THE SENATE
THIRTY-THIRD LEGISLATURE, 2025
STATE OF HAWAII

S.B. NO. 1049

JAN 17 2025

A BILL FOR AN ACT

RELATING TO PARKINSON'S DISEASE RESEARCH.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF HAWAII:

SECTION 1. The legislature finds that Parkinson's disease is a chronic neurodegenerative disease that gradually worsens over time. Parkinson's disease occurs when the brain cells that produce dopamine, a neurotransmitter that coordinates movement, become slow, stop working correctly, or die. There is no known treatment to stop or reverse the progression of Parkinson's disease, nor is there a cure. The legislature also finds that there are approximately one million people in the United States living with Parkinson's disease, which is estimated to rise to 1.6 million by 2037. At least one hundred ten thousand veterans in the United States, and between four and seven thousand people in the State, live with Parkinson's disease.

The legislature further finds that the estimated annual national economic burden to society from Parkinson's disease is $52 billion each year in medical and non-medical expenses. That number is expected to exceed $79 billion by 2037. The importance of collecting critical research data is the first

step to better understand who develops Parkinson's disease and why.

Accordingly, the purpose of this Act is to expand the State's understanding of Parkinson's disease to ultimately improve the lives of those affected, determine incidence and prevalence of Parkinson's disease more accurately by state, and improve understanding of the link between Parkinson's disease and military service, since a larger portion of the veteran community has Parkinson's disease as compared to the general population, by establishing a Parkinson's disease research collection database within the department of health.

SECTION 2. Chapter 321, Hawaii Revised Statutes, is amended by adding a new part to be appropriately designated and to read as follows:

"**PART . PARKINSON'S DISEASE RESEARCH**

§321-A. Definitions. As used in this part:

"Department" means the department of health.

"Director" means the director of health.

"Parkinsonisms" means related conditions that cause a combination of the movement abnormalities seen in Parkinson's disease, such as tremor at rest, slow movement, muscle rigidity,

impaired speech or muscle stiffness that often overlap with and can evolve from what appears to be Parkinson's disease, such as multiple system atrophy, dementia with Lewy bodies, corticobasal degeneration, and progressive supranuclear palsy.

"Parkinson's database" means the Parkinson's disease research collection database established pursuant to section 321-B.

"Parkinson's disease" means a chronic and progressive neurologic disorder resulting from deficiency of the neurotransmitter dopamine as the consequence of specific degenerative changes in the area of the brain called the basal ganglia characterized by tremor at rest, slow movements, muscle rigidity, stooped posture, and unsteady or shuffling gait.

"Parkinson's disease research collection database advisory committee" or "advisory committee" means the Parkinson's disease research collection database advisory committee established pursuant to section 321-C.

§321-B Parkinson's disease research collection database. (a) There is established the Parkinson's disease research collection database to be administered by the department. The Parkinson's database shall house a collection of data on the

incidence of Parkinson's disease in the State and other epidemiological data as defined in this section. The Parkinson's database, system of collection, and dissemination of information shall be under the direction of the director.

(b) All patients diagnosed with Parkinson's disease or related Parkinsonisms shall be provided oral and written notice regarding the collection of information and patient data on Parkinson's disease and the right to opt-out of data collection. Patient participation in the Parkinson's database shall be voluntary; provided that patients who do not wish to participate in the collection of data for purposes of the database shall affirmatively opt-out in writing.

(c) The department shall:

(1) Establish a system for collecting and disseminating information determining the incidence and prevalence of Parkinson's disease and related Parkinsonisms, as advised by the advisory committee;

(2) Require that Parkinson's disease and related Parkinsonisms diagnoses and treatment be reported to the department; provided that, for any patient who does not participate in the Parkinson's database, the

mere incidence of a patient with Parkinson's disease shall be the sole required information;

(3) Provide notification of the mandatory reporting of Parkinson's disease and Parkinsonism on its website, to associations representing physicians and hospitals, and directly to the Hawaii medical board at least ninety days before requiring the information to be reported;

(4) Maintain an accurate record of all persons who are given access to confidential information from the Parkinson's database, which shall include:

(A) The name of the person authorizing access;

(B) The name, title, address, and organizational affiliation of persons given access, and dates of access; and

(C) The specific purpose for which information is to be used; and

(5) Promulgate a coding system that removes any identifying information about the patient.

(d) The department may:

(1) Enter into contracts, grants, or other agreements necessary for the administration of the Parkinson's database;

(2) Create, review, and revise a list of data points required as part of mandated Parkinson's disease reporting under this section; provided that the list shall include necessary triggering diagnostic conditions, consistent with the latest international statistical classification of diseases and related health problems, and resulting case data including diagnosis, treatment, and survival;

(3) Implement and administer this part through a bulletin or similar instruction to providers, which shall be exempt from the rulemaking process pursuant to chapter 91;

(4) Enter into data sharing contracts with data reporting entities and their associated electronic medical record systems vendors to securely and confidentially receive information related to Parkinson's disease testing, diagnosis, and treatment; and

(5) Enter into agreements to furnish data collected in the Parkinson's database 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; provided that, before confidential information is disclosed, the requesting entity shall agree in writing to maintain the confidentiality of the information, and in the case of health researchers, shall:

(A) Obtain approval of their governing committee or institutional review board for the protection of human subjects established in accordance with Title 45 Code of Federal Regulations, section 46.101 et seq.; and

(B) 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.

(e) Any hospital, facility, physician, surgeon, physician assistant, nurse practitioner, or other health care provider deemed necessary by the department, diagnosing or providing primary clinical treatment for Parkinson's disease or Parkinsonism patients shall report each case of Parkinson's disease and Parkinsonisms to the department in a format prescribed by the department.

(f) This section shall not preempt the authority of facilities or individuals providing diagnostic or treatment services to patients with Parkinson's disease to maintain its own facility-based Parkinson's database.

§321-C Parkinson's disease research collection database advisory committee. (a) The department shall establish a Parkinson's disease research collection database advisory committee, which shall consist of an odd number of members, not less than nine, who shall be appointed by the director and include at least one of each of the following:

(1) General neurologist;

(2) Movement disorder specialist;

(3) Primary care physician;

(4) Physician informaticist;

(5) Patient living with Parkinson's disease;

(6) Public health staff;

(7) Population health researcher familiar with registries;

(8) Parkinson's disease researcher; and

(9) Any other member the department deems appropriate and necessary.

(b) Each member shall serve for a term of three years; provided that the director shall initially appoint three or more members to serve for one year; three members to serve for two years; and three members to serve for three years. No member shall serve for more than two consecutive three-year terms.

(c) Vacancies occurring before the expiration of a member's term shall be filled by election by the advisory committee. Individuals elected to fill a vacancy shall serve only for the remainder of the unexpired term.

(d) The advisory committee shall appoint from its members a chairperson, vice chairperson, secretary, treasurer, and other officers that the advisory committee deems necessary or desirable to carry out its functions.

(e) Members of the advisory committee shall serve without compensation, but may be reimbursed for the necessary expenses,

including travel expenses, incurred in the performance of their duties.

(f) The advisory committee shall:

(1) Assist in the development and implementation of the Parkinson's disease research collection database;

(2) Determine the types of data that shall be collected; and

(3) Advise the department.

§321-D Confidentiality of information. (a) Except as otherwise provided in this section, all information collected pursuant to this part shall be confidential.

(b) Notwithstanding any other law to the contrary, a disclosure authorized by this part shall include only the information necessary for the stated purpose of the requested disclosure, used for the approved purpose, and shall not be further disclosed. The record of access shall be open to public inspection during normal operating hours of the department.

(c) Any person, agency, or entity who complies with this part shall not be held civilly or criminally liable for providing the information authorized by this part.

(d) Any information disclosed pursuant to this part shall not be considered a waiver of any privilege or a violation of a confidential relationship.

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

(f) This section shall not prohibit the department from publishing reports and statistical compilations that do not identify individual cases or sources of information.

(g) Notwithstanding the restrictions in this section, the individual to whom the information pertains shall have access to their own information.

§321-E Database webpage; annual reports. (a) No later than January 1, 2026, the department shall create and maintain a Hawaii Parkinson's disease research collection database webpage, where the public may obtain information related to the registry established by this part, a yearly program summary, and any

other relevant or helpful information related to the registry as deemed necessary by the Parkinson's disease research collection database advisory committee.

(b) No later than January 1, 2026, and every year thereafter, the department shall submit a report to the legislature that provides a yearly summary update on the incidents and prevalence of Parkinson's disease in the State by county, the number of records that have been included and reported in the registry, and the demographic information of patients by age, gender, and race. A copy of the report shall be made available and posted on the department's webpage established pursuant to subsection (a)."

SECTION 3. In codifying the new sections added by section 2 of this Act, the revisor of statutes shall substitute appropriate section numbers for the letters used in designating the new sections in this Act.

SECTION 4. This Act shall take effect upon its approval.

INTRODUCED BY: _____

S.B. NO. 1049

Report Title:
DOH; Parkinson's Disease; Parkinson's Disease Research Collection Database; Parkinson's Disease Research Collection Database Advisory Committee; Webpage; Reports

Description:
Establishes the Parkinson's Disease Research Collection Database to be administered by the Department of Health, to house a collection of data on the incidence of Parkinson's disease in the State. Establishes the Parkinson's Disease Research Collection Database Advisory Committee. Requires the Department to create a Parkinson's disease research collection database webpage by 1/1/2026, and submit annual reports to the Legislature.

The summary description of legislation appearing on this page is for informational purposes only and is not legislation or evidence of legislative intent.