Crystal Burke
Hancock
LD 1688

Good afternoon, Senator Bailey, Representative Mathieson and honorable members of the Health Coverage, Insurance, and Financial Services Committee. My name is Crystal Burke, I live in the town of Hancock, and I am here to testify in favor of LD 1688. I represent myself, the many of members of the Maine Chapter of C19 Longhauler's Advocacy Project (a patient support group), along with several other patient advocacy groups I am a member of in the Dysautonomia, ME/CFS, Long Covid, and other relevant IACC patient groups. I also advocate before ME's SILC and am a rural patient representative for the NIH RECOVER project.

I am an "OG Longhauler". This means that I was infected with SARS-CoV-2 back in March 2020 and I never really recovered. I have had a fever nearly every day since then. My heart rate still wildly fluctuates, causes my heart rate monitor to ping repeatedly for A.Fib and abnormal heart rates of 150 bpm and higher, my blood pressure continues to climb, and this is while I am on the meds to control it that I only was able to talk my doctor into a bit over a year ago when I caught nurses changing my stats so they didn't have to send me to the ER and pointed it out with a threat to report it. I am one of the "lucky cases" with cardiac, respiratory, and neurological symptoms along with random symptoms that fluctuate and come and go when I exert effort; physical, mental, or emotional. My testimony here comes at a cost to me. I won't know what it is until I experience it, but I care enough about this to risk my health and possible permanent damage to share why I think this bill is so important.

I would love to give you the long history of my challenges in accessing appropriate medical care for my Infection Acquired Chronic Conditions, but the best possible summary is happening tomorrow. It took over two and a half years to get my doctor to acknowledge that something was wrong with me and diagnose me with ME/CFS. Even then, she told me she wanted it to be a mental health problem because she didn't want the things I showed her, the research, peer reviewed studies, CDC, NIH, and Congressional testimony to be real. I moved to a new doctor who agreed I am experiencing Long Covid, and with my help, learned he could diagnose me with POTS (and what POTS was), and finally sent me to a cardiologist, something I was told needed to be done urgently 2 years before. The cardiologist wanted to make me repeat a cardiac stress test, something that I had been unable to complete and that made me bedbound 2 years prior. I refused and asked to be referred to a specialist who understood the potentially permanent harms the CST could cause in someone with ME/CFS. He is sending me to get a Tilt Table Test in Boston tomorrow. Now for those in the audience who are keeping up on research; I saw the warnings from The Sick Times and the American Heart Association against this test for patients with ME/CFS and Long Covid and I will refuse this test too. I will be fighting with the 3rd set of doctors in a row for them to perform either the NASA Lean Test or the Active Stand Test. These tests are actually recommended for patients like myself as being less harmful, especially with modifications to make them less likely to cause long term damage. I will still need to drive to Boston and back to "advocate for myself" against doctors who choose not to learn about the conditions I have. For those who don't know; for a healthy person a TTT is no big deal. For folks like myself, whose bodies can't figure out how to regulate heart rate, blood pressure, or blood flow, it can and more frequently does cause heart arrest, neurological damage, and a permanent decrease in physical condition. As the single income in my household, I cannot risk that, especially when the test is being done to appease my doctor's curiosity more than to change my treatment in any way. I am being asked to drive to Boston, with an energy limiting chronic condition, for a test that may cause me permanent harm, that will in no way affect my treatment if my doctors would simply treat me for my symptoms as they presented.

Because I have an IACC connected to my symptoms, they are refusing to treat many of my current symptoms and want to wait 10 plus years to be handed a protocol with my condition listed at the top. Meanwhile, folks in my cohort are beginning to die of organ failure and other consequences of denial of adequate medical care. Several medical and patient groups, including folks like the Bateman Horne Center have released guidance on how to treat and manage our conditions, offer continuing medical education trainings on our conditions and so much more. Harvard, Yale, and many other medical schools offer free trainings. Dr Putrino and other national Long Covid clinics offer CME and education sessions. Doctor Rowe offers guidance on the treatment of POTS and Orthostatic Intolerance and Dysautonomia. There are so many more that I know about as a patient and an advocate and yet I haven’t met a doctor in the state of Maine willing to research these conditions in order to more properly care for myself or any of their other patients. That is why it falls on legislation like LD 1688 to require, or at least “encourage” that they offer the necessary care.

Nationwide, estimates are that a minimum of 7% of the American populus is dealing with the symptoms and consequences of Long Covid and that was stated as likely a gross undercount with actual numbers possibly being multiples higher than the estimated 40 million Americans under and unemployed as a consequence of this illness. The costs to our economies are estimated in the trillions annually and a recent report from an insurance reinsurer suggested that we will see around 200 thousand deaths a year for the next 10 years as the long term consequences of Covid if we do nothing. Maine’s estimates for percentage of the population were slightly higher than the national average because variables like age, employment status, and wealth are correlated to the likelihood of developing IACCs.

One of the most concerning parts of this is the estimated 1-3% of our children who are estimated to be dealing with the long term consequences of Covid infections. As a school board member who is active at the state level, I am unaware of a single student who has been identified and is receiving accommodations or supports to help them deal with Long Covid. This is a massive failure of our schools for our students. These are students who may find themselves too exhausted to learn, to get out of bed after a test, to compete in athletics, or to consistently attend school. Instead of supporting these students, we are accusing them or their parents of laziness and taking actions that perpetuate or exacerbate the harms.

I know that my other school board members don’t want to talk about Covid. Many boards and legislatures have fallen into the twin traps of “it’s too sad to talk about or acknowledge” and “it’s too political”. But this is our job, to find and support these students and help them become the next generation to grow up supporting Maine and loving it because it supported and loved them. The schools point to you, the Maine CDC, the medical community, and the lack of communication and awareness about Long Covid, ME/CFS, Lyme, and other invisible disabilities and chronic conditions as their model for why they do nothing. I do my job and point out these errors. Ignoring a problem has never made it disappear. I work with the many patient communities I am a part of to help them find care even when I can’t. I do everything I can with my very limited energy.

Now we all need you to step up and lead and tell the medical community that they can’t ignore us any longer either. They must learn how to identify, safely test for, treat, and manage our conditions. We can’t keep getting sent out of state. We can’t keep getting referred to damaging care or psychologists that are only needed because of the lack of appropriate medical care. Maine cannot remain a medical desert and thrive. Tell our medical providers that they need to learn, to support our advocacy, and to make Maine healthier and stronger. They can’t abandon us any longer.

Thank you for your time. Please let me know if there are any questions or if you would like links to any of the data or resources I suggest above.