

# MaineHealth

## MaineHealth Local Health Systems

Franklin Community  
Health Network  
LincolnHealth  
MaineHealth Care At Home  
Maine Behavioral Healthcare  
Memorial Hospital  
Maine Medical Center  
NorDx  
Pen Bay Medical Center  
Southern Maine Health Care  
Synernet  
Waldo County General Hospital  
Western Maine Health

## Part of the MaineHealth Family

MaineHealth Accountable  
Care Organization

## MaineHealth Affiliates

MaineGeneral Health  
Mid Coast-Parkview Health  
New England Rehabilitation  
Hospital of Portland  
St. Mary's Health System

## Testimony of Sarah Calder, MaineHealth In Support of LD 2007, “An Act to Create the Amyotrophic Lateral Sclerosis Incidence Registry”

March 7, 2022

Senator Claxton, Representative Meyer, and distinguished members of the Joint Standing Committee on Health and Human Services, I am Sarah Calder, Director of Government Affairs at MaineHealth, and I am here today to testify in support of LD 2007, “An Act to Create the Amyotrophic Lateral Sclerosis Incidence Registry.”

MaineHealth is a non-profit health care system that provides the full continuum of health care services to the residents of eleven counties in Maine and one in New Hampshire through its nine acute care hospitals, physician practices, lab, home health care services, an integrated continuum of inpatient and community-based behavioral health services and, importantly, through a broad spectrum of research at Maine Medical Center Research Institute (MMCRI).

MaineHealth is dedicated to improving the health of our patients and communities by providing high-quality affordable care, educating tomorrow's caregivers, and researching better ways to provide care. Central to our mission is research and, with that said, we strongly believe that robust data collection on disease incidents contributes to finding lifesaving cures and prevention strategies. It is for that reason we support the legislation before you today, which creates an Amyotrophic Lateral Sclerosis (ALS) registry, similar to that of cancer and some infectious diseases.

We would urge the Committee, however, to amend LD 2007 to require the Department of Health and Human Services implement the registry in accordance with the US CDC's ALS registry, ensuring that Maine contributes its information to the national registry and supports national research efforts. Moreover, we believe that there are federal and private funds available to establish disease incidence registries, and we would request the Department seek those funding opportunities. As it has done with other registries, we would also ask the Department to consult with Maine providers who treat ALS patients and ALS researchers, like MMCRI, as it works to create the registry.

Thank you and I would be happy to answer any questions you may have.