



VERMONT LEGISLATIVE Joint Fiscal Office

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Fiscal Note

Date 3/15/22

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S.90 – an act relating to establishing an amyotrophic lateral sclerosis registry

As recommended by the Senate Committee on Health and Welfare, Draft 2.2

<https://legislature.vermont.gov/Documents/2022/WorkGroups/Senate%20Health%20and%20Welfare/Bills/S.90/Drafts,%20Amendments,%20and%20Legal%20Documents/S.90~Katie%20McLinn~As%20Recommended%20by%20the%20Senate%20Committee%20on%20Health%20and%20Welfare~3-11-2022.pdf>

Bill Summary

The bill would require the Commissioner for the Vermont Department of Health (VDH) to establish a unified statewide population-based amyotrophic lateral sclerosis (ALS) registry system for the collection of information determining the incidence of ALS and related data. It would also require the Commissioner to establish a training program for the personnel of participating health care facilities and a quality control program for ALS data as well as collaborate in studies with clinicians and epidemiologists and publish reports on the results of such studies.

Sec. 2 would require the Department to seek and apply for grants to fund the ALS registry. It would also require the Department to describe any grants applied for or awarded for this purpose or other identified funding as part of its fiscal year 2024 budget presentation to the Legislature.

According to VDH, there would be costs associated with the implementation of an ALS registry as required in this bill. Preliminary estimates are:

- \$50,000 for IT costs.
- \$25,000 to \$50,000 for costs related to staffing
 - In addition to existing personnel, the department may need an additional .25 or .5 FTE to assist with outreach and training for participating providers, data scrubbing and quality control, and other manual work associated with maintaining a registry.

Fiscal Summary

There is **no FY 2023 appropriation required** since the effective date for the establishment of the ALS registry is not until July 1, 2023. However, in the event the Department is unable to secure grants or other funding, it is estimated the Department would need an appropriation of between \$75,000 to \$100,000 in FY 2024 to set up and implement the registry.

Note: Approximately 89% of the Departments budget are through federal grants and much of its general fund appropriation is used for match or maintenance of effort for the federal grants. As such, it would be difficult to implement the provisions of this bill within their existing budget framework.