Amyotrophic Lateral Sclerosis (ALS) Registry

2026 Report to the Legislature

January 15, 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

In 2025, the Department of Health (Department), in response to feedback received from health care providers, updated the case reporting form to make it easier for health care providers to collect and submit amyotrophic lateral sclerosis (ALS) patient data to the Department.

Because the Department has received only some of the ALS patient data for the 2024 reporting year, we cannot provide a complete report on the 2024 ALS patient data at this time. The Department continues to communicate with providers to facilitate data submissions and expects to provide a complete report on this data in 2026.

The Department continues to regularly engage with health care providers to solicit their feedback for improving Vermont ALS Registry processes. It will also assess whether an annual reporting cadence is most effective in the future.

Acknowledgements

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

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:
https://www.healthvermont.gov/stats/registries/amyotrophic-lateral-sclerosis-registry

By March 28, 2023, a letter describing the Vermont ALS Registry and a summary of the reporting requirements on health care providers was mailed to physicians identified as neurologists with the potential to provide care to Vermont resident ALS patients. Once the ALS Registry became operational in June 2023, the case reporting form was redistributed to neurologists with the request to complete the form for each ALS patient they had diagnosed or provided care to since January 2022, or to indicate they had not cared for ALS patients in that time frame.

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 2025

The Department regularly engages with health care providers to solicit their feedback for improving the Vermont ALS Registry process. At the request of health care providers, the Department made several changes to the case reporting form, including:

- Allowing the submission of ALS diagnostic criteria used in making the diagnosis, the site of ALS onset, and details about genetic traits;
- Requiring only the year of diagnosis instead of the month/day/year of diagnosis; and
- Removing the date of symptom onset.

The new form and modified data elements are expected to make it easier for health care providers to collect and submit data to the Department.

Data Collection Activities of the Vermont ALS Registry

In June 2025, the Department reviewed the health care provider mailing list and removed those providers who had previously reported that they do not see ALS patients. The Department then added additional providers that were identified in the recently released Health Care Workforce Census and subsequently 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 providers contacted the Department to report that they did not diagnose any patients with ALS in 2024. Other providers have indicated that they experienced delays due to incorporating the new form into their own systems and are working on their submission of

2024 patient data. One clinic was able to submit amyotrophic lateral sclerosis patient data for the 2024 reporting year to the Department in mid-December 2025; however, this was too late to include in this report. The Department is communicating with the remaining providers to assist and encourage them in this work so we can gather the data needed for a complete report.

Next Steps

Once the Department finishes receiving amyotrophic lateral sclerosis patient data from health care providers for the 2024 reporting year, the Department will process the data and generate incidence statistics as required by 18 V.S.A. § 175.