

Bill Number: SB 0392
Position: FAVORABLE

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Written Testimony in Support of SB 0392

Long COVID Innovation Grant and Loan Program

My name is **Ellen O'Connor**. I live in **North Carolina**, and I am submitting this written testimony in **support of SB 0392**, the Long COVID Innovation Grant and Loan Program.

I am one of the estimated **6–9 million** people living with **myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)**, a serious **infection-associated chronic condition**. Research suggests that **up to half of people with Long COVID meet the diagnostic criteria for ME/CFS**. I became ill in the 1990s at just 11 years old after what doctors considered a “minor” infection. Like many Long COVID patients today, I never recovered.

Long COVID is not new. It is simply the newest iteration of something that has happened for generations: people develop an infection, and they never get better.

As a child, my parents spent seven years taking me to doctors in four different states, desperately trying to find help. Instead of treatment, many doctors told us my illness was psychological. One physician even falsely accused my loving parents of child abuse, and I was briefly removed from my family. During those years, I continued to decline because medical professionals did not understand my illness.

By my teenage years, I was over 90% bedbound and dependent on a feeding tube. When I turned 18, instead of applying to college, I was applying for disability benefits—applications my mother had to complete for me because I was too sick to do so myself.

More than three decades later, I am still severely disabled. I experience profound fatigue, cognitive impairment, and post-exertional malaise—an extreme worsening of symptoms after even minimal activity. I cannot work, cannot live independently, and require a caregiver for basic daily needs such as bathing and meals. Like roughly 75% of people with ME/CFS, I am unable to work—not because I lack motivation, but because there are no FDA-approved treatments and no cure.

This is what happens when medical science does not invest in infection-associated chronic conditions. Patients are gaslit, doctors lack education, and lives are permanently derailed.

Tragically, my story is no longer rare. I recently met a mother from New Jersey who described fighting for care for her 13-year-old son, who has been sick for two years with Long COVID. **30 years after my diagnosis, his story - the fight for care and accusation of abuse - echoes mine.**

SB 0392 represents a critical opportunity to change this trajectory. By investing in research, treatment development, and innovative manufacturing solutions for Long COVID and related conditions, Maryland can accelerate diagnostics, identify effective treatments, and reduce long-term disability. This progress would reduce disability costs and caregiver dependence while restoring lives and productivity.

For these reasons, I urge the committee to support SB 0392. Thank you for the opportunity to submit testimony and for recognizing the urgency of addressing Long COVID and other infection-associated chronic conditions.

Respectfully submitted,
Ellen O'Connor
ME/CFS Patient Advocate

