

# LONG COVID News

Beth Israel Lahey Health   
Beth Israel Deaconess  
Medical Center

A publication from the **CRITICAL ILLNESS AND COVID-19 SURVIVORSHIP PROGRAM**



---

**April 2026**

---

**Hello BIDMC Long COVID Community,**

Since our last newsletter in November, the Long COVID landscape has continued to evolve—oftentimes in quiet, incremental ways that are easy to miss, especially for those living the day-to-day reality of this condition. As we move into April and see the early signs of spring, this edition centers on something that can feel complicated but essential: hope.

Hope, in the context of Long COVID, is not about quick fixes or guarantees. It's not about minimizing the challenges or suggesting that recovery follows a predictable path. Instead, it's grounded in progress, however gradual, and in the growing recognition that Long COVID is real, multifaceted, and deserving of sustained attention and care.

In this issue, we'll explore where that sense of hope is emerging—from new scientific insights to personal stories. Whether you are navigating Long COVID yourself, caring for someone who is, or working to better understand it, we hope this edition offers both useful information and a reminder that progress is happening, even when it feels slow.

Thank you for staying connected with us,

**Amberly Ticotsky, RN**

## **International Long COVID Awareness Day**

International Long COVID Awareness Day, observed annually on March 15, was an important moment to recognize the millions of people worldwide living with persistent symptoms after COVID-19 infection. This day serves as an ongoing reminder of the need for continued research, compassionate care, and public awareness. Supporting those affected means listening to their experiences, advocating for better treatment options, and acknowledging that recovery is not always linear.

Our sincere thanks to everyone who was able to join our Long COVID awareness education sessions. Your participation helped foster meaningful conversation, deepen

understanding, and strengthen our shared commitment to supporting those affected.

It is encouraging to see that the U.S. Department of Health & Human Services has refreshed its Long COVID resource webpage. It's a helpful, user-friendly source of information for patients, caregivers, and providers. We encourage you to [explore the updated site here](#).

## Finding Hope - Patient Perspective

*Written by a patient and member of our COVID-19 Survivorship community. Shared with permission.*

When I was asked to write about hope and finding hope, I wasn't sure that I was the right person for this because I have lost hope many times over these past six-plus years—especially when we were all trying to survive the COVID pandemic and then dealing with and living with Long COVID. And to be honest, if I had been asked to do this at any other time before now, I don't think that I would've been able to offer any words of hope because I myself didn't have a lot of hope.

So, what is hope? According to [Merriam-Webster's online dictionary](#), some of the definitions of hope include:

- (v): to cherish a desire with anticipation; to want something to happen or be true
- (n): desire accompanied by expectation of obtaining what is desired or belief that it is obtainable

I think that those are very positive and aspirational definitions. But when you think of what hope means from a Long COVID perspective, I think that it's a bit more complicated and nuanced.

I think that having hope, just like dealing with loss and grief, does not always happen in a straightforward way. When you are feeling your worst and you are at your lowest, it is difficult or almost impossible to find hope. Or when you are just trying to make it through each day and your body is betraying you, it's tough to have hope. Or when it takes all of your energy to do things that were so easy before you got sick, it's hard to have hope. Or when you see a specialist after months (or even years) and then you are gaslit by them, it is easy to lose hope. Or when you finally start to feel a little bit better, but then you have a setback, or a crash, or your baseline is lowered, it is really hard to have hope after that.

It is hard to remain hopeful when you know that any progress that you have made can be lost in an instant. It is easy to lose hope when not only our bodies are falling apart, but everything around us is also falling apart. It doesn't feel fair when it seems like everyone else in the world has moved on and you see others living their best lives, but you have been left behind and are stuck living with this nightmare that is Long COVID. I could go on and on, but I think that many of you already understand how hard it is to have hope or remain hopeful when you are living with Long COVID.

I am fairly certain that none of us ever wanted to get Long COVID, but since we all did, we now have to try and live with it, but we also have to continue to hope that we will get better

and we can't give up that hope. Hope for better health for yourself and for others. Hope for healing. Hope to return to some semblance of ourselves and our lives. Hope for a better future. I know that you already know this, but living with Long COVID is absolutely awful, full stop. And you are not alone—even though it feels like it at times. Once you get Long COVID, you automatically became part of this 'club' that includes millions of people from around the world that are also dealing with and living with Long COVID—even though none of us ever asked for or wanted to be a part of this 'club.' (I wish that we could cancel our 'membership' to this club and get a full refund for our health back!) Yes, it is tough and it can often feel impossible most days to keep going, but please don't give up! You are still here and we are so glad that you are! And I know that it doesn't always feel like it, but you are very strong—especially because it takes everything that we have to try and get through each and every day! While we all have had to mourn the loss of who we once were and try to accept the fact that we are forever changed, we can still hope that we will get better, that we will get back to some semblance of who we once were, and that we can keep the best parts of who we once were. All of us can hope that instead of just surviving each day, that we actually will get to live our best and fullest lives, thriving each and every day.

We can also hold onto hope because there are still good people out there that want to help, are willing to help, and are helping in whatever way they can. We may or may not know them, but there are people from all over the country and around the world who are dedicated to finding new treatments and interventions that will hopefully help us feel better and get better. There are researchers, scientists, medical professionals, etc., that really do care and want to help. There are a lot of exciting and promising research studies that have been happening and will be happening over these next few years. There are also patient-led groups that can also provide us with support and hope. And then there is each of us, and whether we know it or not, we are also helping, whether it is by seeing specialists and providing important information about our symptoms, by participating in a research study, by being part of a support group, by sharing what has or hasn't worked for us, etc. And we need to continue to ask for help from whatever supports are available—whether it is asking for help from your family (or your chosen family), your friends, your caregiver(s), whoever is part of your community or support network, and/or anyone in your life who is willing to step up and help you when you feel like you just can't and/or don't have the energy. So, there is still hope even when it doesn't always feel that way.

We are all acutely aware of how quickly our lives, and especially our health, can completely change in a split second and how difficult it is to have hope during those times. As I mentioned previously, I have lost hope a lot over these past six-plus years and I know that I could lose hope again. But if/when that happens, I will make sure to not only ask for help from others, but I will also ask them to have hope on my behalf until I can have hope once again.

I'd like to end with what the word hope means *for me* when it comes to dealing with and living with Long COVID:

**H** - Helping and Healing

**O** - Ourselves while

**P** - Persevering

**E** - Each and Every day

Please hang in there, take care of yourselves, and I truly hope for better health and better days ahead for all of us!

*Written by a patient and member of our COVID-19 Survivorship community. Shared with permission.*

## Research Update

A recent [article](#) by Beth Israel Deaconess Medical Center researchers, published in *Nature Immunology*, offers encouraging insights into the biology of Long COVID. Researchers found clear evidence that ongoing symptoms are linked to measurable changes in the immune system—particularly persistent inflammation and immune dysregulation months after infection. While these findings help explain why recovery can be prolonged, they also point to something hopeful: the mechanisms behind Long COVID are becoming increasingly understood through studies like these, and with that understanding comes clearer pathways toward targeted treatments and more effective care.

---

**Read the full article:** [Long COVID involves activation of proinflammatory and immune exhaustion pathways](#)

---

## Long COVID Research at BIDMC

BIDMC continues to support research studies looking at the impact of Long COVID.



### Mind-Body Study

- Evaluating a mind-body approach to reduce symptoms and improve your quality of life.
- The study is conducted entirely virtually. Click [here](#) for more information.

---

### NIH RECOVER Clinical Trials

- BIDMC is not currently enrolled in any active NIH studies. However, we have submitted applications for upcoming studies. Stay tuned for more information as it becomes available.

- More information on the RECOVER clinical trials and the work they are doing to study Long COVID can be found [here](#).

---

Other studies have concluded enrollment and are currently in the data analysis phase! This is good news and we should have more information by this fall! We will share updates in future communications.

---

To find out about additional research happening around you, visit our [research website](#). You can check out this [slide deck](#) with information about different studies and considerations when searching for research studies to be a part of.

## Ongoing Opportunities

### Caregiver Support Group

In collaboration with the Brigham and Women's COVID Recovery Team, we are happy to continue to offer a monthly Long COVID Support Group for the important people in your life. Please ask your loved ones to RSVP and receive the meeting link by emailing Jackie French at [jfrench2@bidmc.harvard.edu](mailto:jfrench2@bidmc.harvard.edu).

---

### Breathing Better: Online Wellness Program

[The Sadhguru Center for a Conscious Planet](#) continues to offer workshops intended to support patients with Long COVID in their physical and mental wellness, through yogic breathing and meditation practices. The workshops are completely online. Email the team at [sadhgurucenter\\_programs@bidmc.harvard.edu](mailto:sadhgurucenter_programs@bidmc.harvard.edu) for more information or to schedule a session.

---

### Need Help Navigating Long COVID?

Get on the Long COVID Survivorship waitlist by calling the Pulmonology Office at **617-667-5864**. Be sure to set up your [MyBILH Chart](#) account so that Amberly, our program RN, can contact you with the initial intake email and follow up with you about your symptoms.

**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](#)

