Amy Blackstone LD1688 Testimony

Hello, co-chairs, members of the committee and thank you Rep Rana for sponsoring this bill.

My name is Dr. Amy Blackstone. I'm a proud resident of downtown Bangor and have been living with Long COVID since March of 2020.

I'm also a member of the Patient-Led Research Collaborative, a group of Long Covid patients who are all credentialed researchers whose mission is to facilitate patient-led research into Long Covid.

Life as I'd known it for my first 47 years ended on March 15, 2020; the day I felt a tickle in my throat that would soon become a full blown case of acute COVID-19. On that date I entered what I now call life 2.0, a somewhat familiar but much less enriching copy of what had been a full, happy existence including deep relationships, community engagement, and a thriving career.

Although Long COVID has been my condition for the past 5 years it has only been my diagnosis for 3.5 years. You see, it took over 18 months for me to receive the proper diagnosis because my PCP at the time denied the many requests I made for referrals that might have helped us both better understand the strange complex of symptoms I found I couldn't shake following my COVID-19 infection.

You might think we've come a long way since those earliest days when I struggled to get the right diagnosis and in some ways we have but I can tell you that even today, it is still more common than not for me to encounter providers in Maine who claim not to have heard of my condition.

In the recent past, at a visit to the emergency department while suffering a severe migraine, I was immediately quarantined because the intake provider thought - incorrectly - that having Long COVID meant I was contagious.

At a visit to a local GI specialist, upon learning I was there due to complications from Long COVID, a provider corrected me saying, "You mean you've had COVID-19 many times." I have only had COVID-19 one time.

These experiences are common - and mild - compared to my visit to a local neurologist who told me that in his experience most people who claim to have Long COVID don't actually have the condition, they simply have mental health problems.

Recently, I have been in close contact with members of the Maine Medical Association regarding LD1688. Though our positions on this bill differ, we all share the value that ensuring the very best possible outcomes for patients - proper diagnoses without delay and access to the most up-to-date treatments available - is and must remain the top priority.

As someone who has watched her own sister - a family practice doctor at the Mayo Clinic in Minnesota - work herself to the bone in service to her patients, I empathize with providers and what may feel like yet another mandate coming from on high.

At the same time, I want to make clear that this bill requires absolutely nothing beyond a simple ask: to please consider that ANY of the dozens of hours of education that providers must already take be in some area we know is at best misunderstood by providers and at worst completely unknown to some.

If LD1688 does not pass, I want to emphasize my sincere pledge to continue working with medical leadership in Maine to improve education opportunities for providers in our state. Patients and providers are partners, not opponents. I know that we can and will work together moving forward.

Thank you for the opportunity to share my story and to speak with you today.