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Portland
LD 1688

Good afternoon, Senator Bailey, Representative Mathieson and honorable members of the Health Coverage, Insurance, and Financial Services Committee. My name is Bethany O'Meara and I live in Portland. While I wish I could be there to submit testimony in favor of LD 1688, due to my chronic illnesses I'm unable to participate in person or on zoom.

I first became chronically ill in 2013, at age 23, after having a serious dual infection post sinus surgery. It took me months to recover from the infections, but little did I know I would never feel healthy again. Instead of pursuing my professional goals, I had to move back in with my parents after becoming too ill to work full time. It took nearly two years but I was eventually diagnosed with ME/CFS and then POTS another 5 years later. Over the last decade my health has degraded to the point I'm unable to work at all or even spend much time out of bed. I've acquired multiple autoimmune diseases and have permanent nerve damage stemming from these conditions.

One of the hardest parts of these illnesses is dealing with scary new symptoms while trying to find a diagnosis. This is exponentially more difficult when very few doctors have the diagnostic knowledge or know the hallmarks of the illness. Then there's the fact that some of these illnesses have been historically thought of very differently than they are now. Tragically, some doctors will still tell patients their symptoms are all in their head or that 'X' illness isn't real. Back when I was first diagnosed the advice from my doctor was to push my hardest to get healthy- to exercise and go to therapy. Over the first few years I continued to deteriorate and scientific consensus now recommends ME/CFS patients avoid or be very careful with exercise. There are many other patients just like me who have been prescribed graded exercise therapy and then immediately decline. The science now recommends pacing instead of exercise. Providers need to know this so they aren't hurting their patients with outdated advice.

On my chronic illness journey not only have I been given bad treatment information, I dealt with incompetence and gaslighting from medical professionals that delayed proper diagnosis and care. I was completely misdiagnosed by Maine Med Neurology as having an inner ear problem when that was not the case. They ignored tell tale signs of ME/CFS and dysautonomia because of that lack of education. A cardiologist at Maine Med flat out refused to give me a tilt table test requested by my PCP because I wasn't "fainting upon standing." Tilt table tests are a primary way to diagnose POTS, but many POTS patients do not actually faint and this doctor was completely unaware of that fact. I ended up having to travel to Florida to see an ME/CFS specialist and to NH for proper care for my POTS because no doctors in state are educated enough to know how to treat these illnesses.

I have noticed specifically since the pandemic started and more long covid patients are developing these chronic conditions, more of my providers are at least aware of POTS, but still few are able to actually treat the condition. Wait times for the few specialists in the region are going up. My POTS specialist now schedules out over a year in advance. We desperately need more doctors to learn in depth about these conditions.

I urge you to support this bill's passage so we can strive for a state and a nation where patients don't have to go through all the difficulties I have on top of dealing with the debilitating symptoms of post infective chronic illness. We should be able to rely on our doctors for accurate and safe information to help us deal with these very prevalent illnesses.
Thank you.