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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 1.6. Richard Paul Hemann Parkinson's Disease Program [103870 - 103870.1] (*Chapter 1.6 added by Stats. 2017, Ch. 52, Sec. 12.)*

103870. (a) Beginning January 1, 2018, the department shall collect data on the incidence of Parkinson's disease in California. The program shall be known, and may be cited, as the Richard Paul Hemann Parkinson's Disease Program.

(b) The department shall establish a system for the collection of information determining the incidence and prevalence of Parkinson's disease. The department shall designate Parkinson's disease as a disease required to be reported in the state or any part of the state. All cases of Parkinson's disease diagnosed or treated in California shall be reported to the department.

(c) The department shall provide notification of the mandatory reporting of Parkinson's disease on its Internet Web site 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) Beginning July 1, 2018, a hospital, facility, physician and surgeon, or other health care provider diagnosing or providing treatment to Parkinson's disease patients shall report each case of Parkinson's 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) All physicians, hospitals, outpatient clinics, and all other facilities, individuals, or agencies providing diagnostic or treatment services to patients with Parkinson's disease shall grant to the department or the authorized representative access to all records that would identify cases of Parkinson's disease or would establish characteristics of Parkinson's disease, treatment of Parkinson's disease, or medical status of any identified Parkinson's disease patient. 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 section, all information collected pursuant to this section shall be confidential. For purposes of this section, 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.

(*Added by Stats. 2017, Ch. 52, Sec. 12. (SB 97) Effective July 10, 2017.*)

103870.1. (a) Persons with a valid scientific interest who are engaged in demographic, epidemiological, or other similar studies related to health who meet qualifications as determined by the department, and who agree, in writing, to maintain confidentiality, may be authorized access to confidential information collected by the department pursuant to Section 103870.

(b) The department may enter into agreements to furnish confidential information to other states' Parkinson's disease registries, federal Parkinson's disease control agencies, local health officers, or health researchers for the study of Parkinson's disease. 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) The department shall maintain an accurate record of all persons who are given access to confidential information. The record shall include: the name of the person authorizing access; name, title, address, and organizational affiliation of persons given access; dates of access; and the specific purpose for which information is to be used. 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, criminal, administrative, or other proceeding. The confidential information shall not be deemed admissible as evidence in any civil, criminal, administrative, or other tribunal or court for any reason.

(1) This subdivision does not prohibit the publication by the department of reports and statistical compilations that do not in any way 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 his or her own information in accordance with Chapter 1 (commencing with Section 1798) of Title 1.8 of the Civil Code.

(g) For the purposes of this section, "Parkinson's disease" means a chronic and progressive neurologic disorder resulting from deficiency of the neurotransmitter dopamine as the consequence of degenerative, vascular, or inflammatory changes in the area of the brain called the basal ganglia. It is characterized by tremor at rest, slow movements, rigidity of movement, droopy posture, muscle weakness, and unsteady or shuffling gait.

(h) This section does not preempt the authority of facilities or individuals providing diagnostic or treatment services to patients with Parkinson's disease to maintain their own facility-based Parkinson's disease registries.

(Added by Stats. 2017, Ch. 52, Sec. 12. (SB 97) Effective July 10, 2017.)