

Fall 2023

Welcome!

Dear Members of the BIDMC Long COVID Community,

Welcome to the second edition of our Long COVID Newsletter!

We got some really good feedback that we are working to implement and make sure that we are sharing relevant and informative information.

We always love to hear from you - about things you like, or with productive criticism! Specifically, we would be interested in hearing from you if you would like to share some of your reflections for inclusion in the new *Patient Voices* section of the newsletter.

Sincerely,

Jason Maley, MD, and Amberly Ticotsky, RN

COVID-19 and Critical Illness Survivorship Program

BIDMC COVID-19 Survivorship Program

In our previous edition, we inadvertently forgot to mention a very important part of the team - Dr. Robert Thomas and the Sleep Medicine Division. Sleep disturbances can impact cognitive and physical health and we know there is a good deal of correlation between sleep and Long COVID. Dr. Thomas and his colleagues focus on this connection and work with patients to help improve sleep and in turn, overall health.

Dr. Thomas and the Sleep Medicine team are leading ongoing research on the impact of sleep related to Long COVID. In May 2023, [an abstract was published on this topic](#).

Sleep Medicine is doing important work in Long COVID research and our Long COVID collaborative is infinitely better due to their efforts. Thank you, Dr. Thomas, for all of your work in this area and beyond.

Long COVID Research at BIDMC

There are several studies currently recruiting patients at BIDMC looking at the impact of COVID-19 on the heart and the connection between sleep and pain as part of Long COVID. Beginning this fall, BIDMC will also be a site for RECOVER treatment trials for Long COVID. We plan on providing more information as details become available in the near future.



To find out about research happening around you, visit our [research website](#). The following research studies are currently being conducted at BIDMC. Please reach out to if you are interested in learning more about participating:

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

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.

New study that is looking for 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

Transitions



Similar to life, change within our collaborative is inevitable. This year, we are anticipating saying goodbye to several colleagues within our team as they move away, retire from practice, or take on alternate roles within and outside of BIDMC. We're also thinking about what Long COVID looks like, what is most helpful for patients, and what we want this work to look like moving ahead. Expect to hear about some changes, adjustments, and some realignment as these transitions occur - we are even planning some updates to the website. We remain thankful for BIDMC's ongoing

commitment to putting patients first.

If you have found that the provider that was recommended to you is no longer at BIDMC, please message Amberly at SurvivorshipProgram@bidmc.harvard.edu, who will put you on a list of people to inform once a new provider has been identified/hired.

Team Member Spotlight

Our Physical Therapy Team has been leveraging work from before the pandemic with Post Exertional Malaise and Chronic Fatigue Syndrome to create a Long COVID framework, which has helped many patients. We currently have four PT members on the Long COVID collaborative.

John Schery, PT, CCS, CSCS, has been a physical therapist for more than 20 years including 15+ years specializing in cardiopulmonary conditions ranging from the ICU to outpatient clinic. He is a board-certified clinical specialist in cardiovascular and pulmonary physical therapy with the majority of his career spent in cardiovascular surgery, cardiac rehab, and pulmonary rehab. In early 2020, John began treating patients with acute COVID-19 shortly after they were disconnected from mechanical ventilation. He is an original member of BIDMC's Critical Illness and COVID-19 Survivorship Program and has been treating patients with Long COVID symptoms since Fall 2020.



Long COVID Resources

Yale has a Long COVID study called LISTEN. As a part of this program, they offer regular 'town hall' meetings around Long COVID and have made all the recordings available on YouTube. You can find them here: [Hugo Health - YouTube](#)



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? [Email the Newsletter](#) to identify your interest!

Huge shout out to Jen Hohl for going first and being so vulnerable. Hope you are as inspired as we are. Thank you, Jen for your beautiful words!

Lessons Learned from Long COVID

In 2017, I found the joy of exercise and started competing in obstacle course races. It quickly became a passion of mine and drove me to challenge myself

to do things I never would've imagined I was capable of. During the start of COVID in 2020, obviously there were no events which was upsetting, but I kept up with my training. Then in December of 2020, I contracted COVID and it all went downhill from there. Instead of running multiple miles on my treadmill, I would have to crawl to get from my bed



to the bathroom as I literally couldn't walk on my legs. I would have to take a break at the landing from walking up or down five stairs as I couldn't breathe. Some doctors told me that I needed to grieve my previous life and accept my new one and its limitations. That was not acceptable to me. I found a great group that was supportive of my recovery, that gave me solutions to manage my symptoms, and actually encouraged me to get better. Since then, there have been a lot of ups and downs and I have learned a lot along the way.

I learned that there has to be some acceptance of living with Long COVID, but not in its permanency. I have learned that if my symptoms flare up, that is my body's way of telling me to slow down and do things a little differently. I don't have to stop everything altogether, but figure out a better way so that my body and brain don't feel as threatened. It actually has been a good lesson that can be applied more holistically. It is easy to get caught up and overwhelmed with the fullness of life, but it is crucial to take care of ourselves along the way to prevent illness, injury, or negative outcomes. Living with Long COVID is a constant reminder to take care of myself. And even when I do not necessarily think I am doing too much, I might be, and I need to take a step back and address it. I learned I have to give myself grace. I am living with something that is not yet researched or fully understood. I cannot compare myself to others, or even to myself before COVID. This is my journey, my health, my comfort, my life. I am able to do what I want to, maybe not to the extent or everything all at once, but I am still blessed with the life I have. Yes, I may be more limited than I want to be, but as long as I am always moving forward, I am okay.

Want to connect? Jen would love to see you over on Facebook:

<https://www.facebook.com/jen.hohl/>

Wellness Corner

This edition's Wellness Corner comes from Hope McCarrick, OT, who shares some different ways of addressing cognitive fatigue:

- Focus on energy conservation through pacing (take breaks through tasks, ideally before you start to feel tired - try to build in 'rest breaks').
- Do not rush yourself with tasks; pushing through fatigue can often make long haulers feel worse with a longer recovery time.
- Try to do demanding tasks earlier in the day or week.

- Reduce external stimuli to the extent that you can (noise-cancelling headphones, sunglasses, etc).
- Write everything down, and keep a notebook with you or use the notes app accessible on your phone.
- Use deep breathing and grounding techniques to reduce your stress. These can be used during your built-in 'rest breaks' during tasks. One useful app is **Breathe+**, linked [here](#).
- Prioritize good sleep hygiene. One way to do this is to create a sleep routine, with limited screentime and caffeine before bed, and try to do the same activities each night before bed to train your body to wind down. You can also use sleep aids like eye masks, noise machines, and blackout curtains to improve sleep quality.

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
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