

HB0027 – FAV

Testimony submitted by

Emily Fraser  
2904 Viola St,  
Oakland, CA 94619

Dear Delegate Wims and Members of the Health Committee,

I am submitting testimony in favor of HB0027. This March marks 6 years of losing my entire life to severe Long Covid. Like many patients, my Long Covid case involves a number of comorbid and historically neglected infection associated chronic conditions including Myalgic Encephalomyelitis, Dysautonomia, Mast Cell Activation, reactivated chronic infections, & craniocervical instability. I have to spend 23 hours a day in bed, I'm unable to work, only able to bathe 3-4 times a month, only able to leave the house rarely for medical care, & am severely limited by neurocognitive dysfunction & post exertional neuroimmune exhaustion, which limit my ability to tolerate thinking, conversation, music, video, & screens. I've seen no one but medical workers since July. And I'm far from the most severe case.

Before Long Covid I was a Stanford-trained documentary filmmaker & cinematographer. I taught film at Santa Clara University & CA College of the Arts. I was a backpacker, a runner, & an environmental activist. I was recently married & preparing to have kids.

Since 2020 I've paid tens of thousands of dollars out of pocket for specialist care which stopped a precipitous decline & gave me modest symptom relief. I'm incredibly privileged to have been able to access this amount of care when there are only a few dozen or so experts in infection associated chronic conditions in the entire world & an even smaller number covered by insurance. However, after all that money & effort I lost my modest gains due to a Covid reinfection in 2024. My husband left me shortly after, convinced by his therapist that I was "faking the illness to control him."

The lack of education among medical professionals and the general public, lack of research funding, lack of financial & social support, & lack of infection control is killing people & subjecting us to inhumane levels of suffering & abandonment. Every week I see deaths reported on social media of Long Covid & Myalgic Encephalomyelitis patients around the world in their 20s, 30s, & 40s—many dying of euthanasia after years of profound suffering. It's Schrodinger's disease:

simultaneously severe enough for the state to put you out of your misery, yet not severe enough for investment into a single validated treatment.

There are around half a billion people with Long Covid around the world, mostly young & middle aged women like me, but all genders & ages are affected, including teens and young children. It's now considered the most common chronic illness in children, surpassing asthma. Yet there are zero approved treatments, with much of the early research funding wasted on already disproven theories because the world's leading experts in infection associated chronic conditions were not given NIH funding & their existing research was ignored rather than built upon.

We know the risk of Long Covid increases with reinfection—it doesn't decrease. We know vaccination does not prevent Long Covid. And we know Covid continues to mutate & spread at rates higher than during the first year of the pandemic when mitigation measures were in place. This problem is clearly not going to disappear on its own. Investments into Long Covid and other infection associated chronic conditions is the smart choice and the only ethical choice.

Sincerely,

Emily Fraser