PATIENT-LED
RESEARCH
COLLABORATIVE

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Patient-Led Research Collaborative Supports Maine's LD1688

On Wednesday, April 30, Maine's Joint Health Coverage, Insurance and Financial Services Committee will hear testimony regarding LD1688, An Act to Encourage Education Relating to Certain Infection-Associated Chronic Conditions for Physicians and Nurses.

As the first to research Long COVID, and as a leading patient-led research and advocacy organization, we support this groundbreaking bill, recognizing the role it will play as a pivotal moment of change in improving the health and well-being of those suffering from Infection-Associated Chronic Conditions (IACCs) in Maine.

IACCs are long-term chronic conditions triggered by infections and impacting approximately 31 million Americans. They include conditions like myalgic encephalomyelitis (sometimes called "chronic fatigue syndrome"), postural orthostatic tachycardia syndrome (or POTS), dysautonomia, Long COVID, and chronic Lyme disease, a condition that up to 20 percent of people treated for Lyme can experience.

At least 1 in 19 American adults are currently living with Long COVID, similar to rates of diabetes. An estimated 272,000+ Mainers are already living with this condition, with many additional cases likely going undiagnosed or misdiagnosed. Maine's LD1688 promises not only to address these undiagnosed and misdiagnosed cases, but also improve services by bringing greater awareness of Long COVID and other IACCs and available treatments to the state.

Only 7 percent of physicians report feeling very confident diagnosing Long COVID and only 4 percent say they are confident treating it. LD1688 will go a long way toward empowering Maine's medical providers to effectively treat the state's most chronically ill patients. We applaud Representative Ambureen Rana's efforts in sponsoring LD1688 and heartily support this crucial legislation.

About PLRC:

Patient-Led Research Collaborative (PLRC) strengthens and facilitates research into Long COVID and advocates for policies that improve the quality of life for Long COVID patients. We conduct our own patient-led research; partner with health and research organizations globally to improve study design, guidelines, and education for medical providers and the general public; and advocate for better treatment, care, and support for all patients. We ground our work in the principles of disability justice and participatory research methods, and in the knowledge that those who experience an illness are best able to identify research questions and solutions. Follow us on X and Instagram or reach out to team@patientledresearch.com.