
**Report to
The Vermont Legislature**

**Amyotrophic Lateral Sclerosis (ALS) Registry
2025 Report to the Legislature**

**In Accordance with 18 V.S.A. chapter 4A
An Act relating to establishing an amyotrophic lateral sclerosis registry.**

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

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Amyotrophic Lateral Sclerosis (ALS) Registry 2025 Report to the Legislature

Introduction

In 2022, the General Assembly passed Act 149 requiring implementation of the Vermont Amyotrophic Lateral Sclerosis (ALS) registry by July 1, 2023. The ALS registry is maintained by the Vermont Department of Health, with health care providers who screen for, diagnose, or provide therapeutic services to patients with ALS 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. Annually, the Department of Health is required to submit “the statewide prevalence and incidence of ALS, including any trends occurring over time across the State.”

Previous Activities 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 our efforts to design written educational materials, the Vermont ALS webpage and case reporting forms.

The Vermont ALS registry website launched on 12/30/2022:

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

By March 28th 2023, a letter describing the Vermont ALS registry and the reporting requirements of healthcare providers was mailed to 108 physicians identified as neurologists with the potential to provide care to Vermont resident ALS patients.

The Vermont ALS Registry was operational in June 2023, with previously identified neurologists (108) provided with the case reporting form. They were asked 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.

Improvements to the Vermont ALS Registry Since its Launch

While not required by statute, registry staff led outreach efforts with providers to augment the value of the registry and to make it efficient and user-friendly. In their outreach, registry staff discussed with providers how to streamline reporting.

- Registry staff stressed to providers that the fields marked as being optional were just that, and providers should feel free to not report those fields if doing so would require significant time or resources.
- Provider feedback identified fields that are problematic for them to collect. This information will inform future edits to the case reporting form.
- Registry staff informed providers that it is not the intent of the Vermont ALS Registry that providers reach out to patients to collect information solely for the purpose of completing the case reporting form.
- Registry staff discussed with providers and ALS clinics that serve Vermont patients the feasibility of the ALS clinics acting as the conduit of case reporting on behalf of its providers to reduce the burden on its providers. Two ALS clinics have adopted this approach and use it for reporting of their ALS patients from 2023. Registry staff also worked with these clinics to allow the patient data to be submitted in a single Excel file rather than a separate document for each patient.

To further streamline reporting, registry staff developed a secure web portal reporting form that is HIPAA compliant. This was launched April 2024 and providers will be directed to it in the future as an alternative option to submitting a physical Case Reporting Form.

Data Collection Activities of the Vermont ALS Registry

In April 2024, the Vermont ALS Registry sent a request for data on patients diagnosed with ALS to 44 providers and two ALS clinics. This was a smaller number of providers than in 2023. Initial communication with all providers allowed registry staff to remove providers who do not see ALS patients or otherwise unlikely to provide patient data.

To date, 10 providers and clinics have reported 46 records for ALS patients diagnosed in 2023. These records yielded 32 unique patients, of which 27 are Vermont residents. The initial data request to providers also asked for patients diagnosed in 2022, and 5 providers submitted 24 records for that year. But as some providers were not able to report complete information for that year, the data from 2022 is considered incomplete and is not used in any further analysis in this report.

Of the 27 Vermonters reported as having an ALS diagnosis in 2023:

- 12 females, 13 males, and 2 patients where the reporting provider indicated that the sex at birth was unknown.
- 8 were below 65 years of age and 19 were 65 or above at the time of diagnosis.

| Vermont Residents Diagnosed with ALS in 2023 | | | |
|--|------------|--------------------|----------------------------|
| | Case Count | Vermont Population | Incidence Patients/100,000 |
| Total | 27 | 647,464 | 4.2 |
| Sex at Birth | | | |
| Female | 12 | 326,028 | 3.7 |
| Male | 13 | 321,436 | 4.0 |
| Unknown | 2 | | |
| Age at Diagnosis | | | |
| Under 65 years of age | 8 | 504,341 | 1.6 |
| 65 or older years of age | 19 | 143,123 | 13.3 |

In past reports, the CDC has estimated the incidence of ALS to be approximately 2 cases per 100,000 US population.¹ If Vermont's data for 2023 is age adjusted in relation to the 2000 US Census population, Vermont's ALS incidence goes from 4.2 patients per 100,000 residents to an age adjusted rate of 2.9 patients per 100,000 residents. Given the relatively small amount of time since the registry launched, the Department is not yet able to make any statements about trends over time in prevalence or incidence of ALS in Vermont using registry data.

Next Steps

Modifications to the case reporting form will be considered and implemented by early 2025, when the request is sent to providers to submit their 2024 ALS cases.

¹ <https://doi.org/10.1080/21678421.2021.2023190>