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HEALTH AND SAFETY CODE - HSC

DIVISION 102. VITAL RECORDS AND HEALTH STATISTICS [102100 - 103925] (*Division 102 added by Stats. 1995, Ch. 415, Sec. 4.)*

PART 2. POPULATION AND PUBLIC HEALTH SURVEILLANCE [103825 - 103925] (*Part 2 added by Stats. 1995, Ch. 415, Sec. 4.)*

CHAPTER 1.7. California Neurodegenerative Disease Registry Program [103871 - 103871.2] (*Chapter 1.7 added by Stats. 2021, Ch. 143, Sec. 20.)*

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.

(Amended by Stats. 2023, Ch. 522, Sec. 1. (AB 424) Effective January 1, 2024. Repealed as of January 1, 2028, pursuant to Section 103871.2.)

103871.1. (a) A person with a valid scientific interest who is engaged in demographic, epidemiological, or other similar studies related to health who meets qualifications as determined by the department, and who agrees, in writing, to maintain confidentiality, may be authorized access to confidential information collected by the department pursuant to Section 103871.

(b) The department may enter into agreements to furnish confidential information to other states' neurodegenerative disease registries, federal neurodegenerative disease control agencies, local health officers, or health researchers for the study of

neurodegenerative diseases. Before confidential information is disclosed to those agencies, officers, researchers, or out-of-state registries, the requesting entity shall agree in writing to maintain the confidentiality of the information, and in the case of researchers, shall also do both of the following:

(1) Obtain approval of their committee for the protection of human subjects established in accordance with Part 46 (commencing with Section 46.101) of Title 45 of the Code of Federal Regulations.

(2) Provide documentation to the department that demonstrates to the department's satisfaction that the entity has established the procedures and ability to maintain the confidentiality of the information.

(c) Notwithstanding any other law, a disclosure authorized by this section shall include only the information necessary for the stated purpose of the requested disclosure, used for the approved purpose, and not be further disclosed.

(d) The furnishing of confidential information to the department or its authorized representative in accordance with this section shall not expose any person, agency, or entity furnishing information to liability, and shall not be considered a waiver of any privilege or a violation of a confidential relationship.

(e) (1) The department shall maintain an accurate record of all persons who are given access to confidential information. The record shall include all of the following information:

(A) Name of the person authorizing access.

(B) Name, title, address, and organizational affiliation of persons given access.

(C) Dates of access.

(D) Specific purpose for which information is to be used.

(2) The record of access shall be open to public inspection during normal operating hours of the department.

(f) Notwithstanding any other law, the confidential information shall not be available for subpoena, shall not be disclosed, discoverable, or compelled to be produced in any civil or administrative proceeding, or other similar proceeding. The confidential information shall not be deemed admissible as evidence in any civil or administrative proceeding, or other similar tribunal or court for any reason.

(1) This subdivision does not prohibit the department from publishing reports and statistical compilations that do not identify individual cases or individual sources of information.

(2) Notwithstanding the restrictions in this subdivision, the individual to whom the information pertains shall have access to the individual's own information in accordance with Chapter 1 (commencing with Section 1798) of Title 1.8 of Part 4 of Division 3 of the Civil Code.

(g) This section does not preempt the authority of a facility or an individual providing diagnostic or treatment services to a patient with a neurodegenerative disease to maintain their own facility-based neurodegenerative disease registry.

(Added by Stats. 2021, Ch. 143, Sec. 20. (AB 133) Effective July 27, 2021. Repealed as of January 1, 2028, pursuant to Section 103871.2.)

103871.2. This chapter shall remain in effect only until January 1, 2028, and as of that date is repealed.

(Added by Stats. 2021, Ch. 143, Sec. 20. (AB 133) Effective July 27, 2021. Repealed as of January 1, 2028, by its own provisions. Note: Repeal affects Chapter 1.7, commencing with Section 103871.)