

JAN 19 2022

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# 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 to the general  
11 population.

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**

16 **§321-A Parkinson's disease research collection database.**

17 (a) There is established the Parkinson's disease research  
18 collection database within the department of health. The  
19 database shall house a collection of data on the incidence of  
20 Parkinson's disease in the State and other epidemiological data  
21 as defined in this section. The database, system of collection,



1 and dissemination of information shall be under the direction of  
2 the director of health.

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

11 (c) The department shall:

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

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



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

3 (3) Provide notification of the mandatory reporting of  
4 Parkinson's and Parkinsonism on its website, to  
5 associations representing physicians and hospitals,  
6 and directly to the board of medicine at least one  
7 hundred eighty days before requiring information be  
8 reported;

9 (4) Maintain an accurate record of all persons who are  
10 given access to confidential information from the  
11 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 program;
- 3           (2) Create, review, and revise a list of data points  
4           required as part of mandated Parkinson's disease  
5           reporting under this section; provided that the list  
6           shall include necessary triggering diagnostic  
7           conditions, consistent with the latest international  
8           statistical classification of diseases and related  
9           health problems, and resulting case data including  
10          diagnosis, treatment, and survival;
- 11          (3) Implement and administer this part through a bulletin,  
12          or similar instruction, to providers without  
13          promulgating rules pursuant to chapter 91;
- 14          (4) Enter into data sharing contracts with data reporting  
15          entities and their associated electronic medical  
16          record systems vendors to securely and confidentially  
17          receive information related to Parkinson's testing,  
18          diagnosis, and treatment; and
- 19          (5) Enter into agreements to furnish data collected in the  
20          Parkinson's database to other states' Parkinson's  
21          registries, federal Parkinson's control agencies,



1 local health officers, or health researchers for the  
2 study of Parkinson's; provided that before  
3 confidential information is disclosed, the requesting  
4 entity shall agree in writing to maintain the  
5 confidentiality of the information, and in the case of  
6 health researchers, shall:

- 7 (A) Obtain approval of their governing committee or  
8 institutional review board for the protection of  
9 human subjects established in accordance with  
10 Part 46 (commencing with section 46.101) of Title  
11 45 of the Code of Federal Regulations; and  
12 (B) Provide documentation to the department that  
13 demonstrates to the department's satisfaction  
14 that the entity has established the procedures  
15 and ability to maintain the confidentiality of  
16 the information.

17 (e) Any hospital, facility, physician, surgeon, physician  
18 assistant, nurse practitioner, or other health care provider  
19 deemed necessary by the department, diagnosing or providing  
20 treatment to Parkinson's disease or Parkinsonism patients shall



1 report each case of Parkinson's and Parkinsonisms to the  
2 department in a format prescribed by the department.

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

7 (g) For the purposes of this section:

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

15 "Parkinson's database" means the Parkinson's disease  
16 research collection database established by this section.

17 "Parkinson's disease" means a chronic and progressive  
18 neurologic disorder resulting from deficiency of the  
19 neurotransmitter dopamine as the consequence of specific  
20 degenerative changes in the area of the brain called the basal



1 ganglia characterized by tremor at rest, slow movements, muscle  
2 rigidity, stooped posture, and unsteady or shuffling gait.

3       **§321-B Parkinson's disease research collection database**  
4 **advisory committee.** (a) The department shall establish a  
5 Parkinson's disease research collection database advisory  
6 committee, whose members shall be appointed by the director of  
7 health consisting of one representative from at least the  
8 following:

- 9       (1) General neurologist;
- 10       (2) Movement disorder specialist;
- 11       (3) Primary care physician;
- 12       (4) Physician informaticist;
- 13       (5) Parkinson's disease patient;
- 14       (6) Public health staff;
- 15       (7) Population health researchers familiar with
- 16             registries;
- 17       (8) Parkinson's disease researcher; and
- 18       (9) Other parties as the department deems necessary.
- 19       (b) Each member shall serve for a term of three years;

20 provided that the director shall initially appoint three members  
21 to serve for one year, three members to serve for two years, and





1 three members to serve for three years. No member shall serve  
2 for more than two consecutive three-year terms.

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

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

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

14 (f) The committee shall:

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

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

19 (3) Advise the department of health.



1       §321-C Confidentiality of information. (a) Except as  
2 otherwise provided in this section, all information collected  
3 pursuant to this part shall be confidential.

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

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

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

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

21 Confidential information shall not be deemed admissible as



1 evidence in any civil, criminal, administrative or other  
2 tribunal or court for any reason.

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

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

9 SECTION 3. In codifying the new sections added by section  
10 2 of this Act, the revisor of statutes shall substitute  
11 appropriate section numbers for the letters used in designating  
12 the new sections in this Act.

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

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INTRODUCED BY: \_\_\_\_\_

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

# S.B. NO. 2029

**Report Title:**

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

**Description:**

Establishes the Parkinson's Disease Research Collection Database to be administered by the Department of Health.

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

