

Winter 2024

Long COVID Awareness

Hello BIDMC Long COVID Community,

Thank you to those that reached out with your own stories and feedback. I continue to be thankful for this community - the shared experiences and the willingness to be vulnerable. It is inspiring and encouraging. Please be in touch and continue to share your stories within this space, but also with your own communities. They are impactful tales of struggle and perseverance. Your stories help to shine a light on Long COVID.

This Friday, March 15th, is Long COVID Awareness Day. While every day could be Long COVID Awareness for all of us in the collaborative (patients and staff!), Friday is a day to join with other patients around the country to help bring some important light and information to the forefront of people's minds. The long hauler advocacy project has a [page dedicated to action items](#) that will help to spread awareness on the issue.

In Solidarity,
Amberly Ticotsky, RN

Program Update

Dr. Jason Maley has moved to a research position focused on finding treatments for immune and inflammatory diseases. Sadly, this means he is no longer seeing patients in clinic. Dr. Maley's creativity and initiative are what created this program and helped to impact so many patients. His work has been invaluable to both BIDMC patients and the greater Long COVID community. Thank you, Dr. Maley!

At this time, we are not planning to have a new program director; instead, our focus will remain as a referral collaborative, connecting patients with specialists who believe in and support the Long COVID experience as wonderful care providers. The regular interdisciplinary staff meetings will continue. We will also continue to stay up to date with the research, and continue to support the research efforts at BIDMC and more broadly. We continue to think of ways to reduce the bottlenecks to care and make sure that we are reaching the most patients in an efficient but also effective manner. Change can be tricky, but we feel fortunate that BIDMC remains committed to Long COVID care.

Long COVID Research at BIDMC

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



SLEEP Study: Looking to understand the role of sleep in the development and persistence of symptoms that are common in Long COVID, such as pain. Email the research team for more information at COVIDSleep@bidmc.harvard.edu. **Enrollment closes at the end of March - get in touch soon if you're interested!**

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 NEURO studies, with hopes to add more in the near future. 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](#).

Long COVID Developments



In January there was a COVID-19 wave - of both acute infections and scientific developments! While the infections seemed to have peaked in late January, information continues to be published. Below are some highlights of information:

- On March 1, the CDC dropped their COVID isolation guidelines: the CDC now recommends isolating based on respiratory symptoms, saying people can “go back to normal activities” after just one day if symptoms are mild and improving. This is a change from the previous recommendation that people stay home for five days after testing positive. The new recommendations aren’t supported by a change in data or science on infectiousness and received heavy backlash. Experts have cited numerous studies showing that people with COVID-19 remain contagious well beyond five days this week in response to the CDC’s guidance change. One large-scale 2022 study in [JAMA Network Open](#) assessed the duration of rapid antigen test positivity during the Omicron BA.1 wave. The study concluded that “rapid antigen test positivity remained high 5 days after symptom onset, supporting guidelines requiring a negative test to inform the length of the isolation period.”
- In January, the U.S. Office of Long COVID Research and Practice, an office under the Department of Health and Human Services, has named the first director, Dr. Ian Simon. The office's goal is to coordinate Long COVID efforts across the federal government.

- On January 18th, the Senate Committee on Health, Education, Labor, & Pensions (HELP) held a hearing about Long Covid. They discussed research priorities and healthcare challenges for the disease. Scientists and patients with Long COVID spoke at the hearing. [University of New Mexico had an informative post](#) about the hearing.

- [New data published in Nature](#) indicates that risk for COVID transmission increases linearly by 1% chance per hour. Longer interactions are going to increase risks. This is helpful information when considering risks and what decisions you want to make for your own health.

- [STAT News](#) did a nice job covering research that came out in *Science* which reports that Long COVID patients have noticeable differences in blood proteins compared to the control group. While we don't have treatments for this yet, it could lead to targeted therapies and diagnostic testing tools. This will be interesting information to keep informed on.

Team Member Spotlight

Jaclyn French, LICSW, our team social worker and all around staff all-star!

Jackie has been working in the hospital for seven years in a variety of roles. She first got involved in COVID-related work when the inpatient unit where she worked transformed into a COVID ICU. She has been involved with the COVID Collaborative since its inception, and provides both individual and group support to clinic patients. Jackie's work focuses on exploring the impact of Long COVID Illness on each person's life and identity, with particular attention to mental health.



[Click here to check out an article on WCVB5](#) where Jackie and some Long COVID patients reflect on experiences with the condition.

Long COVID Resources

New(ish): [The Sick Times](#) is a journalist-founded website chronicling the Long Covid crisis. With a website and weekly [newsletter](#), this is a good resource to follow the information that's coming out about Long COVID. One of the founders was highlighted on a recent [podcast](#).

The Body Politic Support Group has created a new research group. [Patient-Led Research Collaborative](#) has ongoing advocacy and research that you can learn more about on their website.

DID YOU KNOW?

The Sadhguru Center offers a free holistic program for COVID long-haulers that teaches evidence-based yogic breathing and meditative practices to support their recovery from both physical and mental symptoms?
Click [HERE](#) for more

Patient Voice

Welcome to a new section of the newsletter where we aim to share patient voices and highlight people who are also experiencing Long COVID. Want to be featured in a future edition? [Email the Newsletter](#) to identify your interest and share your story!

Wellness Corner

This edition's Wellness Corner comes from Vasundhara Prudhivi, Tulsi Chase, and the Sadhguru Center, who share some Dos and Don'ts rooted in the core yogic elements for health with an understanding of Long COVID. [Click here for a PDF of the recommendations](#) or see the image below:

	Do	Avoid
Stay Hydrated Proper hydration is essential for overall health and can help alleviate symptoms such as headaches and fatigue.	Drink plenty of water throughout the day and incorporate food with high water content such as fresh fruits and vegetables. In colder winter months, incorporate cooked food items with higher water content, such as curries and soups.	Food items that can easily dehydrate the body (such as food with high sugar content and caffeine).
Balanced Nutrition Nutrient-dense foods can support your immune system and help with energy levels.	Consume a <u>balanced</u> diet rich in fruits, vegetables, lean proteins, and whole grains. Incorporate more raw fruits, nuts and vegetables into your diet – these can quickly boost energy levels.	Eating heavily processed food items.
Gentle Exercise Gentle physical activity can help improve circulation, reduce stress, and boost mood without overtaxing your body.	Engage in gentle exercises such as walking, yoga, or tai chi, as tolerated. Try to do these activities outdoors to the extent possible and weather permitting – fresh air can further help with reducing stress and elevating mood.	Sitting for long hours (especially at work) without any breaks to stretch the body.
Breathing Techniques Chronic stress can worsen symptoms, so finding effective coping mechanisms is crucial.	Practice stress-reducing techniques such as alternate nostril breathing, deep breathing and meditation. You can access a safe and free breathing technique at this link . This can be practiced for 5-10 minutes each day.	
Ventilation Studies have shown that high CO2 levels in indoor spaces can increase dullness and reduced cognitive function.	Regularly ventilate your indoor spaces by opening windows for a few minutes each day, especially in the colder months. Get fresh air by spending time outside.	Staying indoors without access to fresh air for long periods of time.

Beth Israel Deaconess Medical Center
Division of Pulmonary, Critical Care and Sleep Medicine
330 Brookline Avenue, Boston, MA 02215

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

Beth Israel Deaconess
Medical Center



HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL

Share this email:



[Manage](#) your preferences | [Opt out](#) using TrueRemove®

Got this as a forward? [Sign up](#) to receive our future emails.

View this email [online](#).

330 Brookline Ave
Boston, MA | 02445 United States

This email was sent to .

To continue receiving our emails, add us to your address book.

emma®

[Subscribe](#) to our email list.