



# LONG COVID RESEARCH MOONSHOT ACT CALL TO ACTION GUIDE.

The bill is supported by Long COVID patient organizations COVID-19 Longhailer Advocacy Project (C19LAP), Long Covid Campaign (LCC), Long Covid Moonshot (LCM) and Patient-Led Research Collaborative (PLRC), along with over 50 other organizations!

[Read Bill Here](#)



## Join the Long COVID Community's Call to Action to Support this Monumental Bill!

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### WHO CAN PARTICIPATE?

- PEOPLE W/ LONG COVID
- CAREGIVERS
- COMMUNITY ALLIES
- FRIENDS & FAMILY
- COVID CONSCIOUS COMMUNITY
- EVERYONE!



**C19LAP** ASSOCIATED CONDITIONS LONG COVID & COVID-19  
**LONGHAULER  
ADVOCACY  
PROJECT**

# What Does the Long COVID Research Moonshot Act Do?

The Long COVID Research Moonshot Act would require the NIH to establish a new \$10 billion research program, led by a director with Long COVID research expertise and in consultation with an empowered advisory board of Long COVID and infection-associated chronic condition (IACC) researchers and patients. Responding to patient community organizing ignited by a October 2023 Nature call to action from PLRC's McCorkell and University of California-San Francisco clinician-researcher Dr. Michael Peluso, the bill includes not only substantive funding, but also a slate of new transparency, reporting, consultation, and grant expediting requirements.

Alongside prioritization of expedited clinical trials and development of new interventions, the Long COVID Research Moonshot Act provides an additional \$1.4 billion in mandatory funding for robust provider and public education, surveillance, and clinical trial support efforts across the Food and Drug Administration, Centers for Disease Control, Health and Human Services and other U.S. government agencies to collaboratively address the growing public health crisis. The proposed legislation will also ensure Long COVID research coordination and findings benefit people living with Infection-Associated Chronic Conditions similar to Long COVID.

**The bill would ensure targeted, robust investments in Long COVID research, education and awareness across U.S. government agencies, over the next 10 years:**

- **CDC: \$32 million/year for the next 10 years for Long COVID and IACC surveillance; \$45 million/year for the next 10 years for grants to state, local, and tribal health departments; \$21.5 million/year for the next 5 years for a national public education campaign.**
- **FDA: \$16.6 million/year for the next 10 years to continue electronic reporting for patients to identify current treatments and treatments under development for Long COVID; \$9 million/year for the next 10 years to develop and validate clinical outcome assessments.**
- **HHS: \$3 million/year for the next 10 years for provider education.**
- **AHRQ: \$10 million/year for the next 10 years to continue the Long COVID Care Network; \$10 million/year for the next 10 years to develop and distribute best clinical care practices**
- **National Institute on Disability, Independent Living, and Rehabilitation Research: \$10 million/year for the next 5 years for applied research on Long COVID and other IACCs.**
- **IACCs: The Long COVID Research Program will ensure timely cross-agency coordination on IACC advances; conduct comparative research on Long COVID and other IACCs; grant awards will be prioritized for research that includes patients with IACCs with similar phenotypes to Long COVID; Organizations that represent IACCs with similar phenotypes to LC will be consulted on the Research Plan; CDC directed to collect data on the incidence, prevalence, and severity of IACCs.**

# How Does the Long COVID Research Moonshot Act Help?

## FDA Funding

1. \$16.6 million/year for the next 10 years to continue electronic reporting for patients to identify current treatments and treatments under development for Long COVID

- For Long COVID Patients: Access to a centralized database of treatments can empower patients to make informed decisions about their care.
- For Caregivers: Caregivers can easily access information about new treatments and clinical trials, improving their ability to support loved ones.
- For the General Public/Community: Public access to treatment information can facilitate broader understanding and acceptance of emerging Long COVID therapies.

2. \$9 million/year for the next 10 years to develop and validate clinical outcome assessments

- For Long COVID Patients: Validated clinical assessments ensure that treatments are based on reliable and standardized measures, improving care quality.
- For Caregivers: Reliable outcome assessments can provide clear benchmarks for patient progress, helping caregivers track improvements and setbacks.
- For the General Public/Community: Standardized assessments can be used in public health research, leading to better community health strategies and resource allocation.

## AHRQ Funding

1. \$10 million/year for the next 10 years to continue the Long COVID Care Network

- For Long COVID Patients: A dedicated care network can streamline patient access to specialized Long COVID treatments and services.
- For Caregivers: Care networks provide caregivers with resources and support systems, easing the burden of care.
- For the General Public/Community: Centralized care networks improve public health infrastructure, enhancing the overall quality of healthcare services.

2. \$10 million/year for the next 10 years to develop and distribute best clinical care practices

- For Long COVID Patients: Best practices ensure patients receive the most effective and up-to-date treatments available.
- For Caregivers: Clear guidelines help caregivers provide consistent and effective support to patients.
- For the General Public/Community: Widespread adoption of best practices improves healthcare outcomes and reduces disparities in care.



## HHS Funding

1. \$3 million/year for the next 10 years for provider education

- For Long COVID Patients: Educating healthcare providers about Long COVID ensures patients receive knowledgeable and compassionate care.
- For Caregivers: Educated providers can offer better guidance and support to caregivers, improving overall care coordination.
- For the General Public/Community: Increased provider knowledge leads to better public health outcomes and a more informed healthcare system.

## National Institute on Disability, Independent Living, and Rehabilitation Research Funding

1. \$10 million/year for the next 5 years for applied research on Long COVID and other IACCs

- For Long COVID Patients: Applied research can lead to the development of innovative treatments and interventions, improving patient outcomes.
- For Caregivers: Research findings can inform the creation of caregiver resources and support programs.
- For the General Public/Community: Applied research benefits public health by advancing knowledge and treatment of Long COVID and related conditions, leading to overall health improvements.

2. Conduct comparative research on Long COVID and other IACCs

- For Long COVID Patients: Comparative research can identify commonalities and differences, and coordinated research efforts lead to faster breakthroughs and more comprehensive treatment options by ensuring timely cross-agency coordination on IACC advances
- For Caregivers: Improved coordination ensures caregivers have access to the latest information and resources.
- For the General Public/Community: Cross-agency coordination enhances public health initiatives and policy-making, benefiting the wider community.

3. Grant awards will be prioritized for research that includes patients with IACCs with similar phenotypes to Long COVID

- For Long COVID Patients: Targeted research funding ensures that diverse patient needs are addressed.
- For Caregivers: Inclusive research provides caregivers with better tools and strategies for care.
- For the General Public/Community: Prioritized funding leads to more comprehensive and inclusive healthcare solutions, benefiting all.
- By addressing these key areas, the Long COVID Research Moonshot Act promises to make significant strides in improving the lives of Long COVID patients, their caregivers, and the general public.

**We need your help gaining congressional support!**

# Call Your Democratic Senators

Teal =  
Signed on in  
support

Support the Long COVID Research Moonshot Act S.4964

## Arizona

1. Mark Kelly: (202) 224-2235

## California

1. Alex Padilla: (202) 224-3553

## Colorado

1. Michael Bennet: (202) 224-5852
2. John Hickenlooper: (202) 224-5941

## Connecticut

1. Richard Blumenthal: (202) 224-2823
2. Christopher Murphy: (202) 224-4041

## Delaware

1. Thomas Carper: (202) 224-2441
2. Christopher Coons: (202) 224-5042

## Georgia

1. Jon Ossoff: (202) 224-3521
2. Raphael Warnock: (202) 224-3643

## Hawaii

1. Mazie Hirono: (202) 224-6361
2. Brian Schatz: (202) 224-3934

## Illinois

- **Tammy Duckworth: (202) 224-2854**
- Richard Durbin: (202) 224-2152

## Maryland

- Benjamin Cardin: (202) 224-4524
- Chris Van Hollen: (202) 224-4654

## Massachusetts

1. **Edward Markey: (202) 224-2742**
2. Elizabeth Warren: (202) 224-4543

## Michigan

1. Gary Peters: (202) 224-6221
2. Debbie Stabenow: (202) 224-4822

## Minnesota

1. Amy Klobuchar: (202) 224-3244
2. **Tina Smith: (202) 224-5641**

## Montana

1. Jon Tester: (202) 224-2644

## Nevada

- Catherine Cortez Masto: (202) 224-3542
- Jacky Rosen: (202) 224-6244

## New Hampshire

- Margaret Wood Hassan: (202) 224-3324
- Jeanne Shaheen: (202) 224-2841

## New Jersey

- Cory Booker: (202) 224-3224
- Robert Menendez: (202) 224-4744

## New Mexico

- Martin Heinrich: (202) 224-5521
- Ben Ray Luján: (202) 224-6621

## New York

1. Kirsten Gillibrand: (202) 224-4451
2. Charles Schumer: (202) 224-6542

## Ohio

1. Sherrod Brown: (202) 224-2315

## Oregon

1. Jeff Merkley: (202) 224-3753
2. Ron Wyden: (202) 224-5244

## Pennsylvania

1. Robert Casey, Jr.: (202) 224-6324

## Rhode Island

1. Jack Reed: (202) 224-4642
2. Sheldon Whitehouse: (202) 224-2921

## Vermont

1. Peter Welch: (202) 224-4242

## Virginia

1. Tim Kaine: (202) 224-4024
2. Mark Warner: (202) 224-2023

## Washington

1. Maria Cantwell: (202) 224-3441
2. Patty Murray: (202) 224-2621

## West Virginia

1. Joe Manchin, III: (202) 224-3954

## Wisconsin

1. Tammy Baldwin: (202) 224-5653

# Call Your Independent Senators

Support the Long COVID Research Moonshot Act S.4964

## Independents

### Vermont

1. Bernie Sanders: (202) 224-5141

### Maine

1. Angus King: (202) 224-5344

# Call Your Republican Senators

Support the Long COVID Research Moonshot Act S.4964

## Alabama

1. Katie Britt: (202)-224-5744
2. Tommy Tuberville: (202) 224-4124

## Alaska

1. Lisa Murkowski: (202) 224-6665
2. Dan Sullivan: (202) 224-3004

## Arkansas

1. John Boozman: (202) 224-4843
2. Tom Cotton: (202) 224-2353

## Florida

1. Marco Rubio: (202) 224-3041
2. Rick Scott: (202) 224-5274

## Idaho

1. Mike Crapo: (202) 224-6142
2. James Risch: (202) 224-2752

## Indiana

1. Mike Braun: (202) 224-4814
2. Todd Young: (202) 224-5623

## Iowa

1. Chuck Grassley: (202) 224-3744
2. Joni Ernst: (202) 224-3254

## Kansas

1. Jerry Moran: (202) 224-6521
2. Roger Marshall: (202) 224-4774

## Kentucky

1. Mitch McConnell: (202) 224-2541
2. Rand Paul: (202) 224-4343

## Louisiana

1. Bill Cassidy: (202) 224-5824
2. John Kennedy: (202) 224-4623

## Maine

1. Susan Collins: (202) 224-2523

## Mississippi

1. Roger Wicker: (202) 224-6253
2. Cindy Hyde-Smith: (202) 224-5054

## Missouri

1. Eric Schmitt: (202) 224-5721
2. Josh Hawley: (202) 224-6154

## Montana

1. Steve Daines: (202) 224-2651

## Nebraska

1. Deb Fischer: (202) 224-6551
2. Pete Ricketts: (202) 224-4224

## North Carolina

1. Ted Budd: (202) 224-3154
2. Thom Tillis: (202) 224-6342

## North Dakota

1. John Hoeven: (202) 224-2551
2. Kevin Cramer: (202) 224-2043

## Ohio

1. J.D. Vance: (202) 224-3353

## Oklahoma

1. Markwayne Mullin: (202) 224-4721
2. James Lankford: (202) 224-5754



## Pennsylvania

1. Pat Toomey: (202) 224-4254

## South Carolina

1. Lindsey Graham: (202) 224-5972

2. Tim Scott: (202) 224-6121

## South Dakota

1. John Thune: (202) 224-2321

2. Mike Rounds: (202) 224-5842

## Tennessee

1. Marsha Blackburn: (202) 224-3344

2. Bill Hagerty: (202) 224-4944

## Texas

1. John Cornyn: (202) 224-2934

2. Ted Cruz: (202) 224-5922

## Utah

1. Mike Lee: (202) 224-5444

2. Mitt Romney: (202) 224-5251

## West Virginia

1. Shelley Moore Capito: (202) 224-6472

## Wisconsin

1. Ron Johnson: (202) 224-5323

## Wyoming

1. John Barrasso: (202) 224-6441

2. Cynthia Lummis: (202) 224-3424

# Write Your Senators

Support the Long COVID Research Moonshot Act S.4964



**SCAN ME**

to use the C19LAP  
pre-written Action Network  
tool or Click [Here](#)



**SCAN ME**

to write to your senator  
via their website or  
Click [Here](#).



# Sample Phone Script

**\*Be sure to leave your phone number or email address\***

## **As a Long COVID Patient**

"Hello, my name is [Your Name] and I am a constituent from [Your State]. I am calling to urge Senator [Senator's Name] to support the Long COVID Research Moonshot Act (S.4964). As someone who has been suffering from Long COVID for [number of months/years], I know firsthand how devastating this condition can be. This bill will provide crucial funding for research, education, and support that is desperately needed. Please support this bill to help improve the lives of millions of Americans like me. Thank you."

## **As a Caregiver for a Long COVID Patient**

"Hello, my name is [Your Name] and I am calling from [Your State]. I care for a loved one who has been suffering from Long COVID for [number of months/years]. I am urging Senator [Senator's Name] to support the Long COVID Research Moonshot Act (S.4964). This legislation is vital for providing the necessary resources and research to understand and treat this condition. Please support this bill to help improve the lives of countless families like mine. Thank you."

## **As a COVID-Conscious Person and Ally to the Long COVID Community**

"Hello, my name is [Your Name] and I am a constituent from [Your State]. I am calling to express my strong support for the Long COVID Research Moonshot Act (S.4964). As someone who is deeply concerned about the impacts of COVID-19 and its long-term effects, I believe this bill is essential for advancing our understanding and treatment of Long COVID. I urge Senator [Senator's Name] to support this critical legislation. Thank you."

## **As a Clinician and/or Researcher**

"Hello, my name is Dr. [Your Name] and I am a [clinician/researcher] from [Your State]. I am calling to advocate for the Long COVID Research Moonshot Act (S.4964). This legislation is critical for advancing our scientific understanding and developing effective treatments for Long COVID. As a professional in the field, I see the urgent need for the resources and support this bill provides. I urge Senator [Senator's Name] to support this important legislation. Thank you."

# Sample Written Script

\*Be sure to sign "Sincerely, [Your Name] [Your Address] [Your Email]"\*

## As a Long COVID Patient

"Dear Senator [Senator's Name],

I am writing to you as a constituent and a Long COVID patient. For the past [number of months/years], I have been struggling with the debilitating effects of Long COVID. The introduction of the Long COVID Research Moonshot Act (S.4964) offers hope for me and millions of others who are in dire need of better treatments, education, and support. I strongly urge you to support this critical legislation and help us find the answers we need to reclaim our health and lives.

## As a Caregiver for a Long COVID Patient

"Dear Senator [Senator's Name],

As a caregiver for a loved one with Long COVID, I have witnessed the immense challenges and suffering that come with this condition. The Long COVID Research Moonshot Act (S.4964) represents a crucial step towards finding effective treatments and providing support for patients and caregivers alike. I urge you to support this important legislation to help families like mine who are struggling every day.

## As a COVID-Conscious Person and Ally to the Long COVID Community

"Dear Senator [Senator's Name],

I am writing to you as a concerned constituent and ally to the Long COVID community. The Long COVID Research Moonshot Act (S.4964) is a vital piece of legislation that will provide much-needed funding for research and support for those affected by Long COVID. I urge you to support this bill to help ensure a better future for all those impacted by this condition.

## As a Clinician and/or Researcher

"Dear Senator [Senator's Name],

As a [clinician/researcher] who is deeply involved in the study and treatment of Long COVID, I am writing to express my strong support for the Long COVID Research Moonshot Act (S.4964). This bill is essential for advancing our understanding of Long COVID and developing effective treatments. The proposed funding and support for research, education, and clinical trials are crucial for addressing this public health crisis. I urge you to support this vital legislation.

# Script Bonus

1. **Request a meeting** to discuss the needs of local Long COVID constituents. If contacted, C19LAP will help coordinate those interested in attending.  
contact@longhauler-advocacy.org
2. **Add in more specifics** about how the bill will help you. ie: \$21.5 million/year for the next 5 years for a national public education campaign will help because....

## Meeting with Senators

is a critical step in advocating for the passage of legislation like the Long COVID Research Moonshot Act.

### **Personal Impact and Stories:**

- Humanize the Issue: Personal stories from constituents help senators understand the real-world impact of Long COVID, making the issue more relatable and urgent .
- Evidence of Need: Sharing personal experiences and hardships underscores the necessity of the proposed funding and legislation, providing concrete examples of how Long COVID affects lives .

### **Constituent Influence:**

- Voter Connection: Senators are elected to represent their constituents. Hearing directly from voters can significantly influence their stance on legislation .
- Local Relevance: Highlighting how the bill will benefit the senator's state or district makes the issue more relevant to their legislative priorities.

### **Accountability and Pressure:**

- Public Commitment: When constituents meet with their senators, it creates a sense of accountability. Senators are more likely to act on issues they've publicly committed to addressing .
- Visibility of Support: Demonstrating widespread constituent support through meetings can pressure senators to align with the majority view to maintain their voter base and public image



# How Meetings Can Sway Senators

## Personalized Advocacy:

- Tailored Arguments: Constituents can provide tailored arguments that address specific concerns or interests of the senator, making the case for the legislation more compelling.
- Direct Dialogue: Face-to-face meetings allow for a direct exchange of ideas and concerns, which can lead to a deeper understanding and stronger commitment from the senator.

## Demonstrating Broad Support:

- Unified Voices: Coordinated efforts where multiple constituents or groups meet with the senator demonstrate a unified demand for action, showcasing the broad support for the bill .
- Diverse Perspectives: Bringing together a diverse group of advocates, including patients, caregivers, healthcare providers, and researchers, shows the wide-ranging impact and support for the legislation.

## Building Relationships:

- Long-term Engagement: Regular engagement with senators builds a relationship of trust and cooperation, making it more likely they will support current and future initiatives .
- Collaborative Approach: Establishing a collaborative relationship can encourage senators to become champions for the cause, advocating for the bill within their legislative circles.

## Informative and Educational:

- Knowledge Sharing: Constituents can provide senators with the latest data, research, and personal anecdotes that highlight the importance and urgency of the bill .
- Clarifying Misconceptions: Meetings provide an opportunity to clarify any misconceptions or misinformation about Long COVID and the proposed legislation, ensuring the senator has accurate information to base their decisions on.

**By meeting with their senators, constituents can effectively advocate for the Long COVID Research Moonshot Act, increasing the likelihood of its passage and ensuring that vital resources are allocated to combat Long COVID and its associated conditions.**

**Interested  
in meeting  
with your  
senator?**

Click [Here](#) or



**SCAN ME**