
**Report to
The Vermont Legislature**

**Amyotrophic Lateral Sclerosis (ALS) Registry
2024 Report to the Legislature**

In Accordance with 18 V.S.A. § 175

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

Submitted by: Mark Levine, M.D., Commissioner,
Vermont Department of Health

Prepared by: The Division of Health Statistics and Informatics
Vermont Department of Health

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108 Cherry Street, PO Box 70
Burlington, VT 05402
802.863.7280
healthvermont.gov

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**Amyotrophic Lateral Sclerosis (ALS) Registry
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Introduction

In 2022, the General Assembly passed Act 149 requiring the the Department of Health (Department) to establish, maintain, and operate a statewide amyotrophic lateral sclerosis (ALS) registry that is operational by July 1, 2023. The legislation also requires that health care providers that screen for, diagnoses, or provides therapeutic services to patients with ALS to report to the Department of Health all individuals as having ALS, no later than six months from the date of diagnosis.

This report is submitted in accordance with 18 V.S.A. § 175, requiring the Department to submit an annual report on the statewide prevalence and incidence of estimates of ALS, including any trends occurring over time across the State.

Development of the Vermont ALS Registry

The Department used the Center for Disease Control and Prevention’s National Amyotrophic Lateral Sclerosis Registry and the Argeo Paul Cellucci ALS Registry of Massachusetts to inform its creation of the Vermont ALS Registry, associated educational materials, and case reporting form.¹

The Department collaborated with the Michigan Department of Health and Human Services and the Maine Department of Health and Human Services who assisted the Department in the drafting of the Vermont ALS case reporting form.

In December 2022, the Department’s ALS Registry website launched:
<https://www.healthvermont.gov/stats/registries/amyotrophic-lateral-sclerosis-registry>

In February 2023, the Department identified 108 Vermont licensed physicians as neurologists with the potential to provide care to individuals living in Vermont with ALS.

In March 2023, the Department mailed each of these Vermont licensed physicians a letter introducing the Vermont ALS Registry, along with a review of the physicians’ reporting requirements, in accordance with the legislative mandate.

In June 2023, the ALS case reporting form was mailed to the identified neurologists, asking them to complete a case reporting form for each patient with ALS that they had diagnosed or provided

¹ See Appendix 1 to view the Department’s ALS Case Reporting form.

care to, since January 2022, or, to indicate that they had not seen any patients with ALS since January 2022.

Initial Reports to the Vermont ALS Registry

Since July 1, 2023, Registry staff have processed the following from the ALS case reporting forms:

- Three providers reported 27 unique patients with ALS; and
- Twelve providers indicated that they have not seen any ALS patients since January 2022.

Given the relatively small period since the Registry was launched and the limited number of reports received at the time of this report, the Department is not yet able to make any statements about the prevalence or incidence of ALS in Vermont using Registry data.

Next Steps

To streamline reporting, Registry staff are developing an electronic, HIPAA compliant reporting form, expected to be released in 2024.

Appendix 1: Current ALS Case Reporting Form



ATTN: Brennan Martin – ALS Registry
 Vermont Department of Health
 108 Cherry Street – PO Box 70
 Burlington, VT 05402-0070
 Tel; (802) 863-7611; Fax (802) 828-7305

Healthcare Provider Amyotrophic Lateral Sclerosis (ALS) Reporting Form

Act 149 (2022) requires healthcare providers that screen for, diagnose, or provide therapeutic services to patients with ALS to report to the Department all individuals diagnosed as having ALS not later than six months from the date of diagnosis, unless the provider knows that a report for that patient has already been made to the Department.

Fields marked with an asterisk (*) are required.

REPORTING HEALTHCARE PROVIDER INFORMATION			
Name of Reporting Provider *			Date of Report * / /
Reporting Provider Mailing Address *			
City *	State *	ZIP Code *	Phone Number *

For each patient that has been diagnosed in the previous calendar year, please submit one reporting form with the information below filled in.

A PATIENT INFORMATION			
Patient's Name (Last, First, MI, Suffix) *			Date of Birth * / /
Town of Residence *		State of Res. *	Years living here?
Mailing Address *			Is this a nursing home? * <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
City *	State *	ZIP Code *	
If less than 10 years living in town then list the previous town of residence			
Previous City/Town of Residence		Prev. Res. State	Years lived there?
Race (check all that apply) * <input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> Black or African American <input type="checkbox"/> Native Hawaiian or Other Pacific Islander <input type="checkbox"/> White <input type="checkbox"/> Other (Specify) _____ <input type="checkbox"/> Unknown	Ethnicity * <input type="checkbox"/> Hispanic <input type="checkbox"/> Non-Hispanic <input type="checkbox"/> Unknown		Payer Type (check all that apply) <input type="checkbox"/> Medicare <input type="checkbox"/> Medicaid <input type="checkbox"/> HMO <input type="checkbox"/> Private Insurance <input type="checkbox"/> Self-pay <input type="checkbox"/> VA <input type="checkbox"/> HMO <input type="checkbox"/> Other
	Gender <input type="checkbox"/> Woman <input type="checkbox"/> Man <input type="checkbox"/> Non-binary <input type="checkbox"/> Unknown		
	Sex assigned at birth * <input type="checkbox"/> Female <input type="checkbox"/> Male <input type="checkbox"/> Intersex <input type="checkbox"/> Unknown		
	Military Veteran: * <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown If Yes, Which branch, war/years?		

B OCCUPATION AND INDUSTRY (see instructions below)			
Enter the usual occupation. Do not enter retired. Provide the kind of work that was done such as claims adjuster, farmhand, store manager, college professor, nurse, civil engineer. The industry is the kind of business to which the occupation is related such as insurance, farming, retail clothing, university, hospital, or government. If someone never worked outside of the house then record "homemaker" for Occupation and in Industry put down "own home".			
	Current/Most Recent Occupation	Last Date if not Currently Employed / /	Years in this Occupation
	Industry		
	Previous Occupation	Years in Previous Occupation	
	Industry		
C DIAGNOSIS			
	Name of provider who made the initial ALS diagnosis (if known)?	Date of Diagnosis / /	
	Facility of provider who made the initial ALS diagnosis (if known)?	Date of Symptom Onset / /	
	Patient diagnosed with dementia by a neurologist? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	El Escorial Criteria as determined by an ALS specialist (check one) * <input type="checkbox"/> Definite <input type="checkbox"/> Probable <input type="checkbox"/> Probable (lab supported) <input type="checkbox"/> Possible <input type="checkbox"/> Not Classifiable <input type="checkbox"/> Unknown	
	Family history of ALS or other neurological diseases? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk. <u>If yes, please describe.</u>		
	Patient tested positive for an ALS genetic trait? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <u>If yes, please describe.</u>		
	Does the patient have a history of concussion or other head trauma? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <u>If yes, please describe.</u>		
	Was the ALS diagnosis confirmed? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown * <u>If yes, how was that diagnosis confirmed? *</u>		
<p>Guidance for El Escorial Criteria for diagnosing ALS including definite, probable, and possible ALS:</p> <ol style="list-style-type: none"> Lower Motor Neuron signs (by clinical, electrophysiological, or neuropathological examination) in 1 or more of 4 regions (bulbar, cervical, thoracic, and lumbosacral). Signs of lower motor neuron degeneration include: weakness, muscle atrophy and fasciculations. Upper Motor Neuron signs (by clinical examination) in 1 or more of the 4 regions. Signs of upper motor neuron degeneration included: slowed movements, increased muscle tone or spasticity, spastic gait. Progression of signs within a region or to other regions <p>Definite ALS = Upper Motor Neuron + Lower Motor Neuron signs in 3 regions Probable ALS = Upper Motor Neuron + Lower Motor Neuron signs in 2 regions with Upper Motor Neuron signs rostral to Lower Motor Neuron signs Probable ALS, lab supported = Upper Motor Neuron + Lower Motor neuron signs in 1 region with evidence by EMG of lower motor neuron involvement in another region. Possible ALS = Upper Motor Neuron + Lower Motor Neuron signs in 1 region or Upper Motor Neuron signs in 2 or 3 regions, such as monomelic ALS, progressive bulbar palsy, and primary lateral sclerosis</p>			