



COVID-19 **LONGHAULER**
ADVOCACY
PROJECT



November 2025 Newsletter

Fulfilling C19LAP's Mission

Advocacy, Education, Cross-Sector Collaboration, Research, Resource Development, & Peer Support

Educating Public Health Partners

The COVID-19 Longhailer Advocacy Project (C19LAP) was proud to attend and present at APHA 2025, the largest public health conference in the country, hosted by the American Public Health Association. This year, we had the opportunity not only to present three official sessions but also to exhibit on the main floor, engaging directly with public health professionals across sectors.

Our presence was powerful and deeply felt: from medical students and academic institutions, to Departments of Health, hospital systems, clinicians, and researchers, all of whom shape and serve the general public. Like last year, every person we spoke to knew someone with Long COVID, and many shared their own lived experiences. Through these conversations, and by distributing over 1,000 high-quality N95 masks, we helped elevate awareness, equip frontline professionals, and advocate for systemic change. We look forward to the collaborations discussed with others soon!

C19LAP Featured Sessions:

- Mobilizing state, local, and territorial health departments to confront Long COVID amid the public health consequences of federal abandonment and the erasure of programs serving tens of millions. (*Section: Community Resilience and Response: Strengthening Public Health Systems Through Preparedness, Advocacy, and Recovery*)
- Clinical and public health implications of the NASEM Long COVID definition and its role in standardizing care – a roadmap to long covid assessment, diagnosis, documentation, care management, and support. (*Section: Innovations in Training and Education for Challenging Clinical Conditions and Scenarios (organized by HCWG)*)
- Patient-led partnership models for rebuilding public health trust: lessons from Long COVID patient-driven advocacy and the COVID-19 pandemic (*Section: Science, Justice and Health Equity*)



Videos: [Day 1](#), [Day 2](#), [Day 3](#), [Day 4](#)



Advocating for Urgent & Scaled Action on Long COVID



The COVID-19 Longhailer Advocacy Project made it a priority to ensure that Long COVID was not only represented inside the convention halls, but across the heart of the nation's capital. Our team took to the streets with urgency and purpose, visiting key sites including the Department of Health and Human Services, the U.S. Capitol, and the White House.

At every stop, we elevated the same clear, direct message:

"Long COVID is a public health crisis impacting millions across the United States. The absence of approved treatments, standardized care guidelines, coordinated public education, and a national response leaves millions behind. We urgently need a cross-sector, federally coordinated response."

We engaged with people everywhere we went from passersby, workers, community members, and countless others who make up the fabric of our nation's capital. Whether grabbing a meal or walking between sessions, we carried the message of Long COVID with us, making it visible in everyday conversations, in places where it's too often overlooked.



For five years, the Long COVID community has fought to be seen, heard, and resourced to confront this complex and disabling condition. Many of the programs that emerged were the direct result of tireless, patient-led advocacy. Yet despite these efforts, nearly all federal initiatives have now been dismantled. Once again, the responsibility of advancing solutions has fallen on those most impacted - the individuals who are chronically ill and under-resourced.



This federal abandonment has stalled critical progress. Tens of millions remain without access to treatments, coordinated care, or national guidance, worsening over time, and in too many cases, dying. The gutting of these programs has harmed our community and shattered the hope, optimism, and trust patients had fought to sustain.

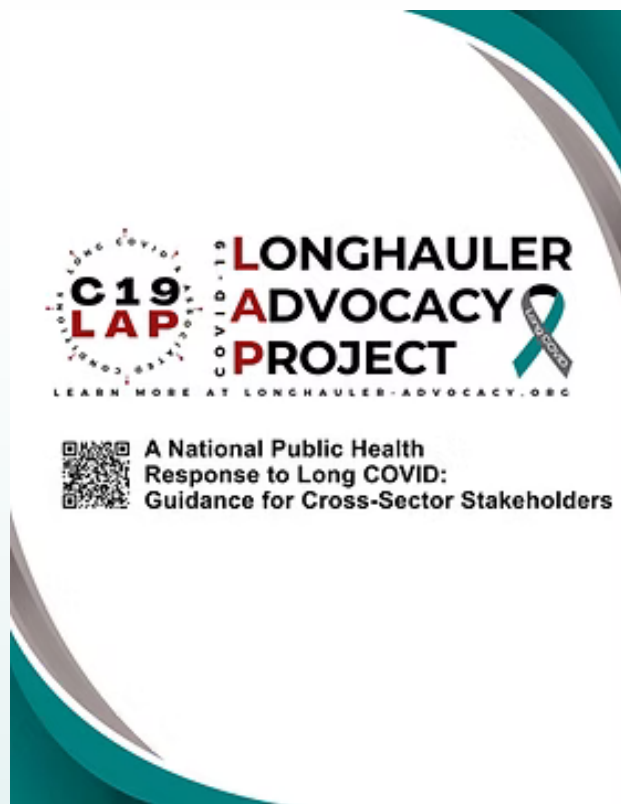
Recently, HHS Secretary Kennedy convened a Long COVID roundtable to introduce plans for a Long COVID Consortium. The event brought together U.S. Senators Roger Marshall and Todd Young, Congressman Jack Bergman, and key health officials, including Dr. Jay Bhattacharya and Dr. Marty Makary.



We are especially grateful to the Office of U.S. Senator Roger Marshall, with whom we met to elevate the needs and priorities of the Long COVID community. Our discussion focused on partnering with patients as essential stakeholders; expanding public and clinician education; strengthening research, documentation, and resource allocation; and improving surge response systems.

We look forward to continuing these critical conversations, fostering bipartisan collaboration, and advancing real, impactful solutions to this public health crisis. **Please help elevate the urgent need to address Long COVID and the importance of C19LAP's inclusion by contacting your members of Congress today!**

Developing Resources & Roadmaps for Cross-Sector Prevention & Response to Long COVID



Long COVID is a national public-health crisis affecting an estimated 70 million Americans, roughly 20% of those infected, with risk increasing after each reinfection. It impacts all ages, and among children, more than 80% report limitations in daily functioning. Long COVID has now surpassed asthma as the leading chronic illness among U.S. youth. The result is a generational health crisis.

The consequences are profound: U.S. disability rates have risen 20% since 2020, mirroring Long COVID prevalence. Only 15% of clinicians feel prepared to identify it, leaving millions undiagnosed and unsupported. The annual economic cost reaches into the hundreds of billions in healthcare spending, lost income, and reduced productivity, threatening workforce stability and national economic health.

National momentum is growing and bipartisan. Leaders, including HHS Secretary Kennedy, Senators Todd Young and Roger Marshall, and Congressman Jack Bergman, have signaled renewed support for

coordinated Long COVID action, creating a rare window for unified, cross-party progress. The urgency is clear: every day of inaction compounds the human and economic toll. Reinfections continue to drive new cases, and systems built for acute COVID-19 cannot meet the scale of long-term impacts. We cannot wait for federal solutions — state, local, and cross-sector partners must mobilize now.



C19LAP has launched this [Long COVID Public Health Resources page](#) to better guide and educate cross-sector stakeholders and public health partners. In the absence of guidance elsewhere, C19LAP has stepped up to the plate to be the leading source for Long COVID education and strategic planning.



In addition to this page, we have just launched a new guide “[A National Public Health Response to Long COVID: Guidance for Cross-Sector Stakeholders](#).”

These resources outline our model for restoring trust in public health by centering lived experience, transparency, and cross-sector collaboration. It highlights Long COVID as a mass-disabling event affecting an estimated 70 million Americans, with rising disability, unprepared clinicians, and major economic impact. Children are significantly affected, reinfections continue to drive new cases, and while bipartisan momentum is emerging federally, immediate mobilization at state and local levels is essential. Several resources are included such as existing publications, public-health guidance, infographics, and C19LAP’s Comprehensive Guide to Long COVID, all supporting coordinated, evidence-based action and roadmaps. The page underscores the essential role of patients and caregivers in shaping effective responses, showing how outcomes improve when lived experience guides decisions.

C19LAP invites partners to collaborate, recommend our involvement, and support efforts to sustain and scale national Long COVID advocacy, education, and public-health coordination. We ask that you help connect us with your local department of health by sharing this resource and our contact information with them, so we can collaboratively work together to serve our community nationwide. Thank you.

Developing Resources to Fill Public Health Communications Gaps

Now in its second volume (first published in 2021), C19LAP's Comprehensive Guide to Long COVID is the most complete, patient-developed resource for cross-sector stakeholders, patients and caregivers, clinicians, researchers, public-health officials, payers, employers, schools, and community leaders, built on five years of frontline, patient-led work. What sets this guide apart is its end-to-end usability (from bedside to policy), the credibility of lived experience paired with clinical rigor, and a cross-sector design that turns education into operations: documentation drives data, data informs policy, and policy allocates resources. Education is the hub of this entire cycle; without accurate, shared learning, care pathways stall, data quality erodes, and policy fails to meet need.

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About Covid-19 Longhailer Advocacy Project: External contributors, purpose of the guide, disclaimers, and how to support C19LAP.

Chapter 1: COVID-19 Prevention & Acute COVID-19 Testing, Treatment, & Documentation: What COVID-19 is, why it remains a major concern, pandemic/Long COVID timeline and data, preventing Long COVID, assessing current data, estimating who may develop Long COVID, potential population size, testing FAQs, helpful acute measures, infection plan, science-driven isolation.

Chapter 2: Introduction to Long COVID: What Long COVID is, 2024 NASEM definition and highlights, adoption recommendation, how people get Long COVID, where/why infection occurs, who can develop it, prevalence estimates, potential causes, systemic/chronic/complex nature, impacts, consensus research and cost studies, government actions and sites, credible patient-led organizations.

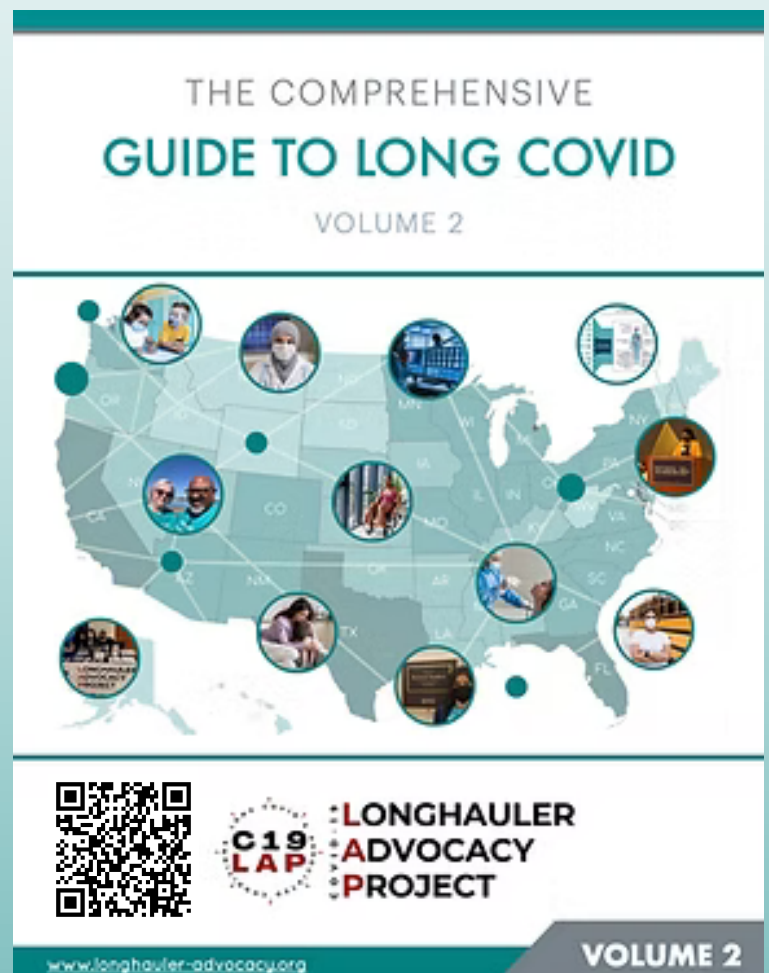
Chapter 3: Long COVID's Symptoms, Associated Conditions, Labs, Tests, & Specialists: Needed clinicians, potential tests and procedures, relevant labs, common associated conditions.

Chapter 4: Intersectionality with Infection-Associated Chronic Conditions & Disability: History of infection-associated conditions, disability intersections and implications.

Chapter 5: Identifying Long COVID & Preparing for Medical Appointments: Acute presentation, recognizing Long COVID, guidance for patients and caregivers, preparing for visits, creating a medical log.

Chapter 6: Locate Long COVID Care, Research, and Support: Finding clinical care, locating research opportunities, accessing support.

Chapter 7: Advocating for Yourself in the Face of Ableism and Gaslighting: What gaslighting is, why people gaslight.



Chapter 8: Navigating the Challenges of Chronic Conditions and Disability: Recognizing impacts, coping strategies, maintaining independence, finding supportive clinicians, managing finances, adaptation, relationships, COVID-19 and Long COVID bereavement, understanding grief and related challenges, community and societal support.

Chapter 9: Applying for Accommodations, Disability, & Support Services: Work accommodations, school accommodations, preparing applications, SSDI/SSI, workers' compensation, short- and long-term disability, FMLA.

Chapter 10: Engaging in Research, Awareness, & Educational Opportunities: Why research matters, finding and enrolling, considerations before enrolling, and what good patient engagement looks like.

Chapter 11: Introduction to Policy & Your Role in Helping Shape and Guiding It: Key terminology, who passes policy, how policy moves, timelines, contacting Congress, telling your story, engaging state/local officials and governors, contacting health departments and city officials.

Chapter 12: Long COVID Community Priorities & Needs: COVID-19 priorities, Long COVID priorities, C19LAP funding requests (Spring 2024, subject to change).

Chapter 13: The Role of Clinicians & Researchers in Long COVID Patient Outcomes: Patient-centered whole-person care, accurate and consistent documentation, gaps in care and research, meaningful patient engagement, advancing understaffed fields, and convening for education.

Chapter 14: Care Coordination & C19LAP Patient-Developed Long COVID Model of Care: What care coordination is, what it involves, benefits, example conditions and symptoms, needed clinicians, potential tests and procedures, C19LAP CLCC3 model of care, overall benefits.

Chapter 15: How the Government Can Help Address Long COVID: COVID-19 mitigation, partnering with patient organizations, research funding and coordination, public-health campaign funding and distribution, clinician education, care coordination and infrastructure, support and economic programs, national/international coordination, legislation and policy.

Chapter 16: Mini Guides, Advice, Logs, & Quick Links: C19LAP chapters/socials/support, quick resource links, myth-versus-fact guidance, community advice.

Common Long COVID Terminology and Acronyms: Organizations and agencies, NIH overview, bills and acts introduced in Congress, acronyms, definitions.

References: Reference list.

Leading COVID-19 & Long COVID Resources

C19LAP Long COVID Public Health Resources Page



This new resource page is designed to be a one-stop shop for cross-sector stakeholders in the Long COVID and public health space. We recommend sharing this resource broadly among your peers and departments of health.

A National Public Health Response to Long COVID: Guidance for Cross-Sector Stakeholders



This resource provides in-depth education, guidance, and roadmaps for public health officials and cross-sector stakeholders to address Long COVID. We recommend sharing this resource broadly amongst your peers and state and local health departments.

Comprehensive Guide to Long COVID



This guide discusses prevention, testing, treatment, documentation, symptom recognition, specialist care, accommodations, chronic-illness navigation, community support, research participation, advocacy, and more.

2024 N.A.S.E.M. Long COVID Definition



The National Academies of Sciences, Engineering, and Medicine's definition of Long COVID, and accompanying report, has been adopted by HHS for use. The purposes of this definition is to unify efforts, develop education, improve research, and improve public messaging.

Pandemic Mitigation Collaborative Dashboard



The Pandemic Mitigation Collaborative (PMC) COVID-19 Data Dashboard is an interactive, up-to-date resource tracking transmission and mitigation trends across U.S. states, regions, and select international locations. It is designed to support multi-layered risk reduction.

C19LAP Community Chapters



C19LAP includes more than 60 chapters across every U.S. state and territory, along with community-based chapters such as Pediatrics, Caregivers, and others. They offer a trusted space to connect with others, access vetted local resources, and organize collective action to drive meaningful change.

Please utilize and help disseminate these resources.

Community Spotlight



Matthew, IL, March 2020 Infection

Matthew is a former hospital housekeeper who worked in the emergency room and enjoyed an active life full of concerts, sporting events, and connections until Long COVID turned everything upside down.

Since becoming ill, everyday activities have become unpredictable. "I have to take things day by day. I can't plan anything in advance because I never know how I'll feel. The hardest part is that some of my own family members still don't believe I have Long COVID."

Despite these challenges, Matthew is speaking out. He has met with U.S. Senator Tammy Duckworth and Congresswoman Jan Schakowsky to share his journey and call for Congressional action on Long COVID. He urges lawmakers to 1. Fund research and treatments, 2. Create financial support for those unable to work 3. Expand access to specialized care, especially outside major cities 4. Recognize Long COVID as a disability, 5. Improve public education, medical training, and cross-agency coordination, and 6. support mental health and community support programs.

Matthew's Message: "We need hope, resources, and recognition, and we need Congress to act. Long COVID is a mass disabling event, and too many of us are being left behind."



Mindy, WA, November 2020 Infection

Mindy is a longtime, dedicated advocate whose work began well before the COVID-19 pandemic. She is one of many individuals with Long COVID who have developed additional, complex health conditions as a result of their infection, complications like POTS, neuropathy, asthma, and mental health challenges induced by the lack of adequate care and support.

Despite receiving multiple diagnoses early in her illness and trying a range of treatments, Mindy continues to face significant daily challenges. The most difficult part, she shares, is the profound sense of isolation and the burden of navigating fragmented care without coordination between providers.

"No one really understands what I'm living with, so they can't really relate," she says. "I found C19LAP, which provided a sense of community, belonging, and advocacy tools." Since then, Mindy has become a tireless voice for Long COVID. Over the last five years, she has given numerous interviews, written articles for Long COVID Awareness Day, and represented C19LAP at the American Public Health Association (APHA) conferences for the last two years. Mindy regularly contacts her state legislators and plans to meet with her local public health department to raise awareness in her community, including launching an annual Long COVID Awareness Day event. She works remotely with accommodations and offers support to others navigating the process.

Mindy's Message: "We are still here and still suffering. We need visibility, coordinated care, and action from our communities and public health systems."



Jobi, WA, January 2021 Infection

Jobi's life changed dramatically after contracting COVID-19 in early 2021. Since then, she has endured a long list of symptoms and conditions, some of which include the development of a brain tumor. "The hardest part for me is that I am no longer who I used to be," Jobi shares. "My family life has suffered, I can no longer work, and I feel like a shell of the person I was."

Despite the severity of her condition, Jobi remains a strong and vocal advocate for the Long COVID community. "I want people to know that I have always been a strong woman. I never felt like there was much I couldn't do

until COVID," she said. She credits the support of groups like C19LAP for helping her feel less alone and for equipping her with information. "It absolutely makes us feel like we are not alone with so many weird symptoms to battle." Jobi has spoken out in interviews with NPR, the Spokane Spokesman, and other media outlets, using every opportunity to raise awareness and push for action. She also recently participated in a Long COVID awareness campaign with the Seattle and King County/ Washington Public Health Department.

Jobi's Message: "The more media coverage we can generate, the longer we stay relevant as members of an ever-growing disabled community. Sharing information is vital to finding answers, treatments, and cures for the hundreds of symptoms we face."



Chris Covell, NY, July 2022 Infection

Two months after their acute COVID-19 infection, Chris lost their voice completely and began experiencing ongoing throat issues. Not long after, they developed gastrointestinal complications, muscle loss, and neuropathy in their legs and feet. Once extremely active and fit, working out with heavy weights five days a week, Chris now struggles to get through light activity without feeling winded, nauseous, or dizzy. In 2024, they were let go from a job they held for nine years after their employer refused to accommodate remote work, despite the position not requiring in-office presence.

The hardest part of living with Long COVID, Chris shares, is the loss of friendships and the painful realization that some people they once counted on have disappeared. Still, they've built meaningful new relationships within the chronic illness and Long COVID community and are grateful for the steadfast support of their husband, who continues to take precautions to protect Chris's health.

Following their job loss, Chris leaned into their creative talents and activism by launching an online shop focused on Long COVID, disability, and masking advocacy. They are a vocal advocate on TikTok, using both serious videos and comedic skits to deliver powerful messages. Chris also participates in digital performances with Productive Action Against COVID. Their goal across all platforms is to give voice to those quietly suffering and isolated due to illness or mitigation strategies. By turning their activism into wearable art, Chris believes even small messages worn on a shirt can spark awareness and challenge misconceptions. Although their advocacy has come at a cost, including lost friendships, Chris remains proud of their work and determined to keep speaking out until real change is achieved.

Chris's Message: "Too many people are dying and suffering. I will never stop talking about it until something is done to change the tide."



Interested in being in the spotlight? [Submit your story here!](#)

In Memoriam



Alice Wong, Disability Justice Leader

The COVID-19 Longhailer Advocacy Project (C19LAP) mourns the passing of Alice Wong, a visionary disability justice leader whose work fundamentally reshaped the landscape of disability rights, public health, and patient advocacy. Through the Disability Visibility Project, which she founded in 2014, Alice built one of the most influential platforms for disabled storytellers of our time, insisting that disabled lives, culture, and history be preserved, amplified, and centered. Her belief that “storytelling is a powerful form of resistance” fueled a decade of transformative work: uplifting thousands of disabled voices through StoryCorps collaborations, publishing ground-

breaking anthologies, including *Disability Visibility* and *Disability Intimacy*, and expanding the public’s understanding of disability through her memoir *Year of the Tiger*. Her forthcoming anthology, *Disability Vulnerability*, continues her legacy of documenting disabled life during the COVID-19 pandemic, including the stories of many in the Long COVID community whom she championed from the earliest days of the crisis.

Alice’s advocacy strengthened the Long COVID movement in critical and lasting ways. She spotlighted the experiences of people with Long COVID, especially people of color, through the Disability Visibility Project and funded the *Color of Long COVID* series in 2024, helping ensure that our community’s stories were told with accuracy, dignity, and power. Her activism, including campaigns like #PodSaveJon and her relentless push for accountability, helped shape national dialogue and contributed to broader public recognition of Long COVID as an urgent disability justice issue. C19LAP honors Alice Wong’s leadership, her solidarity, and her unwavering commitment to amplifying the communities most often pushed to the margins. Her work lives on in every advocate fighting for disabled futures, and in every story that refuses to be silenced. You can contribute to Alice’s legacy and help continue her work [here](#).

In Alice’s final message, she said, “You all, we all, deserve everything and more in such a hostile, ableist environment.” She went on to say, “I’m honored to be your ancestor and believe disabled oracles like us will light the way to the future. Don’t let the bastards grind you down. I love you all.”



Leslie Lee III, Person with Long COVID, critic, writer, host, and teacher.

The COVID-19 Longhailer Advocacy Project (C19LAP) mourns the loss of Leslie Lee III. Leslie’s voice shaped political and cultural conversations across podcasts, journalism, and broadcast media. Known for *Struggle Session*, *The Katie Halper Show*, and appearances with NPR, BBC, and others, Leslie brought depth, clarity, and compassion to every space he entered. After developing Long COVID in 2022, he spoke openly about the profound toll the disease took on his health, career, and daily life. His candor helped countless others feel seen, and he became a vital voice in exposing the reality of Long COVID and the systems failing disabled people. His work, humor, and

courage leaves a lasting imprint on this movement and on everyone who learned from him. You can support Leslie’s family [here](#).

Leslie’s final post reads, “Please start taking COVID seriously before more people have to suffer and die.”



Submit an in memoriam request [here](#).

Supporting C19LAP's Mission

**Donations Help Fulfill Our Mission.
Please Consider Supporting Our Work.**



The **COVID-19 Longhailer Advocacy Project (C19LAP)** is a grassroots, patient-led 501(c)(3) nonprofit organization founded in June 2020 to advance the understanding of Long COVID and expedite solutions and assistance to Longhailers and their families through advocacy, education, research, resource development, cross-sector collaboration, and peer support. C19LAP believes that education is the foundation of all meaningful progress in the Long COVID space. Our work prioritizes education and resource development, drawing on the collective lived experience of patients and caregivers, as well as deep cross-sector collaboration.

As federal programs continue to disappear, our role has become even more essential. We are actively working to bridge the growing gaps in action, address barriers faced by the community, and help shape new, more effective initiatives. Through consistent education, public engagement, and direct collaboration with researchers, public health officials, policymakers, and patients, C19LAP plays a central role in advancing solutions and informing the national Long COVID strategy. C19LAP is uniquely positioned to lead the future of Long COVID response as a trusted and credible resource across government, academic, and clinical sectors.

Without meaningful financial and volunteer support, C19LAP is at risk of discontinuation. As an entirely volunteer-led organization run by individuals living with Long COVID, our capacity is constrained by the very health challenges we fight to address. At a time when Long COVID, disability, and public health need greater support than ever, it is those most impacted who continue to lead the charge. But we cannot do it alone.

One in five people in the United States develops Long COVID. Since 2020, disability rates have climbed by 20 percent, and cancer diagnoses, amongst other debilitating conditions, are rising in the aftermath of COVID-19. Just 15 percent of clinicians feel equipped to diagnose Long COVID, which has now surpassed asthma as the most prevalent chronic condition in children, 80 percent of whom experience disruptions to daily life. With each reinfection, more individuals develop Long COVID, and its toll continues to grow. Members of our community are dying from the cumulative physical and mental health impacts. This crisis is not slowing down; it is intensifying.

We are prepared to launch a robust national strategy over the next five years, spanning both state and federal levels. Yet to move forward, we need your help.

Your support will help us continue bringing lived experience to the forefront, ensuring that patients remain at the center of policy, public health, and clinical response. Please consider making a donation and encouraging others, like friends, family, employers, and networks, to do the same. Together, we can scale the response and bring hope, recognition, and real solutions to the millions living with Long COVID. Thank you.

COVID-19 Longhailer Advocacy Project, Inc. (C19LAP)
501(c)(3) Nonprofit | FEIN 88-1861776
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<https://www.longhailer-advocacy.org> | contact@longhailer-advocacy.org

**We welcome
donations of all
amounts. Please
consider making a
recurring monthly
contribution.**



Fundraising Strategies

Monthly Giving

The COVID-19 Longhailer Advocacy Project (C19LAP) has been a leading national voice since 2020, working to ensure that people living with Long COVID are seen, supported, and represented across public health, research, and policy. To sustain and grow this work, we are calling on our community to help build predictable, recurring support. A monthly gift of just \$5, or \$60 a year, strengthens clinician and public education, state and federal policy advocacy, patient and family support, trusted resource development, rapid response efforts, and coordinated national and state networks. Our goal is to recruit 2,000 monthly supporters and create a stable funding base that ensures long-term continuity and program expansion. If C19LAP has helped you, informed you, or strengthened your advocacy in any way, joining our \$5 monthly donor circle is one of the most effective ways to support this mission.

Workplace Giving, Culture, and Employee Engagement

Workplace giving and employer-matching programs are among the most powerful ways to multiply support. Many companies match employee donations dollar-for-dollar or even two-to-one, turning a \$5 monthly gift into \$10 or \$15. Supporters can ask their HR department about matching options or payroll giving and designate the COVID-19 Longhailer Advocacy Project (EIN: 88-1861776). Employers can further strengthen Long COVID advocacy by hosting payroll-giving opportunities, workplace presentations, employee resource group fundraisers, and charity spotlights that encourage collective action across teams

Employee-driven fundraising creates additional pathways for sustained support. Disability, caregiver, public health, and science-focused employee resource groups can organize fundraisers or awareness drives, and some workplaces allow automatic payroll deductions to make recurring giving simple. Presentations on the impact of Long COVID in the workforce can also inspire company-sponsored donations or foundation grants.

Birthday Fundraisers and Community Storytelling

Supporters can transform their birthdays into moments of real impact by asking friends and family to contribute \$5 in their honor. Birthday fundraisers, on Facebook, for example, work exceptionally well because they are easy to share, personal, and accessible to everyone. Storytelling is another powerful tool that helps broaden our reach. When individuals share why they support C19LAP, how Long COVID has shaped their lives, and why community support matters, these messages resonate deeply and bring new donors into the movement.

Major Gifts

A major gift to C19LAP is an investment in expanding the capacity of the only national, fully patient-led organization with a detailed five-year strategy ready for implementation for the 70 million and growing people living with Long COVID in the United States. As federal initiatives close and funding disappears, the gaps in public health, research, clinician education, and patient support continue to widen, and progress has stalled. Meanwhile, death, worsening disease, and disability have not. Major gifts allow us to build the infrastructure needed to put our strategy into action. This includes hiring essential staff, strengthening national and state networks, expanding clinician and public education, growing policy and research partnerships, and creating the systems of care that patients have been denied for years. This level of support does more than sustain our work. It multiplies our reach, accelerates our impact, and fills the void left by collapsing public health programs. With your partnership, C19LAP can advance the solutions no one else is building and lead the national response that millions of people urgently need. If you would like to set up a meeting, please email contact@longhailer-advocacy.org.

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Volunteers Drive Our Work!

Join Our Team.

VOLUNTEER OPPORTUNITIES



State Lead/ Coordinator - Operations - Fundraising Committee

Let's collaborate for a better future.

The fight for Long COVID solutions, assistance, and prevention is far from over, and it cannot be won without you. Volunteers are the engine behind every milestone we reach. As a fully patient-led, volunteer-run organization, the COVID-19 Longhailer Advocacy Project (C19LAP) relies on the power of people like you to move forward meaningful change. From coordinating state-level advocacy to shaping national policy, educating clinicians, raising public awareness, and securing critical resources, our volunteers are leading the charge.

Your time, skills, and lived experience can directly impact the future of Long COVID response in the U.S. By stepping into a volunteer leadership role, you become a driving force behind a national strategy that centers patients, advances equity, and helps bring real solutions to tens of millions of people living with Long COVID and associated conditions.

Now is the moment. If you've been waiting for a way to get involved, to turn your frustration into impact, or to lend your talents to something bigger, this is it. We have several volunteer positions available, and each plays a vital role in advancing Long COVID solutions. Whether you're interested in leading a state chapter, contributing professional skills to national operations, or helping secure our continuity and futures, there's a place for you. By joining our team, you'll help shape a stronger, more informed, and more equitable Long COVID response, one rooted in lived experience and community leadership.

Review volunteer opportunities here!



State Lead/ Coordinator

<https://bit.ly/c19lapvol26sl>



Operations

<https://bit.ly/c19lapvolc26>



Fundraising Committee

<https://bit.ly/c19lapvolc26>

Calls to Action



We are calling on you to help elevate and recommend the COVID-19 Longhailer Advocacy Project (C19LAP) as a key national leader in Long COVID response. By raising our visibility and advocating for our inclusion in public health initiatives, coalitions, advisory groups, research collaborations, and educational programs, you ensure that people living with Long COVID have a credible, informed, and representative voice at every decision-making table.

As the Long COVID crisis continues to escalate, it is clear that this work cannot be done in isolation. Meaningful progress requires collaboration, trust, and leadership from those most impacted, supported by committed partners across sectors.

C19LAP has been a driving force in this effort since the earliest days of the pandemic. As a fully patient-led, volunteer-run organization with more than 60 chapters across every U.S. state, territory, and key communities such as Pediatrics, Caregivers, and more, we bridge lived experience with institutional action. Our work spans public and clinician education, policy and legislative engagement, research collaboration, community support, resource development, and cross-sector convening, ensuring that solutions are grounded in the realities of those living with Long COVID.

Let's work together to ensure our community's lived experiences inform the policies, care, and research that shape our lives. Your backing is essential to building stronger partnerships and achieving the outcomes millions urgently need.

Please consider recommending the formal participation of C19LAP in federal, state, and local initiatives related to Long COVID, COVID-19, and public health to ensure that programs, research, and policy are shaped by patient-centered expertise, strengthened through coordinated national leadership, and guided by the communities most impacted.



Leave a google review [here](#).



Leave a review we can use for various purposes [here](#).



We are asking individuals to record and submit a short video (no longer than one minute) sharing their story and what the COVID-19 Longhailer Advocacy Project (C19LAP) means to you and why our work matters now more than ever.

Your story can help others understand why investing in this movement is essential, not only for those living with Long COVID, but for the future of public health as a whole.

Whether you are a patient, caregiver, clinician, researcher, or ally, your voice carries power. Please consider submitting a video [here](#).



As a patient-led, volunteer-driven organization, we know the power of lived experience. We're looking to spotlight members of the Long COVID community and their advocacy.

The C19LAP Community Spotlight honors that strength by highlighting individuals whose advocacy and lived expertise are shaping the future of Long COVID awareness, education, and public health.

Whether through organizing, storytelling, peer support, or simply showing up, you make a difference, and we want to amplify your voice. If you'd like to be featured in our newsletter's new Community Spotlight section, please [complete this form](#).

FOLLOW



Social media has been the heart of the Long COVID movement since the beginning, giving patients a place to connect, organize, and find support when no formal systems existed. It remains one of the few accessible spaces for people with Long COVID and other disabilities to learn, share, and engage. It's also one of C19LAP's strongest tools for spreading accurate information and

mobilizing action. Born on Facebook, our community now has 60 chapters spanning each U.S. state and territory, and community-based chapters such as pediatrics, caregivers, and several others.

Join our community today! By following and engaging with us, you help elevate patient-led work and ensure our messaging reaches the public and key decision-makers. Every like, share, and follow strengthens our impact. Join our communities, your engagement drives real change!



Share



SUBSCRIBE



Stay in the know! Subscribe (free) to follow our work and support our mission.

<https://www.longhailer-advocacy.org>



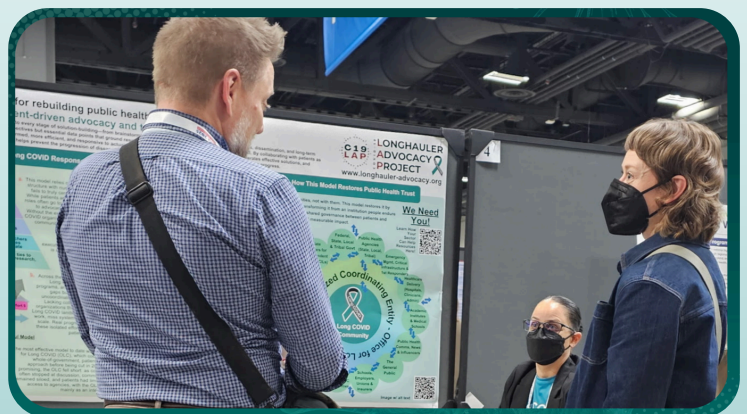
C19LAP is asking you to contact HHS Secretary Kennedy, Senator Marshall, Senator Young, Congressman Bergman, and your own members of Congress to:

- Call for urgent action and adequate resources to address Long COVID at the scale this public health crisis demands.
- Urge expansion of outreach and collaboration with the broader Long COVID community, ensuring that patient voices and lived experience guide research, policy decisions, education, and care models.
- Recommend the inclusion of C19LAP in the new Long COVID Consortium and in all federal and independent Long COVID initiatives, ensuring credible, patient-led leadership is represented at every level.
- Urge codification of telehealth services and cross-state coverage to ensure uninterrupted access to essential medical care, especially for people with chronic illnesses and disabilities who rely on virtual visits. Recent regulatory disruptions have shown how vulnerable telehealth access remains without permanent statutory protections.

Find and write your member of Congress [here](#).



Write HHS Secretary Kennedy:
The U.S. Department of Health & Human Services
Hubert H. Humphrey Building
200 Independence Avenue, S.W.
Washington, D.C. 20201



C19LAP has just launched a new Public Health Resources page on our website and a National Public Health Response to Long COVID Guide for Cross-Sector Stakeholders. We are asking you to reach out to your local department of health by email or send them a letter, requesting that they take up the issue of Long COVID. Share your story, why their involvement is a necessity, and provide them the resources below. C19LAP's strategy is the core patient-led, cross-sector, collaborative initiative our community needs.

**C19LAP Long COVID
Public Health Resources Page**

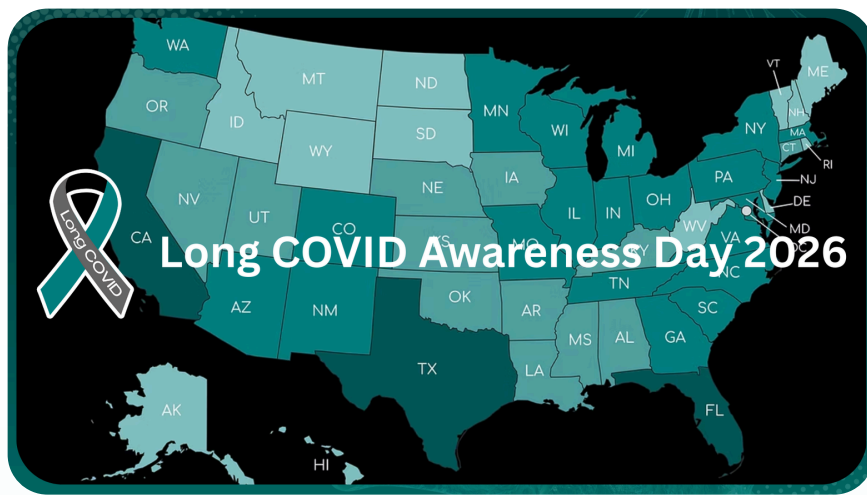


This new resource page is designed to be a one stop shop for cross-sector stakeholders in the Long COVID and public health space. We recommend sharing of this resource broadly amongst your peers and departments of health.

**A National Public Health Response to Long
COVID: Guidance for Cross-Sector Stakeholders**



This resource provides in-depth education, guidance, and roadmaps for public health officials and cross-sector stakeholders to address Long COVID. We recommend sharing of this resource broadly amongst your peers and state and local health departments.



Long COVID Awareness Day is March 15, with global activities and events taking place throughout the entire month of March, especially during Long COVID awareness week. Hundreds of millions suffer with Long COVID globally, and coordinated awareness efforts help elevate visibility, drive action, and push for the recognition, resources, and solutions urgently needed. Now is the time to plan and organize for **#LongCOVIDAwarenessDay**.

C19LAP is building a volunteer team to help plan, organize, and lead this year's awareness actions. We are seeking dedicated volunteers to support event coordination, outreach, public engagement, coalition-building, and community mobilization. Your involvement can help shape national momentum at a time when federal action has stalled and patient needs continue to grow.

Ways to Take Action in March 2026

- Organize a meeting with your U.S. Senator or Representative to discuss Long COVID priorities and request strong legislative action.
- Ask your federal, state, or local elected officials to officially recognize Long COVID Awareness Day and commit to advancing meaningful policy solutions.
- Secure proclamations or resolutions from city councils, county commissions, or state legislatures.
- Get public buildings, landmarks, or bridges to light up in teal or a designated awareness color for Long COVID Awareness Day or Week.
- Host or co-host a community event, such as a public forum, teach-in, panel discussion, walk, candlelight vigil, or art installation.
- Coordinate a virtual event, webinar, or educational session with clinicians, researchers, or community leaders.
- Launch a social media campaign to spread awareness, share patient stories, and call for political action.
- Engage local public health departments to collaborate on awareness and educational outreach.
- Partner with community organizations, disability groups, or faith-based institutions to amplify impact.
- Fundraise for C19LAP to strengthen advocacy, education, and support programs.
- Share your Long COVID story publicly to build understanding and momentum.
- Organize a letter-writing or phone banking campaign to contact elected officials and media outlets.
- Encourage local media coverage, including op-eds, interviews, and news features throughout March.



If you interested in helping out, please [complete this form](#).
Thank you!

SHOP NOW



Help raise awareness about Long COVID wherever you go! **C19LAP makes no profit** and has only provided designs for awareness and education.

Policy, Research, Advocacy, & Clinical Care Updates

Policy Updates

On September 18, 2025, U.S. Department of Health and Human Services (HHS) Secretary Robert F. Kennedy Jr. convened two high-level roundtables on Long COVID: one on patient and caregiver experiences and another on research and clinical strategy. The participants included patients, medical professionals, researchers, caregivers, and legislators such as Senators Roger Marshall (R-KS) and Todd Young (R-IN), and Congressmen Bergman (R-MI).

At the event, HHS announced the formation of a new national “Long COVID Consortium” to coordinate research, diagnostics, treatment development, and data sharing across federal agencies, academia, and industry. The press release described this as the “start of a sustained national effort” to bring what Secretary Kennedy called “invisible illnesses” into broader visibility and action.

The department announced the following actions at the roundtable:

1. A public awareness and education campaign to provide patients, families, employers, and health professionals with science-based information about Long COVID, its symptoms, and available resources.
2. An open-source medical resource platform where physicians, researchers, and health systems can share best practices, clinical guidelines, and diagnostics for Long COVID care.

The roundtable and consortium announcement come amid growing advocacy pressure and frustration from the Long COVID community, especially after the loss of nearly all the programs Long COVID patients had built over the last five years, and after efforts stalled, thereby delaying our progress towards solutions. While the announcement of the consortium marks a shift toward coordinated federal response, specific funding levels, timelines, and full membership of the consortium have not yet been fully detailed, and there have been no public communications or updates since the roundtable was held, while key patient organizations, researchers, and clinicians remain uninvolved at this time.

The Long COVID community is eager to learn about the next steps to reestablish Long COVID initiatives at the national level and learn more about the Long COVID Consortium. [Watch the roundtable here.](#)

C19LAP is asking you to contact HHS Secretary Kennedy, Senator Marshall, Senator Young, Congressman Bergman, and your own members of Congress to:

- Urge them to expand outreach and collaboration with the broader Long COVID community, ensuring that patient voices and lived experience guide research, policy decisions, and care models. Nothing about us, without us.
- Call for urgent action and adequate resources to address Long COVID at the scale this public health crisis demands.
- Recommend the inclusion of C19LAP in the new Long COVID Consortium and in all federal and independent Long COVID initiatives, ensuring credible, patient-led leadership is represented at every level.

Find and write your member of Congress [here](#), and HHS Secretary Kennedy [here](#) (mailing only available).

Research & Clinical Care Updates

CAR-T (Chimeric Antigen Receptor T-cell therapy)

A treatment where a patient's T-cells are engineered to better recognize and attack disease.

CAR-T cell therapy, originally developed for difficult-to-treat blood cancers such as B-cell lymphomas, B-cell acute lymphoblastic leukemia, chronic lymphocytic leukemia, and multiple myeloma, is now emerging as a groundbreaking approach for autoimmune diseases. Scientists are exploring its use in lupus, rheumatoid arthritis, systemic sclerosis, myositis, ANCA-associated vasculitis, and potentially multiple sclerosis, marking what researchers call a new era in treatment.

Instead of simply suppressing the immune system, CAR-T aims to reset it. The process involves engineering a patient's T cells to seek and destroy dysfunctional B cells, reaching even those hidden deep in the body that standard therapies cannot target. This deep depletion may effectively reboot the immune system so that newly formed B cells behave normally. Research is also continuing in solid tumors, chronic viral infections, and fibrosis-related disorders, underscoring CAR-T's expanding potential. **C19LAP hopes to see CAR-T research urgently expand into Long COVID.**

References: [1](#), [2](#), [3](#)

CRISPR (Clustered Regularly Interspaced Short Palindromic Repeats)

A gene-editing technology that allows precise modification of DNA.

CRISPR, originally developed as a precise tool to correct genetic errors, is rapidly becoming a transformative approach for both inherited diseases and complex immune-mediated conditions. Instead of broadly suppressing disease, CRISPR allows scientists to directly edit or deactivate the genes driving illness, offering a level of precision and permanence that traditional therapies cannot achieve.

In recent years, CRISPR has successfully treated disorders such as sickle cell disease and beta-thalassemia by editing patients' stem cells to correct faulty hemoglobin production. Researchers are now expanding its use to conditions like muscular dystrophy, hereditary blindness, cystic fibrosis, high cholesterol (via PCSK9 editing), and certain cancers.

A major new frontier is autoimmune and inflammatory disease. Using CRISPR, scientists can disable malfunctioning immune pathways, engineer immune cells for more precise regulation, or correct genetic drivers of immune dysfunction, potentially offering long-term remission rather than lifelong suppression. Early studies in lupus, type 1 diabetes, inflammatory bowel disease, and rheumatoid arthritis are showing promise as researchers explore CRISPR's ability to rewire immune responses rather than merely contain them.

With ongoing research in viral infections, fibrosis, and even organ transplantation tolerance, CRISPR is positioned to become one of the most powerful medical tools of the next decade, bringing targeted, lasting treatments to diseases once considered untreatable. **C19LAP hopes to see CRISPR research urgently expand into Long COVID.**

References: [1](#), [2](#), [3](#), [4](#), [5](#)

GLP-1 (Glucagon-Like Peptide-1)

A naturally occurring hormone involved in blood sugar control and appetite regulation; GLP-1 receptor agonists are medications that mimic or enhance its effects.

GLP-1 receptor agonists, first developed for type 2 diabetes, have rapidly emerged as powerful metabolic and anti-inflammatory therapies with expanding roles in cancer, Long COVID, and multiple chronic conditions. Beyond their glucose-lowering effects, GLP-1 medications have been highly effective in obesity, metabolic syndrome, cardiovascular disease, PCOS, fatty liver disease (MASLD/MASH), kidney disease, and stroke risk reduction, with growing evidence in neurodegenerative conditions, addiction medicine, and chronic pain due to their impact on inflammation and neural pathways.

In oncology, GLP-1 drugs are now being studied for their potential to reduce tumor-promoting inflammation, modify metabolic stress, and counter obesity-related cancer risk. Early findings suggest they may help slow tumor growth signals and improve treatment response by stabilizing metabolic and immune function.

GLP-1 therapies are also entering emerging Long COVID trials, where researchers are testing whether their effects on inflammation, endothelial repair, autonomic regulation, and metabolic stability can improve symptoms such as fatigue, POTS, cognitive dysfunction, and persistent systemic inflammation. Because Long COVID involves widespread immune-metabolic disruption, GLP-1 medications offer a promising multi-pathway therapeutic approach.

With expanding research across cancer, post-viral disease, and chronic inflammatory conditions, GLP-1 drugs are becoming some of the most versatile therapeutic tools in modern medicine. **C19LAP is pleased to see GLP-1 being investigated in Long COVID.**

<https://cen.acs.org/pharmaceuticals/drug-development/NIH-plans-test-GLP-1s/103/web/2025/09>

References: [1](#), [2](#), [3](#), [4](#)

mAbs (monoclonal Antibodies)

Lab-engineered antibodies designed to target specific cells, proteins, or pathogens such as viruses.)

Monoclonal antibodies (mAbs) are an emerging and important therapeutic approach for Long COVID, grounded in the growing body of evidence that SARS-CoV-2 viral persistence is real and contributes to ongoing disease. These therapies are engineered to directly neutralize the virus, block entry into cells, and aid in clearing persistent viral reservoirs that continue to trigger inflammation, immune activation, and tissue dysfunction long after the initial infection.

SARS-CoV-2-specific mAbs are being investigated for their ability to eliminate lingering viral proteins and low-level replication that drive symptoms such as fatigue, cognitive impairment, autonomic dysfunction, and inflammatory flares. Researchers are also studying mAbs targeting EBV, CMV, and other herpesviruses, as reactivation and sustained viral activity are well-documented in subsets of Long COVID patients and likely contribute to neuropathy, dysautonomia, and systemic symptoms.

By directly addressing persistent viral drivers rather than suppressing the immune system, antiviral mAbs offer a targeted, mechanism-based strategy that aligns with what we now know about Long COVID's underlying biology. As trials expand, these therapies may play a crucial role in restoring immune balance and improving outcomes for patients with virus-driven disease. **C19LAP hopes mAbs will become more accessible in Long COVID care and for treatment during acute COVID-19 infections.**

References: [1](#), [2](#), [3](#)

Ensitrelvir- Post-Exposure Prophylaxis (PEP)

3CL protease inhibitor that blocks SARS-CoV-2 replication.

At APHA, we met a representative from Ensitrelvir (Xocova), a next-generation oral antiviral that directly targets SARS-CoV-2's 3CL protease, the enzyme the virus needs to replicate. It is the first and only COVID-19 oral antiviral to demonstrate successful post-exposure prophylaxis (PEP) in a Phase 3 clinical trial, reducing the risk of developing symptomatic COVID-19 by 67% when taken after exposure. This marks a major breakthrough, as no approved medication has previously been able to prevent infection following contact with a COVID-positive individual.

The SCORPIO-PEP Phase 3 trial included over 2,000 household contacts and showed consistent, significant reductions in infection across multiple analyses, with a safety profile comparable to placebo and no COVID-related hospitalizations or deaths. Ensitrelvir has already been fully approved in Japan for the treatment of COVID-19 and received FDA Fast Track designation in the U.S. for both treatment and post-exposure prophylaxis.

For Long COVID, the implications are substantial: preventing infection and reducing acute viral load are among the strongest known strategies for reducing Long COVID risk, as persistent viral replication, viral debris, and immune dysregulation are key drivers of long-term disease. By directly inhibiting viral replication early—and potentially limiting viral persistence, ensitrelvir may help reduce the downstream inflammation, endothelial injury, and immune disruption that lead to chronic symptoms.

As SARS-CoV-2 continues to circulate, evolve, and evade immunity, ensitrelvir represents a critical tool: an oral antiviral that is easy to administer, variant-resilient, fast-acting, and capable of preventing infection after exposure. With ongoing regulatory review worldwide and additional trials in treatment, prevention, and pediatric populations, ensitrelvir may become one of the most important antiviral interventions for reducing acute disease and lowering the risk of Long COVID at scale. **C19LAP is extremely excited and optimistic about this long-overdue therapy and its potential.**

References: [1](#), [2](#), [3](#)

Anktiva (IL-15 agonist)

An immune-restoring therapy designed to strengthen the body's antiviral defenses by activating and coordinating T cells and natural killer (NK) cells, the two cell types responsible for clearing the virus from tissues.

The INTERRUPT-LC trial is investigating Anktiva (N-803), an IL-15 super-agonist, as a targeted immune-restoration therapy for Long COVID, based on growing evidence that many patients retain persistent SARS-CoV-2 antigens or intact virus in tissue reservoirs. These reservoirs appear to impair the coordination and function of CD8+ T cells and natural killer (NK) cells, which are central to the body's ability to clear intracellular pathogens. Anktiva enhances the development, survival, trafficking, and activation of these antiviral cells, making it a compelling candidate for conditions where viral persistence drives ongoing disease.

As presented by Dr. Michael Peluso at the Polybio symposium, the rationale for INTERRUPT-LC builds on extensive experience using this agent in HIV, where it has shown effects on immune trafficking to reservoir sites, improved cytotoxic responses, and better overall immune control. Applying this to Long COVID, the hypothesis is that repairing and boosting T-cell and NK-cell coordination may enable the immune system to finally clear residual SARS-CoV-2, interrupting the chronic immune activation, tissue injury, and multisystem symptoms that reservoirs are believed to sustain.

By focusing on immune restoration rather than immune suppression, INTERRUPT-LC represents an important shift in Long COVID research: targeting the underlying antiviral deficits that keep patients sick, and testing whether strengthening the immune system's natural clearing mechanisms can produce meaningful clinical improvement.

Combination Therapies

Designed to target multiple biological drivers at the same time, rather than relying on a single drug to fix a complex, multi-system disease.

Long COVID research has made it increasingly clear that the condition is not driven by a single pathway but by a convergence of SARS-CoV-2 viral persistence, viral reactivation such as EBV, chronic immune activation, endothelial injury, autonomic dysfunction, and neuroinflammation. These interconnected processes help explain why patients experience such a wide range of symptoms and conditions and why single-agent therapies often fall short. Because viral reservoirs can continue to trigger immune dysfunction, and reactivated viruses like EBV can worsen autonomic instability and neurological symptoms, researchers are increasingly turning to multi-drug combination therapy as a more biologically aligned treatment approach for Long COVID.

One of the leading efforts in this direction is the upcoming SHIELD clinical trial, planned for 2026 and presented by Dr. David Putrino at the Polybio fall symposium. SHIELD will test a three-drug regimen (Valacyclovir, Paxlovid, and Celecoxib) designed to target the key drivers of Long COVID simultaneously. Valacyclovir addresses EBV and HSV reactivation, which have been repeatedly documented in Long COVID and linked to fatigue, brain fog, dysautonomia, and inflammatory flares. Paxlovid inhibits the 3CL protease to suppress persistent SARS-CoV-2 activity, now well established by tissue studies to persist for months or years after infection. Celecoxib reduces COX-2-mediated inflammation, which supports viral activity, fuels neuroinflammation, and contributes to pain and autonomic dysfunction.

By addressing persistent viral activity, modulating the immune system, and reducing the inflammatory environment that sustains Long COVID, the SHIELD approach represents a coordinated, mechanism-based strategy to improve core symptoms rather than piecemeal symptom management. This reflects a broader shift in the field: the recognition that Long COVID requires multi-pathway treatment regimens capable of interrupting the biological feedback loops that keep patients sick. **C19LAP is pleased to see combination therapies long called for finally being trialed, and hopes to see combinations expanded.**

SARS-CoV-2 RNA Detected in Bone Marrow Biopsies

Emerging tissue-based studies continue to strengthen the evidence that SARS-CoV-2 persists long after the acute infection, with major implications for Long COVID biology and treatment. At the Polybio fall symposium, Dr. Tim Henrich of UCSF presented new data showing that SARS-CoV-2 RNA was detected in multiple bone marrow biopsies from Long COVID patients, an especially significant finding given that bone marrow is a central hub for immune cell development, maturation, and long-term immune memory. Persistent viral material in this compartment could directly disrupt hematopoiesis, alter immune cell function, and contribute to the chronic inflammation, dysregulated immunity, and multisystem symptoms observed in Long COVID. More bone marrow samples are currently being analyzed, and early signals suggest this may be a recurring—and previously unrecognized—reservoir site. These results further reinforce that Long COVID is a chronic, infection-associated condition driven in part by lingering virus in deep tissue niches that traditional blood tests cannot detect. **C19LAP is pleased to see more meaningful high-risk, high-reward research previously recommended.**

References: [1](#), [2](#), [3](#)

Megakaryocytes & Platelets

At the Polybio fall symposium, Morgane Bomsel presented compelling evidence that megakaryocytes and platelets in Long COVID patients harbor SARS-CoV-2 RNA and the Spike protein, suggesting that these blood-forming cells may serve as previously overlooked viral reservoirs. Because megakaryocytes give rise to platelets—cells that circulate widely throughout the body, the presence of viral material within them suggests a mechanism by which SARS-CoV-2 could persist, spread, and continually stimulate the immune system. Bomsel noted that platelets can release infectious virus to other cells, providing a potential explanation for ongoing inflammation, microvascular injury, clotting abnormalities, and systemic symptoms seen in Long COVID. The detection of circulating Spike protein in plasma further supports the idea that viral components are being actively released into the bloodstream. Together, these findings highlight a critical pathway through which SARS-CoV-2 may evade clearance and perpetuate chronic disease.

SARS-COV-2 RNA Present in Female Reproductive and Gut for More than Four Years

At the Polybio fall symposium, Marta Mirabent of the Roan Lab at the Gladstone Institutes presented striking evidence of long-term SARS-CoV-2 persistence in human tissue. Mirabent reported that Long COVID tissue samples from the female reproductive tract and the gut tested positive for SARS-CoV-2 RNA more than four years after the initial infection, underscoring how deeply the virus can embed itself in mucosal and immune-rich tissues. These findings extend the growing body of research showing that SARS-CoV-2 can establish durable reservoirs in multiple organs, which standard blood tests cannot detect.

The persistence of viral RNA in tissues central to immune signaling, hormonal regulation, and mucosal immunity provides a compelling explanation for ongoing inflammation, autonomic dysfunction, pain, gastrointestinal symptoms, and reproductive disturbances reported by many Long COVID patients. Mirabent's work reinforces a core reality of Long COVID: this is a chronic, infection-associated condition sustained by long-term viral persistence, not a post-acute leftover or a resolved infection. **C19LAP is grateful for long-neglected research in women's health.**

Long COVID and Cancer

Growing evidence shows that viral persistence and chronic inflammation in Long COVID may have implications for cancer biology. A recent mouse study demonstrated that both COVID-19 and influenza infections can “awaken” dormant breast cancer cells in the lungs, enabling them to begin proliferating again. Researchers identified IL-6–driven inflammation as a key trigger, an immune pathway known to be chronically elevated in many Long COVID patients. This mechanism aligns with emerging epidemiological signals showing increased cancer incidence and mortality following COVID-19, especially in cancers sensitive to inflammatory environments or immune disruption.

Beyond breast cancer, scientists are examining potential impacts on hematologic malignancies, gastrointestinal cancers, and virus-associated cancers (such as those linked to EBV or HPV), given the dysregulated immunity, persistent viral antigens, and chronic inflammatory signaling observed in Long COVID. Together, these findings suggest that prolonged immune activation and tissue stress from SARS-CoV-2 may create conditions that allow dormant cancer cells to reawaken, tumor surveillance to falter, or viral-linked cancers to become more active, highlighting yet another long-term consequence of unresolved infection. **C19LAP has been tracking Long COVID incidence in our community since 2021 and we are relieved to see that recognition of this issue is finally coming to light and being researched.**

References: [1](#), [2](#), [3](#)

The Role of EBV in Long COVID, Lupus, and Multiple Sclerosis

Lupus has become one of the more frequently diagnosed autoimmune conditions following COVID-19, and mounting research is clarifying why this occurs. Stanford scientists have shown that Epstein-Barr virus (EBV) can directly hijack lupus-linked B cells, transforming them into hyperactive antigen-presenting cells that fuel the widespread immune dysregulation seen in systemic lupus erythematosus (SLE). This work reinforces long-standing evidence that EBV is not simply associated with lupus but plays a causal role in triggering or amplifying autoimmune disease in susceptible individuals. Post-COVID lupus diagnoses and lupus-like syndromes in Long COVID are increasingly recognized within this broader framework of viral reactivation and immune disruption.

EBV's influence extends even further. UCSF researchers have now demonstrated that EBV is not just correlated with multiple sclerosis (MS) but required for its development. Nearly every person with MS carries EBV, and the risk of MS rises more than thirtyfold after EBV infection. EBV targets and reshapes immune pathways involved in myelin injury, neuroinflammation, and long-term immune activation, making it one of the most powerful environmental drivers of autoimmunity identified to date. Reports of new MS diagnoses and MS-like neurological syndromes after COVID-19, including within Long COVID populations, align with this body of evidence and raise concern about SARS-CoV-2 acting as a catalyst for dormant or subclinical autoimmune processes.

A key unifying factor is that COVID-19 is a potent reactivator of EBV. Multiple Long COVID studies show elevated EBV early antigen activity, antibody spikes, viral shedding, and other signs of reactivation shortly after acute infection. Reactivated EBV can intensify inflammation, disrupt B-cell and T-cell function, and drive symptoms that mirror chronic autoimmune disease, including profound fatigue, dysautonomia, neuropathy, cognitive impairment, connective-tissue involvement, and inflammatory flares. This provides a biologically plausible explanation for why lupus, MS, and related autoimmune conditions can arise or worsen after COVID-19, and why so many people with Long COVID exhibit persistent autoimmune-like features.

Taken together, the emerging evidence reveals a consistent pattern. SARS-CoV-2 can awaken EBV from latency, and EBV can ignite or amplify autoimmune pathways that contribute to lupus, MS, and other chronic, infection-associated diseases. This interplay between viruses and immune dysfunction forms a central mechanism in the persistence, severity, and complexity of Long COVID. **C19LAP is encouraged to see expanding scientific attention to EBV, viral reactivation, and the broader family of infection-associated chronic conditions, all of which deepen our understanding of Long COVID and the urgent need for targeted solutions.**

References: [1](#), [2](#), [3](#), [4](#)

A Letter From the C19LAP Board of Directors

Dear Long COVID Community,

As we enter another year of profound challenge and opportunity, the Board of Directors of the COVID-19 Longhailer Advocacy Project (C19LAP) wants to speak directly to each of you — the patients, caregivers, clinicians, advocates, and allies who fuel this movement. Your voices, your strength, and your willingness to fight for recognition and action continue to drive our mission every single day.

Long COVID remains one of the most urgent public health crises of our time. Nearly 70 million people in the United States alone are living with life-altering symptoms, and far too many continue to face barriers to care, a lack of clinical understanding, inconsistent public health messaging, and the erosion of federal programs that once promised progress. We see the impact of these gaps in every email we receive, every story shared, every plea for help. We also see your resilience, and it inspires us.

C19LAP was founded on a simple but powerful commitment: that people living with Long COVID must never be left out of the decisions that shape their health, lives, and futures. Today, that commitment has grown into a national infrastructure spanning all 50 states, U.S. territories, and multiple community-based chapters. Our work now informs clinicians, guides policymakers, supports families, and strengthens the national understanding of Long COVID and infection-associated chronic conditions.

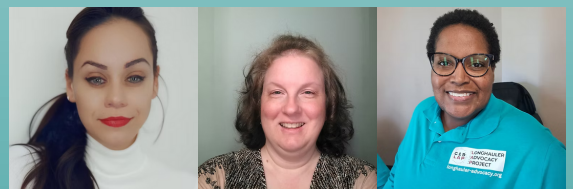
We are proud of what has been built, but we are also painfully aware of how much work remains. Federal Long COVID efforts have been reduced or shuttered entirely. Public health systems continue to struggle with coordination and preparedness. Research remains underfunded. Millions are still losing jobs, disability increases, access to care, financial stability, and quality of life.

For these reasons, the Board has approved a comprehensive five-year strategic plan that positions C19LAP to fill critical national gaps in education, care navigation, policy, patient representation, and public health infrastructure. This plan will allow us to expand our state networks, scale clinician training, strengthen policy leadership, and build the systems of support that have been missing for far too long. But we cannot do it without you.

Your involvement, as a volunteer, advocate, donor, or community voice, is essential. Every action you take, every person you inform, every story you share, and every dollar you contribute strengthen our ability to serve and protect this community. In the absence of federal continuity, patient-led organizations like C19LAP must be empowered to lead the effort forward.

We are honored to serve this community and remain committed to fighting alongside you for recognition, care, research, and justice. Thank you for your trust, your courage, and your continued belief in the power of collective action.

With strength, resilience, and determination,
**The COVID-19 Longhailer Advocacy Project
Board of Directors**



Thank You For
Supporting Our Mission



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