

To: Joint Standing Committee on Health and Human Services

Date: March 7, 2022

Re: LD 2007, An Act to Create the Amyotrophic Lateral Sclerosis Incidence Registry

Written Testimony Submitted by: Laurie McFarren, ALS Association Care Services Coordinator, Maine

To Honorable Committee Chair Claxton, Chair Meyer and Committee Members,

As the care services coordinator in Maine, I represent the ALS Association and our support for LD 2007, for creating an ALS Registry in the state of Maine. We are grateful to the Governor for submitting this bill, to Senator Claxton and Representative Osher for bringing the bill forward, to Karin Smith who has been the fuel behind this bill and to George Smith for his work with Karin in the initial stages.

Maine Registry Testimony

Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease, is an *always* fatal neurodegenerative disease in which a person's brain loses connection with the muscles. People with ALS lose their ability to walk, talk, eat, and eventually breathe. ALS usually strikes people between the ages of 40 through 70, but it can strike anyone at any time. And with no known cure or effective treatment options, the life expectancy after diagnosis is 2 to 5 years. The yearly cost of care for an ALS patient is estimated to be \$250,000.

About the ALS Association

The ALS Association seeks to find treatments and a cure, optimize care for people living with ALS as well as reduce the harms and prevent ALS. The association is the largest private funder of ALS Research worldwide, and our efforts have led to some of the most promising and significant advances in ALS research. The ALS Association also provides a wide range of care services to people living with ALS in every state and supports multi-disciplinary care in ALS Clinics nationwide. Our advocacy has boosted federal and state spending on ALS. One example is that the National Institutes of Health estimates spending on ALS research at \$110 million for 2021; the Department of Defense spends \$40 million on ALS research and the Centers for Disease Control and Preventions spends \$10 million on the National ALS Registry and Biorepository.

The National ALS Registry and Biorepository- National But Not State Data

The bill to create The National ALS Registry and Biorepository was signed into law in 2008. The Registry currently receives \$10 million in federal funding and is administered at the Centers for Disease Control and Prevention (CDC). It includes data from existing national databases (i.e. Medicare and VA) as well as information provided by persons with ALS who choose to participate. Researchers can use Registry data to look for disease pattern changes over time and try to identify whether there are common risk factors.

The Registry also funds 21 academic institutions to identify, examine, and evaluate potential risk factors for ALS. These grants are focused on environmental exposures to heavy metals and persistent organic pollutants, genetics, identification of biomarkers, and occupational exposures. It also funds selected state and metropolitan area ALS surveillance projects because of concerns that data on minority groups might be missing from the National ALS Registry. Lastly, the Registry includes a Biorepository that collects blood, urine, hair and fingernail clipping specimens from people living with ALS and post-mortem collections donations of brain; spinal cord; cerebral spinal fluid; and pieces of muscle, skin, and bone.

However, the National ALS Registry has not been able to provide data that can be used by researchers on a state-by-state basis. This is because of federal regulations preventing release of state specific data, patient privacy regulations and ALS' status as a non-reportable, non-notifiable disease.

Support for the Maine ALS Registry and Massachusetts ALS Registry

In 2002, Massachusetts was one of 7 states awarded funds by the U.S. Centers for Disease Control and Prevention to track health conditions thought to be impacted by the environment. The statewide registry, initially supported by CDC funds but now supported with state funds, was established in 2003 and called for more research into the causes of ALS. Today, the Registry collects patient demographics, clinical symptoms and laboratory data, diagnosis and treatment. State funding for FY 2021 is estimated to be \$290,027 and all documents are available on the Bureau of Environmental Health website. The National ALS Registry is working with the state of Massachusetts to compare their reported ALS cases to that of the Registry's.

About Services in Maine to People with ALS

In addition, to funding the Maine Registry, we urge the Maine legislature to provide funds for direct services to people living with ALS and physician education on ALS.

In Maine, all support services available to people living with ALS and their families are provided free of charge through the Northern New England Chapter of The ALS Association. The chapter has served over 250 Families in Maine in the last 5 years. Chapter Care Service Coordinators provide home visits and follow up on recommendations made by the multidisciplinary team member from The Midcoast Maine ALS Center and other ALS clinics in the region. Equally

important, the coordinators help people with ALS and their families to navigate and secure support from all federal and state programs.

Areas of pressing need for the families served by the Northern New England chapter include funding for case managements staff to provide direct care to more people with ALS – especially in rural areas. Funds needed to support people with ALS staying at home instead of being hospitalized or institutionalized include: 1) home modifications and specialized equipment; 2) travel to medical appointments; 3) technology support for internet access ; 4) specialized ALS equipment loan and purchase support – including communication equipment and much more.

Several states have provided additional state funds to help multi-disciplinary ALS clinics to expand the number of patients seen and to chapters for more case management. State funds have also been provided to ALS chapters for home modification; wheelchairs, ventilators and speech generating devices; respite care; home health aides; emergency assistance; natural disasters support and much more.

Across the county, physician education and training on ALS is need. The disease itself is complex and multifaceted. Primary care and other physicians do not understand ALS and must refer to a neurologist. State funds to support outreach, education and training of physicians and other health care practitioners about ALS would be helpful.

Thank you for your vote to mandate an ALS Registry for Maine, a step toward improved access to care and a cure for those living with ALS.

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OUR VISION Create a world without ALS

OUR MISSION *To discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.*