations for specialist care.

Bring a Support Person: If possible, bring a family member or friend to help remember important information and provide support during the visit. They can also be present on telehealth visits.

Be Honest: Share your full range of symptoms, including mental and emotional health. Long COVID can affect both the body and mind, and it's important to address all aspects of your health.

Our team Social Worker, Jackie French, created <u>this document</u> to help organize these ideas.

Long COVID Research at BIDMC

BIDMC continues to recruit patients for research studies looking at the impact of Long COVID. These include:

Long COVID fatigue: This study will evaluate the effectiveness of **Abrocitinib** in alleviating severe fatigue caused by Long COVID.

Abrocitinib, a Janus kinase (JAK) inhibitor currently approved for eczema, is part of a class of medications used to treat chronic inflammatory conditions.



Contact <u>BIDMC-CVVRTRIALS@bidmc.harvard.edu</u> for more information or call **617-735-4610**.

LIFT (Life Improvement Trial) Study: A clinical trial for fatigue and PEM through the Open Medicine Foundation (OMF). This is a Phase 2 clinical trial evaluating the effects of Iow-dose naltrexone (LDN) and pyridostigmine (Mestinon) in participants with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). Criteria: Patient must meet National Academy of Medicine Criteria (NAM), Canadian Consensus Criteria (CCC), and demonstrate orthostatic intolerance for diagnosis of ME/CFS and onset of symptoms before December 2023. Please contact Jsquires1@bwh.harvard.edu.

CLEO Study: Looking at the long-term effects of COVID-19, specifically how COVID can affect cardiovascular health. Contact CLEO@bidmc.harvard.edu for more information or call 617-735-4124.

Mind-Body Study: Evaluating a mind-body approach to reduce symptoms and improve your quality of life. The study is conducted entirely virtually. www.longcovidstudy.net

NIH RECOVER Clinical Trials: BIDMC is currently participating in the SLEEP and ENERGIZE clinical trials. Information can be found at: https://trials.recovercovid.org/. For more information please contact BIDMC-Recover@bidmc.harvard.edu or call 617-667-0173.

Sleep and Long COVID Study: For those struggling with different aspects of sleep, this study offers a way get personalized sleep information and additional data while helping to support the important research work being done. See the flyer or contact postviralsleep@bidmc.harvard.edu or call 617-667-5243.

To find out about additional research happening around you, visit our <u>research website</u>.

Long COVID Resources and Upcoming Events

Caregiver Support Group: We are proud to to offer a monthly Long COVID support group for the important people in your lives. Please ask your loved one to RSVP and receive the meeting link by emailing Jackie French at jfrench2@bidmc.harvard.edu. (This is offered in collaboration with the Brigham and Women's COVID Recovery Team).

TED Talk with Dr. David Putrino, **Director of Rehabilitation Innovation for the Mount Sinai Health System**: Dr. Putrino discusses what we understand about Long COVID, treatment directions, and the toll Long COVID has on public health. Transcript is available: https://www.youtube.com/watch?v=4XWHLUu6e38

Feb. 20th from 4-5pm: Presentation/Discussion with Dr. Rishab Gupta: Dr. Rishab Gupta is a neuropsychiatrist at Brigham and Women's Hospital with expertise in Long COVID. Neuropsychiatry is a medical field that focuses on the relationship between neurological disorders and psychiatric symptoms. Please join us to learn more about how Long COVID affects mental health, the impact of fear of re-infection, social isolation, and how to foster safe socialization and recreational activities. Click here for Zoom Link

Reminders

March 15th marks the second official Long COVID Awareness Day, continuing the global effort to raise awareness and provide support for those impacted by Long COVID. As awareness grows, the day emphasizes the ongoing challenges that individuals face, from physical symptoms to the psychological toll that can accompany the condition. Advocates are pushing for increased research funding and healthcare resources to better understand Long COVID and develop effective treatments. Stay tuned for details on upcoming events in recognition of this important day.

The Sadhguru Center for a Conscious Planet is doing really great work at BIDMC, in general and for patients with Long COVID. Those with a variety of Long COVID symptoms, including shortness of breath, fatigue, and mental health challenges, are welcome and encouraged to join the program. The workshops are free 60-minute sessions, and you can sign up as per your schedule: Click here for the sign up sheet

Based on data from various sources, we are close to the peak of COVID infections and respiratory illnesses this winter. Due to the high numbers of illnesses and symptoms, BIDMC is requiring all staff to wear masks. Patients, visitors, escorts and support persons are encouraged (but not required) to mask while in health care facilities.

Order your 4 free COVID tests today! Every household in the U.S. is eligible to receive 4 rapid COVID tests free of charge. Ordering them is quick and easy! https://covidtests.gov/

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Visit our Critical Illness & COVID-19 Survivorship Website



