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Senator Virginia Lyons
Chair, Health and Welfare Committee
State of Vermont

Re: Letter Summarizing Testimony for a Mandatory ALS Registry

Dear Senator Lyons:

This is a summary of my testimony today in front of your Vermont legislature committee to consider a mandatory ALS Registry.

I have over 30 years of experience examining patients with neuromuscular disease and have focused my research and clinical efforts on ALS over the last 20 years. The despair associated with the disease has driven me in this direction. It is a devastating disease both for the patients and families alike. I have received substantial funding for ALS research regarding risk factors and genetic susceptibility. The incidence of disease averages about 2/100,000/year, with a prevalence of 7-8/100,000. It is a rare disease largely because people don't live long with it. There is a substantial literature describing clusters of ALS throughout most of the world including Northern New England. It is important to remember that ALS shares common pathological mechanisms to other more prevalent neurodegenerative diseases such as Alzheimer's disease and Parkinson's disease. Unlike Alzheimer's disease, the diagnosis is certain in almost all cases once a thorough neurological evaluation has been performed and patients are reevaluated over time. Hence ALS is a very relevant and relatively opportune neurodegenerative disease to research and can shed light on some of the more common neurodegenerative diseases such as Alzheimer's disease and Parkinson's disease amongst others. There is no doubt that a mandatory ALS registry would not only help research endeavors such as epidemiology but also would be very helpful to patients and their families who have often have no direction from ALS experts.

Having a mandatory registry represents no danger of identification of patients if the proper avenues are taken. We have the support of the National ALS Registry which is not mandatory, but has a very good infrastructure for collecting data and keeping it uncompromised. As discussed by Dr. Mehta today, the National ALS Registry is interested in getting states to initiate mandatory registries. Massachusetts is the only state with a mandatory ALS Registry which was founded after the Massachusetts Governor Paul Cellucci died of ALS. A mandatory ALS registry not only ascertains all cases in a state to improve research but it also directs patients to ALS clinics and ALS Centers of excellence such as those at the University of Vermont Medical Center and Dartmouth Hitchcock Medical Center, the VA system if veterans, clinical

trials, and state of the art treatment options and counseling. Mandatory registries are a very important, a long standing tool for cancer and infectious disease research, and can enhance patient care in many ways.

Vermont is a small state and the cost of having a registry should be minimal. Both Dr. Tandon and myself are certain that we have enough internal funds at our institutions to pay for and maintain a mandatory ALS registry. We have a workforce of residents, fellows, research team members and attending neuromuscular specialists to review the records of all patients reported to such a registry.

Vermont has a history of ALS research. The Farr family in Northeast Kingdom of Vermont was identified many years ago and has been a source of research over the years. We feel Vermont should continue this tradition and be a pioneer in neurodegenerative research.

There was some pushback from the state toxicologist today who stated that my research on cyanobacterial toxins and ALS in particular was flawed. I would point out that I have a myriad of peer-reviewed articles that have been published on the subject of cyanobacterial toxins and ALS, but also on the subject of many other potential toxins linked to ALS funded by federal R01 grants. The major reason to have a reportable registry is not only to improve our research and understanding of ALS, but to help our ALS patients. As mentioned by myself, Dr. Tandon and Dr. Mehta, there are many reasons to have a reportable ALS registry and issues regarding my research should not negate the need for a Mandatory ALS Registry in Vermont.

As mentioned by Dr. Mehta, there should be no danger of any patients being identified as a secure system at an institutional level and a federal level to make this very unlikely. Both The University of Vermont Medical Center and Dartmouth-Hitchcock Medical Center have secure data bases like Redcap. There is a real need for states to come together to help create a mandatory National Registry. Setting a precedence on the state level will likely make this happen. If large states such as California, Michigan and Florida follow suit, we would be on our way to a mandatory National ALS Registry. There are definitely other states interested in this goal. In mandating a reportable ALS registry in Vermont, you have a great opportunity to help set a visionary role.

Please contact me with any questions.

Sincerely,



Stommel, MD, PhD

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