Kristi Woods
Augusta
LD 1688

Testimony of Kristi Woods, Resident of Augusta

Supporting: LD 1688: An Act to Encourage Continuing Education Relating to Certain Infection Associated Chronic Conditions for Physicians and Nurses

April 26, 2025

Senator Bailey, Representative Mathieson and Honorable Members of the Joint Standing Committee on Health Coverage, Insurance & Financial Services:

My name is Kristi Woods, I am a resident of Augusta and I support LD 1688 and appreciate Representative Rana and the other cosponsors for bringing this legislation forward.

My journey with myalgic encephalomyelitis, or chronic fatigue syndrome (ME/CFS), likely began around 2010. Prior to becoming ill, I was a promising high school student. I had the 5th highest GPA in my high school graduating class, was one of the best runners in my district, and president of my senior class. My first year of college I started experiencing fatigue, digestive and gynecological issues. I did not get as much understanding as I needed as a student for my emerging medical difficulties. I was told by a professor that I was on a list of students they felt wouldn't complete the program due to not applying myself, even though I had to work harder than my peers to retain the information. Over the years I continued to develop more symptoms and the ability to function in my career as a nurse became increasingly difficult. I continued to seek out answers from providers farther from my home because locally my symptoms were on multiple occasions downplayed or were inaccurately deemed to be the result of stress or mental health disorders. By the time I was diagnosed with ME/CFS in 2022, I saw over 40 providers across 7 different states and incurred substantial costs. I had to do a lot of the guesswork to find the causes of my symptoms by doing research and asking for the referrals and tests from my PCP who thankfully was always willing to do so. It wasn't until learning of long COVID, that I realized ME/CFS—which shares similarities to long COVID—was the root cause of my suffering. After a mild COVID infection just months following the ME/CFS diagnosis, I deteriorated and became mostly bedbound, lost the career I loved as nursing supervisor of an inpatient mental health unit, and began relying on a wheelchair when I left the house at age 32. Of the millions of people suffering with ME/CFS, it is estimated that 25% of those diagnosed are house or bed bound and have a lower quality of life scale than some better-known diseases such as chronic kidney disease, multiple sclerosis, and some cancers. However, those with ME/CFS face skepticism and poor treatment due to lack of understanding of the diagnosis. Although there are currently no FDA approved treatments, having a correct diagnosis is still important. It allowed me to use appropriate non-medication related strategies to prevent my symptoms from getting worse. Learning material from ME/CFS experts and organizations across the country helped me to discuss existing medications available for other conditions to address certain symptoms with my providers, so I am now mostly housebound rather than bedbound like I was two years ago. Now that I know what is underlying my suffering, I'm left wondering if I had known what was wrong 15 years ago when my symptoms first began, could my level of disability have been avoided? Most people would say being believed by your doctor and treated appropriately is supposed to be the standard of care. It should, and can, be the standard of care for post infectious disorder patients too. And it shouldn't require a nursing background, or leaving the state, to be believed and diagnosed correctly. LD 1688 can bring awareness of ME/CFS among other post infectious illnesses to Maine healthcare providers, leading to education. This will allow Maine patients to be diagnosed faster, face less skepticism and inappropriate treatment and improve their quality of life.

Thank you for your time and I urge you to vote ought to pass LD 1688.

Sincerely,
Kristi Woods, BSN