

April 1, 2022

Representative Ann Pugh  
Chair, House Committee on Human Services  
Vermont State House  
115 State Street  
Montpelier, VT 05633

Dear Chair Pugh:

I write today to express The ALS Association, New England Territory's S. 90, an act relating to establishing an amyotrophic lateral sclerosis (ALS) registry. The ALS Association, New England Territory serves the nearly 40 individuals with ALS living in Vermont and their family caregivers. Our organization also works with a dozen or more New York residents who attend the UVM ALS Clinic. 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.

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, limits imposed by ALS' status as a non-reportable, non-notifiable disease have meant the picture of the state of the disease across the U.S. is not as complete as it might be.

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 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.

With other states like Maine pushing for state ALS registries, this represents an opportunity for Vermont to be at the forefront of the fight against this devastating disease. We hope that you'll consider our proposal and would be happy to discuss it with you in greater detail. Please feel free to reach me at [john.hedstrom@als.org](mailto:john.hedstrom@als.org) or 781-435-3804.

Sincerely,

John E. Hedstrom  
Territory Executive  
The ALS Association, New England Territory  
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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.