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

I've observed that many folks who've never been disabled assume that if something bad happens to them medically, doctors can fix you. For those who have been disabled and experienced chronic illness, we know that's not true. I've been disabled by chronic illness twice in my life. The first time I was 11 years old. My brother and I suddenly developed many food allergies making us unable to eat most food. We were unable to eat most food in a normal grocery store, could not go out to eat at all, were unable to travel without extreme preparation, and with all our precautions we were still so sensitive that exposure to the wrong laundry detergent or a spilled soda resulted in our throats closing and breaking out in hives. In the span of 6 years I saw 10 doctors some of whom did harm and many of whom were dismissive. The last doctor we saw fortunately ordered the right test at the right time and was able to identify that we had rare parasites, then prescribed us a dangerous and possibly lethal dose of the appropriate medication to kill them. We were fortunate that the pharmacist caught the dosage and the medicine that resolved that disability didn't kill me or give me a new one.

The second time I was disabled was at the age of 25 when I had no preexisting conditions and was a healthy newly wed. I caught covid in 2022 and have not fully recovered since. During my infection, I went to urgent care to try to get Paxlovid and was denied it. The provider I saw at urgent care told me the side effects of the meds were likely to outweigh the benefits but also wouldn't give me the choice for myself. Paxlovid may have reduced my chances of contracting Long Covid. I spent multiple years mostly bed bound; unable to sit up without my heart rate spiking and experiencing significant breathing difficulties. At one point I spent 6 months straight with nausea and ended up puking in several public places. I had debilitating brain fog to the point where I could at times not do anything but be in a dark and quiet room. I was about to cut all my hair off because caring for it was too exhausting before I found a treatment that started working.

A few months of not recovering after my initial infection, I started looking for a PCP. The only doctor I could find that would see me in less than a month was a doctor with MD VIP which had a cost of entry of $1,200 not covered by insurance just to receive care in a timely fashion. I hoped that with the extra price tag I would get a provider with capacity to research my condition and support me better than a hospital based PCP. That was unfortunately not my experience. I was prescribed two different inhalers and $400/month in supplements and saw no improvements. My provider was out of ideas when these made no positive impact in a few months and did nothing independently to support me seeing other specialists, and by the end of my care under her, I was getting worse and I was exploring options to file for disability. It was clear she received no specific training or education in chronic illnesses like mine or on Long Covid and my understanding of my condition and current treatments quickly surpassed her own. On the last appointment I had with her, without prompting she told me if I had children, they were more likely to be autistic because I had an autoimmune disorder. Long Covid is not really an autoimmune disorder and there is no current known link between autoimmune disease and autism. Years later I have discovered a likely reproductive impact of my Long Covid - I most likely have a severely depleted ovarian reserve for my age and will likely go into menopause extremely early.

My first PCP referred me to a long covid clinic in Dartmouth after I found the clinic and begged her for a referral. I drove an hour to Portsmith so I was legally where they could treat me for a telehealth appointment. I spoke with a nurse practitioner who referred me to an occupational therapist and offered a support group that never materialized and she never followed up with me. The clinic is now closed even though millions of people have Long Covid and more people continue to contract it with repeat Covid infections. The occupational therapist charged me $600 out of pocket for an hour of her time where she told me that I should focus on doing things that made me feel better. Shockingly, this was something I was already clued into. She referred me to a physical therapist who had experience with long covid. I had to change my PCP to be in the same network to be able to see this PT. The PT was probably the most knowledgeable on Long Covid of any provider I've seen so far. We worked on slowly easing my body into tolerating physical activity again and his knowledge of my illness was very helpful in my recovery. The PCP I switched to in this network truly shocked me when at my first visit with her after sharing my Long Covid symptoms, she asked me if I had any other issues. I told her I did not and she exclaimed "Great! So you're healthy! I love to hear that!". That certainly didn't align with my idea of a healthy 26 year old - I was physically incapable of spending any more than about 1 hour upright at a time, and was spending between 18 and 20 hours a day in bed. I was also experiencing significant cognitive issues from LongCovid and was no longer able to do my job effectively and was requested accommodations to my work expectations, which I am lucky enough that they provided.

There is a link in my written testimony to an art exhibit I made a few years ago called The Lost Year chronicling my first year with Long Covid. I should have named it The Lost Years because I continued to be very ill long past the one year mark with a variety of symptoms and while I am very grateful to have either mostly recovered or to be in remission (only time will tell), it has only been through great privilege and access to time, money, and a caring support system of family and friends.
This bill would have made a difference in my care. It will make a big difference for the care of many with chronic conditions in the future. Covid continues to be a mass disabling event and there are many other chronic conditions aside from Covid that are treated similarly.

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.

The Lost Year: https://my.matterport.com/show/?m=PnVrzmmAx4d