

Testimony of                   The ALS Association  
  *John E. Hedstrom – Territory Executive, New England*

Regarding                    S.90 – regarding a bill to establish a (mandatory) amyotrophic lateral sclerosis registry, to the Vermont House Human Services Committee

Date                            April 20, 2022

Thank you for inviting The ALS Association to testify today, sharing our support, for S. 90. I am John Hedstrom, the Territory Executive for the ALS Association New England region. Until February 1 of this year, I served as the Executive Director of the Massachusetts Chapter and took my current role as our organization undergoes structural changes to better serve our ALS community. Currently, we are serving the nearly 40 individuals with ALS living in Vermont and their family caregivers, as well as a dozen or more New York residents who attend UVM ALS Clinic. The bill you are considering today has an impact beyond Vermonters; it will impact the nearly 1,200 individuals with ALS in New England as well as nationwide and globally by informing ALS research with the registry's data.

For the benefit of anyone listening who is new to ALS, 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 and limited 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's vision is a World Without ALS and our mission is 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. We have set a goal to make ALS a livable condition by 2030.

The Association was founded when smaller organizations established by people living with ALS came together to have greater impact. It is the largest private funder of ALS Research worldwide. 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, including the highest standard of clinic care, the Center of Excellence designation earned by the UVM and the Dartmouth Hitchcock ALS Clinics. Our advocacy in partnership with individuals living with ALS has boosted federal and state spending on ALS. The 2021 federal research investments in ALS include \$110 million at the National Institutes of Health, \$40 million by the Department of Defense; and \$10 million by the Centers for Disease Control and Prevention for the National ALS Registry and Biorepository.



**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.

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

The National ALS Registry has been a valuable resource to researchers seeking to understand the pathology of the disease since its launch in 2010. Collecting natural history data on those affected by ALS is critical in understanding the role that genetic and environmental factors play in the prevalence of the disease and could be the key to unlocking future treatments and cures.

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 to try to identify 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 further 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 postmortem donations of brain; spinal cord; cerebral spinal fluid; and muscle, skin, and bone.

Numbers collected at the national level, through the Registry's algorithm and self-reporting, have been essential thus far to the fight against ALS. 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 – meaning the picture of the state of the disease across the U.S. is not as complete as it might be.

Ideally, state registries would be built on top of the existing public health infrastructure already provided by the National Registry, meaning the initial investment would be comparatively small. Not only would this completely change epidemiological research in those states; it would have a national benefit as well. State registries sharing cases with the National Registry would improve the overall quality of the National Registry's data, which is used by researchers across the country.

### **Support for the Vermont ALS Registry and Massachusetts ALS Registry**

The ALS Association supports the development of a Vermont ALS Registry. Rup Tandan, MD, FRCP, FAAN, Director of ALS Clinical and Research Center of Excellence, estimates that 20% of people living with ALS are unaccounted for and therefore unable to seek the benefits of being evaluated in a specialized clinic. Dr. Tandan's expertise and compassion for people living with ALS speaks for itself. A Vermont ALS Registry would support research efforts and could help identify

people who would benefit from specialized ALS care. The Vermont Registry could build on the model of the Massachusetts ALS Registry which precedes creation of the National ALS Registry in 2008.

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 Registry data

### **About Services In Vermont to People with ALS**

All Association care services are designed to supplement private and public insurance and care systems. They are delivered free of charge to the nearly 40 (and sometimes more) Vermonters living with ALS and their families, and follow up on recommendations made by multidisciplinary Clinic Teams and other providers such as home health agencies and primary care. In addition to UVM and Dartmouth, Vermonters consult MDCs at the VA, Massachusetts General Hospital and St. Peter's Hospital in NY. Equally important, we help individuals and families with confidential support groups, workshops for newly diagnosed individuals, learning labs for family caregivers, durable medical equipment loans, financial grants and referrals to other funding sources (that, while generous, do not meet patient financial need – especially for working single people and child rearing families), peer advocacy opportunities, provider outreach, bereavement supports, an annual Symposium and a large array of evidence based education opportunities from our National staff.

The Association appreciates that whenever possible Vermont has built its public policy and programs to serve Vermonters at comparable financial and functional need regardless of diagnosis or type of disability – an 'all boats float' approach. We hope to have an opportunity to return in the future with Vermonters with ALS to share with you where they are struggling, especially given the high cost of the illness, time urgency, and opportunities to prevent and reduce harms and costs. They are advocating this week for federal funding of the new ACT for ALS federal legislation which can provide great improvements but will not address needs that depend upon state programs and initiative.

Thank you for this opportunity to testify in support of S. 90 and for your committee's interest in Vermonters living with ALS and their families.