

JAN 20 2023

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

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



1 burden to the state is estimated to be between \$200,000,000 to
2 \$300,000,000. The importance of collecting critical research
3 data is the first step to better understand who develops
4 Parkinson's disease and why.

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

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

17 **"PART**

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

19 (a) There is established the Parkinson's disease research
20 collection database within the department of health. 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 of
5 health.

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

14 (c) The department shall:

15 (1) Establish a system for collecting and disseminating
16 information determining the incidence and prevalence
17 of Parkinson's disease and related Parkinsonisms, as
18 advised by the advisory committee established pursuant
19 to section 321-B;

20 (2) Require that Parkinson's disease and related
21 Parkinsonisms diagnoses and treatment be reported to



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1 the department; provided that, for any patient who
2 does not participate in the Parkinson's database, the
3 mere incidence of a patient with Parkinson's disease
4 shall be the sole required information;

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

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

14 (A) The name of the person authorizing access;
15 (B) The name, title, address, and organizational
16 affiliation of persons given access, and dates of
17 access; and

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

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



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

10 (A) Obtain approval of their governing committee or
11 institutional review board for the protection of
12 human subjects established in accordance with
13 Title 45 Code of Federal Regulations Part 46,
14 section 46.101 et seq.; and

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

20 (e) Any hospital, facility, physician, surgeon, physician
21 assistant, nurse practitioner, or other health care provider



1 deemed necessary by the department of health, diagnosing or
2 providing primary clinical treatment for Parkinson's disease or
3 Parkinsonism patients shall report each case of Parkinson's and
4 Parkinsonisms to the department in a format prescribed by the
5 department.

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

10 (g) For the purposes of this section:

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

18 "Parkinson's database" means the Parkinson's disease
19 research collection database established by this section.

20 "Parkinson's disease" means a chronic and progressive
21 neurologic disorder resulting from deficiency of the



1 neurotransmitter dopamine as the consequence of specific
2 degenerative changes in the area of the brain called the basal
3 ganglia characterized by tremor at rest, slow movements, muscle
4 rigidity, stooped posture, and unsteady or shuffling gait.

5 **§321-B Parkinson's disease research collection database**

6 **advisory committee.** (a) The department of health shall
7 establish a Parkinson's disease research collection database
8 advisory committee, which shall consist of an odd number of
9 members, not less than nine, who shall be appointed by the
10 director of health and include at least one of each of the
11 following:

- 12 (1) General neurologist;
- 13 (2) Movement disorder specialist;
- 14 (3) Primary care physician;
- 15 (4) Physician informaticist;
- 16 (5) Patient living with Parkinson's;
- 17 (6) Public health staff;
- 18 (7) Population health researcher familiar with registries;
- 19 (8) Parkinson's disease researcher; and
- 20 (9) Any other member the department deems appropriate and
21 necessary.



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

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

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

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

17 (f) The committee shall:

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

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

21 and



1 (3) Advise the department of health.

2 §321-C Confidentiality of information. (a) Except as
3 otherwise provided in this section, all information collected
4 pursuant to this part shall be confidential.

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

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

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

18 (e) Notwithstanding any other law to the contrary,
19 confidential information shall not be available for subpoena,
20 disclosed, discoverable, or compelled to be produced in any
21 civil, criminal, administrative or other proceeding.



1 Confidential information shall not be deemed admissible as
2 evidence in any civil, criminal, administrative or other
3 tribunal or court for any reason.

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

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

10 **§321-D Database webpage; annual reports.** (a) On or
11 before January 1, 2024, the department of health shall create
12 and maintain a Hawaii Parkinson's research collection database
13 webpage, where the public may obtain information related to the
14 registry established by this part, a yearly program summary, and
15 any other relevant or helpful information related to the
16 registry as deemed necessary by the advisory council.

17 (b) On or before January 1, 2024, and every year
18 thereafter, the department of health shall submit a report to
19 the legislature that provides a yearly program summary update on
20 the incidents and prevalence of Parkinson's in the State by
21 county, the number of records that been included and reported in



1 the registry, and demographic information of patients by age,
2 gender, and race. A copy of this report shall be made available
3 and posted on the department of health's webpage established
4 pursuant to subsection (a)."

5 SECTION 3. 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 4. This Act shall take effect upon its approval.

10

INTRODUCED BY:

A handwritten signature in black ink, appearing to be 'JBL', is written over a horizontal line.

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Report Title:

Parkinson's Disease; Parkinson's Disease Research Collection Database; Department of Health; Webpage; Reports

Description:

Establishes the Parkinson's Disease Research Collection Database to be administered by the Department of Health. Establishes the Parkinson's Disease Research Collection Database Advisory Committee. Requires the Department of Health to create and maintain a database 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.

