

# Patient Perspective: REVERSE-LC Trial

Michael Sieverts  
Patient-Led Research Collaborative

RECOVER-TLC  
2nd Annual Meeting  
September 9, 2025

# Topics

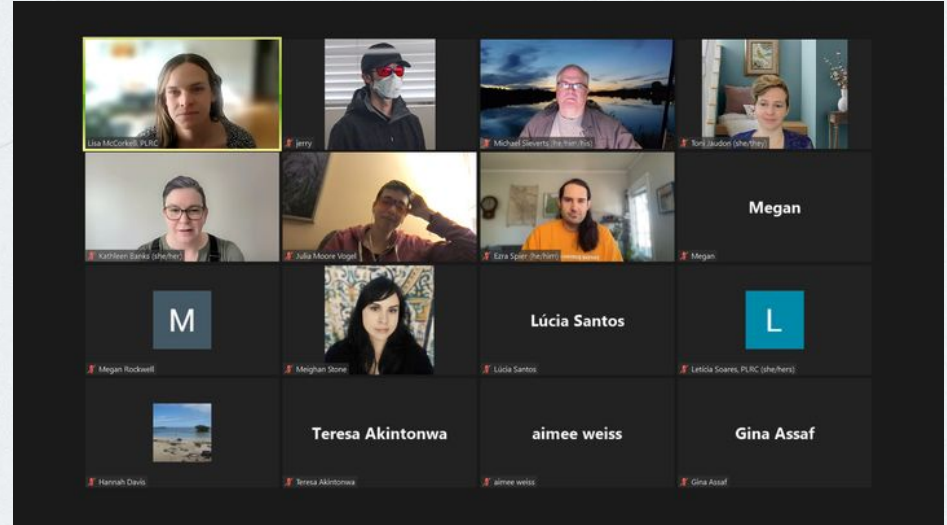
- I. About the Patient-Led Research Collaborative**
- II. About Me**
- III. My REVERSE-LC Experience**
  - A. Logistics**
  - B. Outcomes**



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# About PLRC

- **50+ patient-researchers and advocates** across **5 continents**; all people with Long COVID or another IACC.
- Met and formed in April 2020 in Body Politic COVID Support Group.
- **Interdisciplinary** team across sciences, technology, policy, media.





# About Me

## General Info

- Retired Federal Exec.
  - National Science Foundation, 35 years:
    - Budget Director
    - Deputy Director, CFO Office
  - Earlier: Congressional Budget Office
- C19 in March 2020
  - “Mild” Case
  - LC Symptoms – April
- Study Participant
  - Nath Intramural LC
  - RECOVER – Howard U
  - REVERSE-LC

## LC Symptoms

- Dizziness
  - Nausea
  - Fatigue
  - Brain Fog
  - Vertigo
- } **The 24/7 Hangover**
- Post-Exertional Malaise
  - Dysautonomia – Orthostatic Hypotension
  - MCAS – skin rashes
    - Low Histamine Diet
  - G/I
    - Microscopic colitis
    - Gluten and lactose intolerance



Federally funded by the National Institutes of Health

People living with  
**Long COVID** are  
looking for answers.

**REVERSE-LC** is a study to see if a  
drug called **Baricitinib** can help.



REVERSE LC is a study to  
see if an FDA-approved  
drug called Baricitinib  
(*ber-uh-sit-uh-nib*), which is  
already used to treat  
COVID, can **help improve  
thinking and memory  
problems** and **reduce  
fatigue** for people who  
have Long COVID.



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Well+Being

## Long covid patients are desperate for treatments. These trials may help.

Some trials are focusing on drugs that target the immune system, which is affected by different pathways to long covid.

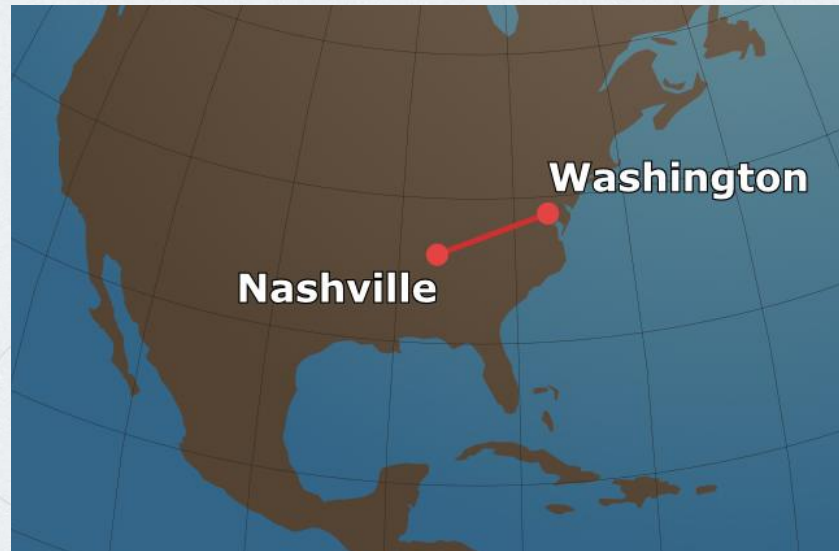
May 16, 2025

► 9 min



Registered nurses Lana Howard (left) and Melissa Lehman help Shannon Watkins, a participant in the REVERSE-LC trial, prepare for a cardiopulmonary exercise test at the Center for Critical Illness, Brain Dysfunction, and Survivorship at Vanderbilt University Medical Center. A cardiopulmonary exercise test helps researchers gather data on a patient's lungs and heart, providing insights into the body's response to exercise and stress. (Photos by Kate Dearnan/For The Washington Post)

By Richard Sima



DC to Nashville: ~560  
miles

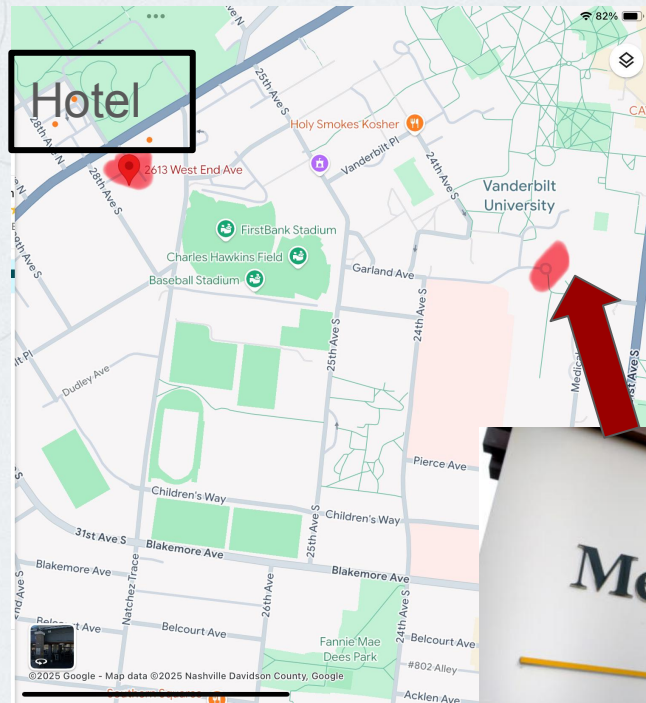
The Washington Post, May 16, 2025





# Nashville Logistics

- Holiday Inn
  - Shuttle to VUMC
    - <5 minutes
  - Sensitivity-aware food options
- VUMC
  - Consistent Masking
  - Awareness of burden
  - Flexible & accommodating



## Study Visits

Procedures	Study Visits		
	Initial/Enrollment (1st Visit)	Monthly (Visits 2-6)	6 Month (Visit 7)
Vitals/Blood Draw	✓	✓	✓
Neurocog Testing	✓		✓
Brain MRI	✓		✓
6 minute walk	✓		✓
CPET	✓		✓



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# Impact of Trial Drug, a.k.a N=1 Observations

## Positives

- Across the board—milder symptoms
- Most noticeable effects:
  - Improved clarity
  - Fatigue – no lead blanket, but still general tiredness
  - Bigger energy envelope
    - But still PEM
- 10% improvement in 6MW, CPET

## Not-so-Positives

- No effect on MCAS, food sensitivities
- Regression following trial
  - Brain fog
  - Lead blanket
  - Vertigo

# Thanks!

## Fellow Patient/Advocates

- PLRC Colleagues
- Jamie Seltzer, ME-Action

## VUMC

- Olivia Vyge
- Megan Wurtz
- Karen Sheppard
- Chris Berkey
- Bianca Plunkett
- Many others.....

- Holiday Inn Staff
  - Shuttle Drivers
  - Room Service
- DCA & BNA Wheelchair attendants
- All the funders of REVERSE-LC!

# CURE ID

## Long COVID Patients, Care Partners, or Healthcare Providers

Learn how YOUR experience may help to inform future research, identify promising treatments, or treatments that are ineffective or harmful.

These treatment experiences may also inform the drugs studied in clinical trials.



## About CURE ID

Working with patient and clinician advocacy groups, the FDA and NIH established CURE ID, an online treatment registry that allows Patients, Care Partners, or Healthcare Providers to share their real-world experiences using existing drugs in new ways, and explore what others have tried.



## Study Partners



## Project URL

<https://cure.ncats.io/pilot-overview/long-covid>

