Good afternoon, Senator Bailey, Representative Mathieson and honorable members of the Health Coverage, Insurance, and Financial Services Committee. My name is Marie Follayttar, I live in South Portland, and I am here to testify in favor of LD 1688.

I lost three years of my professional life fighting to find medical care and diagnoses. I am still picking up the pieces of the life I could not manage while wasting 130 pounds struggling to eat and drink even a few ounces and a few hundred calories a day. I am grateful every day to be alive, to advocate to pass LD 1688 and I honor Maeve Boothby and others with my condition who have starved to death because their condition was not understood by the providers who cared for them. I work 40 hours a month and am slowly rebuilding and re-integrating to the world. My providers are primarily out of state and it is a terrible bind to understand your condition and not have a provider who does. This is not a new story for me. It's the third time I've had a major disruption in my life and I am grateful for taxpayer funded support and the community who cared for me.

Based on my symptoms it is likely my first covid case was 12/19 and my first positive test was Oct 2022. Days before I presented a vision with Former Chair of the Joint Standing Committee on Criminal Justice and Public Safety Charlotte Warren on a body of work to do. I was in the middle of a fellowship in impact investing with my hero who co-founded the Good Pledge with Kat Taylor. You may know my work. I once ran and co-founded Mainers for Accountable Leadership, helped co-found Moral Movement Maine, helped bring the Poor People's Campaign to Maine and the spokesperson on a campaign that raised $4.3 million.

Educating providers about infection associated chronic conditions is not just about defining an illness. It is about defining a care plan and with illnesses like ME/CFS that have no real treatment other than pacing it requires an educated team to even tend to us in the hospital and not harm us. Many of us may only have a palliative treatment option available. But a palliative plan can increase the quality of life and when navigating multiple conditions without cures isn't a better quality of life worth everything?

With unknown illnesses there is an unknown impact on our world. And as patient #2 of the Recover study I am yet to receive the results of my cognitive testing. I was offered cognitive testing but it was to be diagnostic and I asked if they understood the impact of intracranial hypertension, me/cfs, long covid, and they told me no, but that the test would still be diagnostic.

When I asked my dr why I should continue to see a gastroenterologist who had no training in my condition I was not answered. I am on Medicaid. I do not understand why the public is paying for me to see providers who do not understand my conditions. I shop for doctors to give me care that is illness informed. I have 5 infection associated chronic conditions and when I saw the Director of the Harvard Consortium on ME/CFS he theorized that I had struggled with ME/CFS since I was a teenager. I've struggled functioning & managing my disabilities my whole life. Absent informed care I cannot function and I am in bed as I was for most of 2 years. More are in bed like I was. More are lost in systems and scared. More have lost faith in themselves and their right to occupy space and ways to participate in the world. Please help them.

"I urge you to vote in favor of LD 1688. Thank you for your time, I'm happy to answer any questions that you have"