

SB0392 FAV

Written Testimony in Support of Long COVID Funding

Submitted by Ylan Roy

Long COVID Patient, Vermont (Out-of-State Testimony)

Dear Members of the Committee,

Thank you for allowing testimony from individuals outside Maryland. I am submitting my story because Long COVID is not confined by state lines, and the decisions you make will influence national standards for care, research, and disability support.

Before COVID-19, I was healthy, active, and employed full-time. I spent 30 years working in early childhood education, including Head Start, serving families with significant economic and health disparities. During the pandemic, I continued working as an “essential worker,” masked and committed to keeping children safe.

In July 2022, I contracted COVID-19. The initial illness was mild. Like many people, I was told to rest and return to normal life. About a month later, everything changed.

My heart began racing unpredictably. I developed profound exhaustion, dizziness, gastrointestinal dysfunction, and neurological symptoms. Over time, I lost the ability to stand, walk, cook, or care for myself without assistance. Within five months of a “mild” infection, I became fully disabled.

Today, I live with Long COVID, ME/CFS, dysautonomia, and orthostatic intolerance. I require pacing, mobility aids, and strict limits on activity to avoid severe crashes. I cannot exercise my way back to health. I cannot “push through.” These are not choices—they are medical realities.

What has been most devastating is not only the illness, but the absence of coordinated care.

I have seen cardiology, neurology, gastroenterology, hematology, physical therapy, occupational therapy, and more—often with months-long waits and little communication between providers. I was repeatedly advised to exercise despite clear post-exertional symptom worsening. I was offered mental health explanations in place of medical ones. I was left to research my own condition while becoming sicker.

This lack of training and infrastructure causes harm. It delays diagnosis, worsens disability, and pushes people out of the workforce permanently. It also shifts costs—from early intervention and research—to long-term disability, Medicaid, Medicare, and family caregivers.

Long COVID is not rare. It affects adults, children, workers, caregivers, and healthcare providers themselves. It disproportionately harms women, essential workers, and people already facing barriers to care.

Maryland has an opportunity to lead.

Funding for Long COVID research, clinical care models, provider education, and patient support is not optional—it is essential. We need:

- Clinicians trained in post-viral illness and post-exertional symptom management
- Multidisciplinary clinics with real coordination and case management
- Research that includes the sickest patients, not just those well enough to participate
- Clear pathways for disability documentation and support
- Prevention and public education so fewer people join this population

I am one person, but there are millions like me. Many are still trying to work while sick. Many are caring for children with Long COVID. Many are invisible.

Please fund this bill not out of abstraction, but out of recognition that Long COVID is a mass disabling event—and how we respond now will shape lives for decades.

Thank you for listening, and for taking this crisis seriously.

Respectfully,

Ylan Roy

1586 Mountain View Rd, Williston, Vermont

Long COVID Patient and Former Essential Worker