
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 1,600,000 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 \$52,000,000,000 each year in medical and non-medical expenses.
16 That number is expected to exceed \$79,000,000,000 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 state health planning and
12 development agency.

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

16 "PART . PARKINSON'S DISEASE RESEARCH

17 §321-A Definitions. As used in this part:

18 "Agency" means the state health planning and development
19 agency.

20 "Administrator" means the administrator of the state health
21 planning and development agency.



1 "Parkinsonisms" means related conditions that cause a
2 combination of the movement abnormalities seen in Parkinson's
3 disease, such as tremor at rest, slow movement, muscle rigidity,
4 impaired speech or muscle stiffness that often overlap with and
5 can evolve from what appears to be Parkinson's disease, such as
6 multiple system atrophy, dementia with Lewy bodies, corticobasal
7 degeneration, and progressive supranuclear palsy.

8 "Parkinson's database" means the Parkinson's disease
9 research collection database established pursuant to section
10 321-B.

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

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



1 §321-B Parkinson's disease research collection database.

2 (a) There is established the Parkinson's disease research
3 collection database to be administered by the agency. The
4 Parkinson's database shall house a collection of data on the
5 incidence of Parkinson's disease in the State and other
6 epidemiological data as defined in this section. The
7 Parkinson's database, system of collection, and dissemination of
8 information shall be under the direction of the administrator.

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

17 (c) The agency shall:

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



- 1 (2) Require that Parkinson's disease and related
2 Parkinsonisms diagnoses and treatment be reported to
3 the agency; provided that, for any patient who does
4 not participate in the Parkinson's database, the mere
5 incidence of a patient with Parkinson's disease shall
6 be the sole required information;
- 7 (3) Provide notification of the mandatory reporting of
8 Parkinson's disease and Parkinsonism on its website,
9 to associations representing physicians and hospitals,
10 and directly to the Hawaii medical board at least
11 ninety days before requiring the information to be
12 reported;
- 13 (4) Maintain an accurate record of all persons who are
14 given access to confidential information from the
15 Parkinson's database, which shall include:
- 16 (A) The name of the person authorizing access;
- 17 (B) The name, title, address, and organizational
18 affiliation of persons given access, and dates of
19 access; and
- 20 (C) The specific purpose for which information is to
21 be used; and



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



1 receive information related to Parkinson's disease
2 testing, diagnosis, and treatment; and

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

13 (A) Obtain approval of their governing committee or
14 institutional review board for the protection of
15 human subjects established in accordance with
16 title 45 Code of Federal Regulations section
17 46.101 et seq.; and

18 (B) Provide documentation to the agency that
19 demonstrates to the agency's satisfaction that
20 the entity has established the procedures and



1 ability to maintain the confidentiality of the
2 information.

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

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

14 **§321-C Parkinson's disease research collection database**
15 **advisory committee.** (a) The agency shall establish a
16 Parkinson's disease research collection database advisory
17 committee, which shall consist of an odd number of members, not
18 less than nine, who shall be appointed by the administrator and
19 include at least one of each of the following:

- 20 (1) General neurologist;
21 (2) Movement disorder specialist;



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

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

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

19 (d) The advisory committee shall appoint from its members
20 a chairperson, vice chairperson, secretary, treasurer, and other



1 officers that the advisory committee deems necessary or
2 desirable to carry out its functions.

3 (e) Members of the advisory committee shall serve without
4 compensation, but may be reimbursed for the necessary expenses,
5 including travel expenses, incurred in the performance of their
6 duties.

7 (f) The advisory committee shall:

- 8 (1) Assist in the development and implementation of the
9 Parkinson's disease research collection database;
10 (2) Determine the types of data that shall be collected;
11 and
12 (3) Advise the agency.

13 §321-D Confidentiality of information. (a) Except as
14 otherwise provided in this section, all information collected
15 pursuant to this part shall be confidential.

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



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

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

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

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

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

20 §321-E Parkinson's database webpage; annual reports. (a)

21 No later than January 1, 2026, the agency shall create and



1 maintain a Hawaii Parkinson's disease research collection
2 database webpage, where the public may obtain information
3 related to the Parkinson's database established by this part, a
4 yearly program summary, and any other relevant or helpful
5 information related to the Parkinson's database as deemed
6 necessary by the advisory committee.

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

16 SECTION 3. There is appropriated out of the general
17 revenues of the State of Hawaii the sum of \$ or so
18 much thereof as may be necessary for fiscal year 2025-2026 and
19 the same sum or so much thereof as may be necessary for fiscal
20 year 2026-2027 for the establishment and administration of the
21 Parkinson's disease research collection database; provided that



1 the state health planning and development agency may contract
2 the services of an appropriate entity for implementation.

3 The sums appropriated shall be expended by the state health
4 planning and development agency for the purposes of this Act.

5 SECTION 4. In codifying the new sections added by section
6 2 of this Act, the revisor of statutes shall substitute
7 appropriate section numbers for the letters used in designating
8 the new sections in this Act.

9 SECTION 5. This Act shall take effect on July 1, 3000.



Report Title:

SHPDA; Parkinson's Disease; Parkinson's Disease Research Collection Database; Parkinson's Disease Research Collection Database Advisory Committee; Webpage; Reports; Appropriations

Description:

Establishes the Parkinson's Disease Research Collection Database to be administered by the State Health Planning and Development Agency, 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 Agency to create a Parkinson's disease research collection database webpage by 1/1/2026, and submit annual reports to the Legislature. Appropriates funds. Effective 7/1/3000. (SD1)

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

