Amyotrophic Lateral Sclerosis (ALS) Registry Report to the Legislature

November 1, 2026

In Accordance with 18 V.S.A. § 175

Submitted to: Governor Phil Scott
House Committee on Human Services
Senate Committee on Health and Welfare

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Key Takeaways

The Vermont ALS Registry's 2024 data remain incomplete primarily because not all clinics serving Vermont residents have submitted patient data. Despite repeated requests and reminders in 2025 and 2026, the Department has received data from only two of the four known ALS clinics serving the region. The two clinics with outstanding submissions are outside Vermont. One of these clinics was the sole source of nearly one-third of the cases reported for 2023.

The two reporting clinics submitted 16 records representing 15 Vermont residents diagnosed with ALS in 2024. These figures reflect only the cases submitted to the Registry and should not be interpreted as the total number of Vermont residents diagnosed that year. Missing clinic submissions prevent the Department from reliably assessing statewide ALS incidence and prevalence using registry data.

Complete reporting by providers and clinics serving Vermont residents, both within and outside the state, is essential to the Registry's success. The Department continues to provide reporting assistance and follow-up on outstanding submissions. Most specialized ALS clinics serving Vermont residents are outside Vermont, limiting the Department's ability to ensure compliance with reporting requirements.

The Department is also exploring medical claims and death certificate data to supplement clinic submissions and improve identification of ALS cases, including those treated outside Vermont.

Acknowledgements

The Department would like to acknowledge the invaluable assistance of health care providers in Vermont and surrounding states who have advised and supported this work.

Introduction

In 2022, the General Assembly passed Act 149 requiring implementation of the Vermont Amyotrophic Lateral Sclerosis (ALS) Registry by July 1, 2023. The Vermont ALS Registry is maintained by the Vermont Department of Health. Health care providers who screen for, diagnose, or provide therapeutic services to patients with ALS are required to report to the Department of Health all individuals diagnosed within six months of the diagnosis.

ALS is of particular concern to Vermont as the CDC has published studies[1,2] that have estimated the incidence and prevalence of ALS for each state and in these studies, Vermont had the highest incidence and prevalence rates for ALS among all the states.

This report is submitted in accordance with 18 V.S.A. § 175, which requires the Department of Health to annually submit "the statewide prevalence and incidence of ALS, including any trends occurring over time across the State."

Development of the Vermont ALS Registry

At the time the Vermont Department of Health developed the Vermont ALS Registry, there were two existing ALS registries in the United States. These were the National Amyotrophic Lateral Sclerosis (ALS) Registry, run by the CDC, and the Argeo Paul Cellucci ALS Registry of Massachusetts. The Department consulted with both programs, obtaining various research materials and data collection tools, which were used to inform its efforts to design written educational materials, the Vermont ALS webpage, and case reporting forms.

The Vermont ALS Registry website launched on December 30, 2022.

The Department adopted the Amyotrophic Lateral Sclerosis (ALS) Registry Rule with an effective date of February 17, 2024.

In January 2025, the Department published its first annual report that included statistics for Vermont residents diagnosed with ALS in 2023.

Improvements to the Vermont ALS Registry Since January 2026

The Department continues to engage with health care providers to solicit their feedback for improving the Vermont ALS Registry process.

There was significant staff turnover at one of the primary ALS clinics reporting ALS patients to the Department. The Department undertook several actions to ensure the reporting from this clinic continued, including:

- Educating new staff at the clinic about the Vermont ALS Registry
- Reviewing and providing feedback on their data submissions, and
- Transitioning the clinic to a continual reporting process rather than submitting periodic batches of data, which will allow this clinic to make collecting data used in the case reporting form part of their normal patient intake process.

Data Collection Activities of the Vermont ALS Registry

At the request of two of the ALS clinics, the reporting form was revised in the spring of 2025. This resulted in the Department delaying its request for the 2024 cases until June 2025. Prior to the request, the Department reviewed and updated the health care provider mailing list, removing providers who previously reported that they do not see ALS patients and adding providers identified in the most recent Health Care Workforce Census. The

Department sent requests to providers to complete the 2024 reporting form for each ALS patient they had diagnosed, cared for, or to indicate they had not cared for ALS patients in the specified time frame. Several reminders were sent to the clinics in 2025 and again in 2026.

The Department has received amyotrophic lateral sclerosis patient data from two ALS clinics for the 2024 reporting year. While some providers contacted the Department to report that they did not diagnose any patients with ALS in 2024, an additional clinic has indicated that they are working on their submission of 2024 and 2025 patient data. The Department is also aware of a fourth clinic serving ALS patients in this region that has not yet responded to communication from the Department. The Department is exploring ways to establish contact with this and other health care providers who could be providing health care to ALS patients.

To date, two clinics have reported 16 records for Vermont resident ALS patients diagnosed in 2024. These records yielded 15 unique patients.

Among the clinics that have yet to report 2024 cases to the Department, one clinic was the sole source of nearly a third of the cases reported to the Department in 2023.

The Department is not able to evaluate the prevalence and incident of ALS in Vermont using registry data at this time due to gaps in the data.

Next Steps

The Department continues to try to encourage and assist providers and clinics to report outstanding data. As patients with ALS are very likely to be seen at specialized ALS clinics, getting reliable case reporting from these clinics has always been seen as crucial to the ALS Registry. Most of the ALS clinics that serve Vermont residents are outside of Vermont, and indeed the clinic that has still to report cases and the regional clinic that has not responded to the Department are both outside of Vermont. This limits the options available to the Department to ensure compliance with Act 149 (2022).

Moving forward, the Department will be exploring other data sources to supplement the data provided to it by providers and clinics. Specifically, the CDC ALS registry uses an algorithm to identify “probable” and “likely” cases in four medical claims databases. The Department is exploring how to do a similar analysis of the VHCURES all-payer data set to identify possible ALS cases. This approach has the potential to improve the ability of the Department to identify cases of ALS that are being treated out of state.

Death certificate data will also be revisited to provide another complementary source of prevalence estimates.

References

[1] Mehta, P., Raymond, J., Nair, T., Han, M., Punjani, R., Larson, T., … Horton, D. K. (2025). Incidence of ALS in all 50 states in the United States, data from the National ALS Registry, 2012–2019. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, *26*(7–8), 758–766. https://doi.org/10.1080/21678421.2025.2506448

[2] Mehta, P., Raymond, J., Nair, T., Han, M., Punjani, R., Larson, T., … Horton, D. K. (2024). Prevalence of ALS in all 50 states in the United States, data from the National ALS Registry, 2011–2018. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, *25*(7–8), 687–693. https://doi.org/10.1080/21678421.2024.2358786