

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:

1 SECTION 1. The legislature finds that Parkinson's disease
2 is a chronic neurodegenerative disease that gradually worsens
3 over time. Parkinson's disease occurs when the brain cells that
4 produce dopamine, a neurotransmitter that coordinates movement,
5 become slow, stop working correctly, or die. There is no known
6 treatment to stop or reverse the progression of Parkinson's
7 disease, nor is there a cure. The legislature also finds that
8 there are approximately one million people in the United States
9 living with Parkinson's disease, which is estimated to rise to
10 1.6 million by 2037. At least one hundred ten thousand veterans
11 in the United States, and between four and seven thousand people
12 in the State, live with Parkinson's disease.

13 The legislature further finds that the estimated annual
14 national economic burden to society from Parkinson's disease is
15 \$52 billion each year in medical and non-medical expenses. That
16 number is expected to exceed \$79 billion by 2037. The
17 importance of collecting critical research data is the first



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

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

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

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

16 **§321-A. Definitions.** As used in this part:

17 "Department" means the department of health.

18 "Director" means the director of health.

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



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

5 "Parkinson's database" means the Parkinson's disease
6 research collection database established pursuant to section
7 321-B.

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

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

18 **§321-B Parkinson's disease research collection database.**

19 (a) There is established the Parkinson's disease research
20 collection database to be administered by the department. The
21 Parkinson's database shall house a collection of data on the



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

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

13 (c) The department shall:

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

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



- 1 mere incidence of a patient with Parkinson's disease
2 shall be the sole required information;
- 3 (3) Provide notification of the mandatory reporting of
4 Parkinson's disease and Parkinsonism on its website,
5 to associations representing physicians and hospitals,
6 and directly to the Hawaii medical board at least
7 ninety days before requiring the information to be
8 reported;
- 9 (4) Maintain an accurate record of all persons who are
10 given access to confidential information from the
11 Parkinson's database, which shall include:
- 12 (A) The name of the person authorizing access;
- 13 (B) The name, title, address, and organizational
14 affiliation of persons given access, and dates of
15 access; and
- 16 (C) The specific purpose for which information is to
17 be used; and
- 18 (5) Promulgate a coding system that removes any
19 identifying information about the patient.
- 20 (d) The department may:



- 1 (1) Enter into contracts, grants, or other agreements
2 necessary for the administration of the Parkinson's
3 database;
- 4 (2) Create, review, and revise a list of data points
5 required as part of mandated Parkinson's disease
6 reporting under this section; provided that the list
7 shall include necessary triggering diagnostic
8 conditions, consistent with the latest international
9 statistical classification of diseases and related
10 health problems, and resulting case data including
11 diagnosis, treatment, and survival;
- 12 (3) Implement and administer this part through a bulletin
13 or similar instruction to providers, which shall be
14 exempt from the rulemaking process pursuant to chapter
15 91;
- 16 (4) Enter into data sharing contracts with data reporting
17 entities and their associated electronic medical
18 record systems vendors to securely and confidentially
19 receive information related to Parkinson's disease
20 testing, diagnosis, and treatment; and



1 (5) Enter into agreements to furnish data collected in the
2 Parkinson's database to other states' Parkinson's
3 disease registries, federal Parkinson's disease
4 control agencies, local health officers, or health
5 researchers for the study of Parkinson's disease;
6 provided that, before confidential information is
7 disclosed, the requesting entity shall agree in
8 writing to maintain the confidentiality of the
9 information, and in the case of health researchers,
10 shall:

11 (A) Obtain approval of their governing committee or
12 institutional review board for the protection of
13 human subjects established in accordance with
14 Title 45 Code of Federal Regulations, section
15 46.101 et seq.; and

16 (B) Provide documentation to the department that
17 demonstrates to the department's satisfaction
18 that the entity has established the procedures
19 and ability to maintain the confidentiality of
20 the information.



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

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

12 **§321-C Parkinson's disease research collection database**

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

- 18 (1) General neurologist;
19 (2) Movement disorder specialist;
20 (3) Primary care physician;
21 (4) Physician informaticist;



- 1 (5) Patient living with Parkinson's disease;
- 2 (6) Public health staff;
- 3 (7) Population health researcher familiar with registries;
- 4 (8) Parkinson's disease researcher; and
- 5 (9) Any other member the department deems appropriate and
- 6 necessary.

7 (b) Each member shall serve for a term of three years;

8 provided that the director shall initially appoint three or more

9 members to serve for one year; three members to serve for two

10 years; and three members to serve for three years. No member

11 shall serve for more than two consecutive three-year terms.

12 (c) Vacancies occurring before the expiration of a

13 member's term shall be filled by election by the advisory

14 committee. Individuals elected to fill a vacancy shall serve

15 only for the remainder of the unexpired term.

16 (d) The advisory committee shall appoint from its members

17 a chairperson, vice chairperson, secretary, treasurer, and other

18 officers that the advisory committee deems necessary or

19 desirable to carry out its functions.

20 (e) Members of the advisory committee shall serve without

21 compensation, but may be reimbursed for the necessary expenses,



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

3 (f) The advisory committee shall:

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

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

8 (3) Advise the department.

9 **§321-D Confidentiality of information.** (a) Except as
10 otherwise provided in this section, all information collected
11 pursuant to this part shall be confidential.

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

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



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

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

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

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

17 **§321-E Database webpage; annual reports.** (a) No later
18 than January 1, 2026, the department shall create and maintain a
19 Hawaii Parkinson's disease research collection database webpage,
20 where the public may obtain information related to the registry
21 established by this part, a yearly program summary, and any



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

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

13 SECTION 3. In codifying the new sections added by section
14 2 of this Act, the revisor of statutes shall substitute
15 appropriate section numbers for the letters used in designating
16 the new sections in this Act.

17 SECTION 4. This Act shall take effect upon its approval.
18

INTRODUCED BY: _____

A large, stylized handwritten signature in black ink is written over a horizontal line.

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.

