
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. It occurs when brain cells that make dopamine, a
4 chemical that coordinates movement, stop working or die. There
5 is no treatment to slow, stop, or reverse its progression, nor
6 is there a cure. The legislature also finds that there are
7 approximately one million people in the United State living with
8 Parkinson's disease, a number expected to rise to 1.6 million by
9 2037. An estimated one hundred and ten thousand veterans,
10 nationally, and between four and seven thousand people in Hawaii
11 live with Parkinson's disease.

12 The legislature further also finds that the estimated
13 annual economic burden to society from Parkinson's disease is
14 \$58 billion each year in medical and non-medical expenses. That
15 number is expected to rise to \$72 billion by 2037. Half of the
16 expense is paid by the federal government while the economic
17 burden to Hawaii is estimated at \$200 to 300 million. The



1 importance of collecting critical research data is the first
2 step to better understand who develops Parkinson's disease and
3 why.

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

- 12 (1) Establishing the Parkinson's disease research
13 collection database to be administered by the
14 department of health;
- 15 (2) Establishing within the department of health a full-
16 time Parkinson's disease coordinator to implement the
17 Parkinson's disease research collection database; and
- 18 (3) Appropriating funds to establish the Parkinson's
19 disease coordinator position and for other operating
20 expenses.



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

4 "PART

5 §321-A Parkinson's disease research collection database.

6 (a) There is established the Parkinson's disease research
7 collection database within the department of health. The
8 database shall house a collection of data on the incidence of
9 Parkinson's disease in the State and other epidemiological data
10 as defined in this section. The database, system of collection,
11 and dissemination of information shall be under the direction of
12 the director of health.

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

21 (c) The department shall:



- 1 (1) Establish a system for collecting and disseminating
2 information determining the incidence and prevalence
3 of Parkinson's disease and related Parkinsonisms, as
4 advised by the advisory committee established pursuant
5 to section 321-B;
- 6 (2) Require that Parkinson's disease and related
7 Parkinsonisms diagnoses and treatment be reported to
8 the department; provided that for any patient who does
9 not participate in the Parkinson's database the mere
10 incidence of a patient with Parkinson's disease shall
11 be the sole required information;
- 12 (3) Provide notification of the mandatory reporting of
13 Parkinson's and Parkinsonism on its website, to
14 associations representing physicians and hospitals,
15 and directly to the board of medicine at least one
16 hundred eighty days before requiring information be
17 reported;
- 18 (4) Maintain an accurate record of all persons who are
19 given access to confidential information from the
20 database, which shall include:
- 21 (A) The name of the person authorizing access;



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

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

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

8 (d) The department may:

9 (1) Enter into contracts, grants, or other agreements
10 necessary for the administration of the program;

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

19 (3) Implement and administer this part through a bulletin,
20 or similar instruction, to providers without
21 promulgating rules pursuant to chapter 91;



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

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

15 (A) Obtain approval of their governing committee or
16 institutional review board for the protection of
17 human subjects established in accordance with
18 Part 46 (commencing with section 46.101) of Title
19 45 of the Code of Federal Regulations; and

20 (B) Provide documentation to the department that
21 demonstrates to the department's satisfaction



1 that the entity has established the procedures
2 and ability to maintain the confidentiality of
3 the information.

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

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 (g) For the purposes of this section:

15 "Parkinsonisms" means related conditions that cause a
16 combination of the movement abnormalities seen in Parkinson's
17 disease, such as tremor at rest, slow movement, muscle rigidity,
18 impaired speech or muscle stiffness that often overlap with and
19 can evolve from what appears to be Parkinson's disease, such as
20 multiple system atrophy, dementia with Lewy bodies, corticobasal
21 degeneration, and progressive supranuclear palsy.



1 "Parkinson's database" means the Parkinson's disease
2 research collection database established by this section.

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

9 §321-B Parkinson's disease research collection database
10 advisory committee. (a) The department shall establish a
11 Parkinson's disease research collection database advisory
12 committee, whose members shall be appointed by the director of
13 health consisting of one representative from at least the
14 following:

- 15 (1) General neurologist;
- 16 (2) Movement disorder specialist;
- 17 (3) Primary care physician;
- 18 (4) Physician informaticist;
- 19 (5) Parkinson's disease patient;
- 20 (6) Public health staff;



(7) Population health researchers familiar with registries;

(8) Parkinson's disease researcher; and

(9) Other parties as the department deems necessary.

(b) Each member shall serve for a term of three years; provided that the director shall initially appoint three 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 of the committee. Individuals elected to fill a vacancy shall serve only for the remainder of the unexpired term.

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

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

(f) The committee shall:



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

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

5 (3) Advise the department of health.

6 **§321-C Confidentiality of information.** (a) Except as
7 otherwise provided in this section, all information collected
8 pursuant to this part shall be confidential to the extent it is
9 identifiable by individual case or source.

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

17 (c) Any person, agency, or entity who complies with this
18 part shall not be held civilly or criminally liable for
19 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 SECTION 3. In codifying the new sections added by section
18 2 of this Act, the revisor of statutes shall substitute
19 appropriate section numbers for the letters used in designating
20 the new sections in this Act.



1 SECTION 4. There is established within the department of
2 health a full-time Parkinson's disease coordinator to implement
3 the purposes of this Act. The Parkinson's disease coordinator
4 shall be equivalent to a program specialist VI and shall be
5 selected by the director of health or the director's designee.

6 SECTION 5. There is appropriated out of the general
7 revenues of the State of Hawaii the sum of \$165,000 or so much
8 thereof as may be necessary for fiscal year 2022-2023 for the
9 establishment of one full-time equivalent (1.0 FTE) permanent
10 civil service Parkinson's disease coordinator and other
11 operating expenses to carry out its activities pursuant to this
12 Act.

13 The sum appropriated shall be expended by the department of
14 health for the purposes of this Act.

15 SECTION 6. This Act shall take effect on January 1, 2050.



Report Title:

Parkinson's disease; Parkinson's Disease Research Collection Database; Appropriation

Description:

Establishes the Parkinson's Disease Research Collection Database to be administered by the Department of Health. Establishes within the Department of Health a full-time Parkinson's disease coordinator to implement the Parkinson's Disease Research Collection Database. Appropriations funds to establish one full-time equivalent (1.0 FTE) permanent civil service Parkinson's disease coordinator and for other operating expenses. Effective 1/1/2050. (SD1)

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