

Honolulu, Hawaii

FEB 09 2022

RE: S.B. No. 2029
S.D. 1

Honorable Ronald D. Kouchi
President of the Senate
Thirty-First State Legislature
Regular Session of 2022
State of Hawaii

Sir:

Your Committee on Health, to which was referred S.B. No. 2029 entitled:

"A BILL FOR AN ACT RELATING TO PARKINSON'S DISEASE RESEARCH,"

begs leave to report as follows:

The purpose and intent of this measure is to:

- (1) Establish the Parkinson's Disease Research Collection Database (Database) to be administered by the Department of Health;
- (2) Establish within the Department of Health a full-time Parkinson's disease coordinator to implement the Database; and
- (3) Appropriate funds to establish the Parkinson's disease coordinator and for other operating expenses.

Your Committee received testimony in support of this measure from the Executive Office of Aging; Hawai'i Parkinson Association, Inc.; and The Michael J. Fox Foundation for Parkinson's Research. Your Committee received comments on this measure from the Department of Health and Office of Information Practices.

Your Committee finds that little is known about how Parkinson's disease is distributed among different population



groups in the State and whether the patterns of the disease are changing over time. However, the direct and indirect costs to care for the over five thousand people living with Parkinson's disease in Hawaii is approximately \$250 million per year. Finding new treatments, and ultimately a cure would save tens of millions of dollars each year. Establishing a centralized database for incidences of Parkinson's disease in the State would help identify high-risk groups, support patient contact studies, and serve as a valuable data resource to prevent and optimally manage Parkinson's disease; help researchers study patterns incidence and prevalence of Parkinson's over time; and improve the State's understanding of the link between Parkinson's disease and external factors such as pesticide use and military service. This measure establishes the Parkinson's Disease Research Collection Database.

Your Committee heard the testimony of the Office of Information Practices, which noted that the provision relating to information confidentiality in the measure as currently written is ambiguous and offered clarifying language. Your Committee also acknowledges the testimony of the Department of Health, which noted that it has no program or staff focused on Parkinson's disease and would require an appropriation and new positions to implement the systems, governance, and planning required to manage the Database.

Therefore, your Committee has amended this measure by:

- (1) Clarifying that the confidentiality requirement applies to individually identifiable information rather than to aggregated statistical information;
- (2) Establishing a full-time Parkinson's disease coordinator within the Department of Health to implement the Database;
- (3) Adding an appropriation of \$165,000 to establish one full-time equivalent (1.0 FTE) permanent civil service Parkinson's disease coordinator and for other operating expenses;
- (4) Inserting an effective date of January 1, 2050, to encourage further discussion;



- (5) Amending section 1 to reflect its amended purpose; and
- (6) Making technical, nonsubstantive amendments for the purposes of clarity and consistency.

As affirmed by the record of votes of the members of your Committee on Health that is attached to this report, your Committee is in accord with the intent and purpose of S.B. No. 2029, as amended herein, and recommends that it pass Second Reading in the form attached hereto as S.B. No. 2029, S.D. 1, and be referred to your Committee on Ways and Means.

Respectfully submitted on
behalf of the members of the
Committee on Health,



JURETT KEOHOKALOLE, Chair



The Senate
Thirty-First Legislature
State of Hawai'i

Record of Votes
Committee on Health
HTH

Bill / Resolution No.:* SB2019	Committee Referral: HTH, WAM	Date: 2-2-2022
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The Committee is reconsidering its previous decision on this measure.
If so, then the previous decision was to: _____

The Recommendation is:

Pass, unamended 2312 Pass, with amendments 2311 Hold 2310 Recommit 2313

Members	Aye	Aye (WR)	Nay	Excused
KEOHOKALOPE, Jarrett (C)	✓			
BAKER, Rosalyn H. (VC)	✓			
MORIWAKI, Sharon Y.	✓			
SAN BUENAVENTURA, Joy A.	✓			
FEVELLA, Kurt	✓			
TOTAL	5			

Recommendation: Adopted Not Adopted

Chair's or Designee's Signature:
Rosalyn H. Baker

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*Only one measure per Record of Votes