

Summer 2024

Bring on the heat

Hello BIDMC Long COVID Community,

As we enjoy warm days and sunshine into the evening, I know that summer can often be a double-edged sword as these wonderful things can also exacerbate Long COVID symptoms. Summer often involves transitions from routines and adjustments. In this newsletter, we hope to give you some information and resources to support you as you navigate this season of change.

Best,

Amberly Ticotsky, RN

Coordinating with Local Long COVID Groups

We have been meeting with and continue to connect with staff from other local Long COVID clinics. It's exciting to collaborate on resources and find new eyes on the ever-changing landscape of Long COVID treatment options and care. We're really excited about the opportunities for all of us and will continue to share connections as we learn more together. Big shout out to Jackie French for her persistence to make this happen!

We Want Your Recommendations!

One of the first collaborative things The BIDMC Long COVID Collaborative and Brigham and Women's COVID Recovery Center are doing is looking to create a robust spreadsheet, with input from you - the experts!

As a person living with Long COVID, you have become an expert based on the challenging experiences you face every day. Despite ongoing research, Long COVID remains a medical mystery, with many aspects of its causes, mechanisms, and optimal treatments still not fully understood. Your journey likely involves managing a wide range of symptoms, experimenting with various treatments, and trying to advocate for yourself

while navigating the complexities of the healthcare system. If you are living with Long COVID, your insights and recommendations are very important. What healthcare providers, resources, and treatments have you found to be helpful in managing your condition? Whether it's a specific doctor who understands the intricacies of Long COVID, a support group that offers emotional and practical assistance, or treatments and therapies that have made a significant difference, your suggestions can provide much-needed guidance to others navigating this complex and often isolating condition.

Please add your recommendations for healthcare providers, resources, and treatments that have helped you manage Long COVID to the shared spreadsheet so we can collectively benefit from each other's experiences. This working spreadsheet will be available in Dropbox - be sure to check all the tabs along the bottom. Thank you for your contributions!

[Long COVID Patient Recommendations](#)

Long COVID Research at BIDMC

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

CLEO Study: Looking at the cardiac impacts of COVID.
Contact CLEO@bidmc.harvard.edu for more information.

NIH RECOVER Clinical Trials: BIDMC is currently participating in the VITAL and SLEEP studies. More information can be found at: <https://trials.recovercovid.org/> To get connected with the trials, please e-mail BIDMC-Recover@bidmc.harvard.edu or call 617-667-0173.

Psycho-somatic Study: Looking at symptom relief through a mind-body approach to reduce or eliminate pain and improve your quality of life. The study is conducted entirely virtually. www.longcovidstudy.net

To find out about research happening around you, visit our [research website](#).



Upcoming Events

Jackie French has created a great opportunity which should be useful for those struggling with balancing work with your current health needs or trying to get back to work. **July 25 from 12:45pm -1:30pm**, we will hear from **Aaron Konopasky of the Equal Employment Opportunity Commission (EEOC)** to talk to us about **workplace accommodations**.

The event will take place on Microsoft Teams. Use the information below, or [email Jackie \(jfrench2@bidmc.harvard.edu\)](mailto:jfrench2@bidmc.harvard.edu) to get email updates, reminders, and direct links.

[Click here to join the meeting](#)

Meeting ID: 258 192 649 908

Passcode: sssHDm

Also on Thursday, **July 25 at 9:00 a.m. ET**: Join **Washington Post Live** for conversations featuring leading policymakers, medical researchers, and first-hand accounts about the causes, prevalence, and long-term impacts of Long COVID. [Registration: The looming public health challenge of long covid - The Washington Post](#)

Recent News and Publications



The 1st International Conference on Clinical and Scientific Advances in ME/CFS and Long COVID took place in Lisbon, Portugal. The conference featured speakers including David System, Ed Yong, Lucinda Bateman, and Maureen Hanson. [There is a recorded livestream of the conference.](#)

An interesting [article highlighting different causes of Long COVID](#) and links to other great resources from Yale.

[New research](#) about inflammation for patients with Long COVID. Further information is needed, but an exciting start.

[The Economist Impact released a report](#) exploring the burden of Long COVID and highlights some findings that won't surprise you, but are important to have validated.

The National Academies [published their findings](#) which recognizes the seriousness and persistence of the condition for millions of Americans.

Exploring the connection between concussions and Long COVID, [this article](#) provides some optimism for future treatments.

Team Member Spotlight

Tamara Fong, MD, PhD, is a cognitive neurologist and a mainstay of our Long COVID Collaborative and an important motivator for the program. Dr. Fong's area of clinical expertise is cognitive disorders related to aging, including dementia and delirium. Throughout her career, she has made significant contributions and advances in patient care and research. Dr. Fong's interest and passion in cognitive issues has become critical for Long COVID patients in recent years. Her approach to treatment of COVID-related brain fog and other cognitive symptoms is based on individual needs. She has supported ongoing research occurring at BIDMC including her role as an

Investigator of the NIH Researching COVID to Enhance Recovery (RECOVER) study.



Long COVID Resources

[The Sadhguru Center for a Concious Planet](#) is doing amazing work at BIDMC, in general and for patients with Long COVID. We know that their work they is positively impacting patients based on the feedback and research they have completed, but we also know that this is currently one of the popular treatment for patients with Long COVID. The amazing work they are doing for patients with [Long COVID is offered FREE and done from home!](#)

Wellness Corner

Summer is many people's favorite season. Beach trips, cookouts, t-shirts, and time off from school all have a special feel. But did you know that warm weather can also make your Long COVID symptoms feel worse? As you know, Long COVID can make it hard for your body to regulate its temperature. Heat causes your blood vessels to widen, which can result in blood pooling in your legs. Your heart must work harder to regulate your vital signs, and this can lead to fainting, nausea, and dehydration.

Here are some reminders for staying cool:

- Hydrate! Make sure you have water available by packing extra water bottles or making sure you have cash with you. Tip: consider adding electrolytes for some extra support
- Don't overdo it! Make sure to add rest and recovery time to your schedule. Heat intolerance can increase fatigue
- Plan ahead! Plan activities earlier or later in the day to avoid the hottest times of day
- Dress accordingly! Use hats and long sleeves to protect your body from the sun. Use light and breathable clothing to help prevent your body from overheating

- Use gadgets! Think spritz bottles, cooling pads, mini fans - whatever helps you stay cool
- Indulge in summer! Eat the popsicles, swim in the water, get a treat from the ice cream truck!

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[Visit our Critical Illness & COVID-19 Survivorship Website](#)

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