



Home	Bill Information	California Law	Publications	Other Resources	My Subscriptions	My Favorites
------	------------------	----------------	--------------	-----------------	------------------	--------------

**AB-424 Neurodegenerative disease registry.** (2023-2024)

SHARE THIS:  

Date Published: 10/10/2023 09:00 PM

**Assembly Bill No. 424**

**CHAPTER 522**

An act to amend Section 103871 of the Health and Safety Code, relating to public health.

[ Approved by Governor October 08, 2023. Filed with Secretary of State October 08, 2023. ]

**LEGISLATIVE COUNSEL'S DIGEST**

AB 424, Bryan. Neurodegenerative disease registry.

Existing law, until January 1, 2028, and to the extent funds are made available for these purposes, requires the State Department of Public Health to collect data on the incidence of neurodegenerative disease in California, and requires a hospital, facility, physician and surgeon, or other health care provider diagnosing or providing treatment to a patient for a neurodegenerative disease to report each case of a neurodegenerative disease to the department, as prescribed. Existing law specifies that for this purpose, "neurodegenerative disease" may include, but need not be limited to, amyotrophic lateral sclerosis (ALS), among other diseases.

This bill would require the term "neurodegenerative disease" to include, but not be limited to, ALS.

Vote: majority Appropriation: no Fiscal Committee: yes Local Program: no

**THE PEOPLE OF THE STATE OF CALIFORNIA DO ENACT AS FOLLOWS:**

**SECTION 1.** Section 103871 of the Health and Safety Code is amended to read:

**103871.** (a) The department shall collect data on the incidence of neurodegenerative disease in California.

(b) The department shall establish a system for the collection of information determining the incidence and prevalence of neurodegenerative diseases, including, but not limited to, amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease. The department shall designate the specified neurodegenerative diseases as a disease required to be reported in the state or any part of the state. All cases of neurodegenerative disease diagnosed or treated in California shall be reported to the department.

(c) The department shall provide notification of the mandatory reporting of neurodegenerative disease on its internet website and shall also provide that information to associations representing physicians and hospitals and directly to the Medical Board of California at least 90 days prior to requiring information be reported.

(d) A hospital, facility, physician and surgeon, or other health care provider diagnosing or providing treatment for a patient with a neurodegenerative disease shall report each case of a neurodegenerative disease to the department in a format prescribed by the department.

(e) If the hospital or other facility fails to report in a format prescribed by the department, the department's authorized representative may access the information from the hospital or the facility and report it in the appropriate format. In these cases, the hospital or other facility shall reimburse the department or the authorized representative for its costs to access and report the information.

(f) A physician and surgeon, hospital, outpatient clinic, and any other facility, individual, or agency providing diagnostic or treatment services to a patient with a neurodegenerative disease shall grant to the department or the authorized representative access to all records that would identify a case of a neurodegenerative disease or would establish characteristics of a neurodegenerative disease, treatment of a neurodegenerative disease, or medical status of any identified patient with a neurodegenerative disease. Willful failure to grant access to those records shall be punishable by a civil penalty of up to five hundred dollars (\$500) each day access is refused. Any civil penalties collected pursuant to this subdivision shall be deposited by the department in the General Fund.

(g) Except as otherwise provided in this chapter, all information collected pursuant to this section shall be confidential. For purposes of this chapter, this information shall be referred to as "confidential information."

(h) The program shall be under the direction of the director, who may enter into contracts, grants, or other agreements as are necessary for the conduct of the program. The award of these contracts, grants, or funding agreements shall be exempt from Part 2 (commencing with Section 10100) of Division 2 of the Public Contract Code. This chapter shall be implemented only to the extent funds are made available for its purposes.

(i) For the purposes of this section, "neurodegenerative disease" may also include, but need not be limited to, Alzheimer's disease, multiple sclerosis, and Huntington's disease.