Joy Sinclair
Brewer
LD 1688

Good afternoon, Senator Bailey, Representative Mathieson and honorable members of the Health Coverage, Insurance, and Financial Services Committee. My name is Joy Sinclair, I live in Brewer, and I am here to testify in favor of LD 1688.
I have been educating my doctors about the issues I deal with for three decades.

I live with three chronic illnesses and the chronic conditions associated with them. Two are considered disabling, but alas, because I got married, disability is a fight that I don't have the time or money for.
I have been navigating the medical system on my own since I was a teenager. My mother, brought up in the generation where you don't question doctors, didn't push for answers or anything further when I was a child with consistent injuries, aches, and pains. I will never forget hearing her say to a relative on the phone that, "the doctor says there isn't anything physically wrong with her." I was ten.

Fast forward thirty years, and it turns out there was plenty physically wrong with me. It was testable and treatable, even in the eighties. I was diagnosed with Hashimoto's Thyroiditis at 19, an autoimmune disorder in which the thyroid is attacked by the body, usually after a viral infection. I was diagnosed with POTS and an additional form of dysautonomia (autonomic nervous system dysfunction) at 40, and hypermobile Ehlers-Danlos syndrome at 43.
In 2021, when the pharmaceutical company stopped making the generic levothyroxine I'd been on for twenty years, I logged the date I started a new one. Within 27 days I was in a full-blown medication reaction, with symptoms of severe lethargy, dizziness, joint pain, and "brain zaps" (that most doctors will tell you only happen when you stop antidepressants cold-turkey).
These reactions continued for the next four years. I am still getting them, after being progressively put on every single type of thyroid medication available. I am now on the brand-name, purest form of liquid, and still react to it, however less frequently. Due to these reactions, I was diagnosed with Mast Cell Activation Syndrome, and have been put on additional medication (which I have to add one at a time, in case of reactions) to keep my body from having anaphylaxis and other allergic reactions. One of these medications is next to impossible to get, even at a hospital pharmacy. Cromolyn sodium oral (brand name Gastrocrom) has been in "a drug shortage" for the past two years. The FDA and our representatives and Congressfolk don't seem to mind that a medication that keeps at least ten people (that I know of) in the Bangor area out of anaphylaxis is simply not being made.

My specialists, save one, are out of state. The only autonomic specialists - neurologists - available in the northeast are Dr. Farhad in Portsmouth, NH or Dr. Nowak in Boston.
I gave up after my fourth rheumatologist in Maine telling me I was "too young" to have the problems I was asking them to test me for, or them simply saying I had fibromyalgia and leaving the state to practice elsewhere. The closest geneticist to reach out to for the EDS diagnosis was in Boston, and I had a zoom call where she told me "she'd never heard of hypermobility spectrum disorder." We had a terse exchange, where I cited some case studies to her, and she miraculously changed her tune and ordered what I'd contacted her for: genetic testing to rule out the 10 other subtypes of EDS. I had been repeatedly warned about local geneticists and their views on connective tissue disease.
I reached out to a rheumatologist in New Hampshire and got the first positive medical visit I had had in many, many years. Outside of my primary care provider, this was the first medical professional who truly listened to me, didn't immediately dismiss me as anxious or malingering, and looked at my pertinent records that I brought with me. I get copies of all of my medical records since I worked in healthcare in 2003 and discovered that I was never told I had scoliosis, and that I was not informed that my hypothyroidism was autoimmune. I ask for scans on disk in case I have to hand carry

them to another provider, because I never expect the right amount of records to be sent by a referring office. It’s usually one or two office notes and maybe a report, but no films.

I see a local immunologist who diagnosed me with MCAS in 2022 at the age of 41 based on not only my symptoms, but also lab tests and a 24 hour urine collection. That specimen was thrown away THREE TIMES before I was told to take it to the correct lab. I was not only given incorrect delivery instructions, but incorrect procedure instructions - because of my POTS and the 3 liters+ of water I drink daily, I needed to drink less water for the sample not to be too diluted to test.

People with chronic illnesses do not have the energy to continually fight for adequate care. Many, if not most of us, give up and simply stop pursuing diagnosis. The rest of us are deemed “difficult patients” and treated as pariahs.

I urge you to vote in favor of LD 1688 because I, amd many others, are quite literally sick and tired of having to educate board-certified physicians about my existence. Thank you so much to Representative Ambureen Rana for sponsoring this bill.