



**Written Testimony to the Senate Committee on Health
Wednesday, February 2, 2022 at 1:00 PM
State Capitol via Videoconference**

SUBJECT: SB2029 - Establishes the Parkinson's Disease Research Collection Database to be administered by the Department of Health

Aloha Chair Keohokalole and Vice-Chair Baker,

The Hawaii Parkinson Association (HPA) is a 501(c)(3) organization comprised of volunteers with Parkinson's disease, caregivers, family members, health care professionals, and educators. The HPA was established in 1996 with the mission of assisting people with Parkinson's and their family live the best life possible by uniting people, organizations, and resources to treat Parkinson's and ultimately find a cure.

The **HPA STRONGLY SUPPORTS** SB2029 –CREATION OF A PARKINSON'S DISEASE RESEARCH COLLECTION DATABASE.

At its core, this bill is about accurately determining how many people in Hawaii have Parkinson's Disease so we can work to make sure the necessary healthcare resources are available for the proper treatment of those afflicted by this terrible disease.

A study commissioned by the Michael J Fox Foundation and Parkinson's Foundation in 2018 estimated that there were about 4,000 Parkinson's patients in Hawaii with an economic burden on society of approximately \$200M (\$52,000 per year, per person) in direct and indirect costs. While I agree with the cost estimate, I disagreed with the number of patients. I estimate there is closer to 7,000 diagnosed Parkinson's patients. This is a creates huge disparity in in required resources from \$200M to \$350M.

The creation of a Hawaii Parkinson's Disease Research Collection Database will feed de-identified patient information to the State of Hawaii Department of Health. This would be done in a manner similar to the Hawaii Neurotrauma Registry also managed by DoH. The Neurotrama Registry is a voluntary database of Hawaii residents with neurotrauma injury (traumatic brain injury, spinal cord injury or stroke) used to inform lawmakers, providers, and researchers on how to better serve these individuals.

The creation of the Parkinson's database would also feed Hawaii data into the CDC's National Neurologic Conditions Surveillance System (NNCSS) that is under developed. Expectations are that within the next 2-3 years, all states would be required to submit Parkinson's data to NNCSS. This legislation simply puts Hawaii near the head of the line. We want to be the head of the line so we have better access to national level resources.

Surprisingly, little is known about how Parkinson's is distributed among different population groups and whether the patterns of the disease are changing over time.

Nationwide studies indicate that blue collar farm and trade laborers have a higher incidence and prevalence of Parkinson's than white-collar workers. Yet white collar workers are diagnosed at a rate 3X that of blue-collar workers. The main reason for this disparity is that white-collar workers can afford the access to the Movement Disorder Specialist (MDS) certified neurologists.

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Anecdotally, Hawaii is similar to the mainland with the lower income populations of native Hawaiians and Asia-Pacific Islanders being underserved. This legislation will expand our understanding of Parkinson's Disease rates and locations to ultimately improve the lives of those underserved populations by directing more healthcare to where they are needed.

Specifically:

- The data will help identify high-risk groups, support patient contact studies, and serve as a valuable data resource to prevent and optimally manage Parkinson's disease.
- The data will help researchers study patterns incidence and prevalence of Parkinson's over time.
- Help determine if certain regions of the state that use more pesticides have higher incidents of Parkinson's. Studies have shown a correlation between higher pesticide use and increases in Parkinson's cases.
- Improve our understanding of the link between Parkinson's and military service since a larger portion of the veteran's community has Parkinson's compared to the general population.

This legislation is part of a larger initiative by the Hawaii Parkinson Association (HPA) and the The Queen's Medical Center's Parkinson & Movement Disorder Center (PMDC) to provide treatment and support to Hawaii's underserved native Hawaiians and Asia-Pacific Islanders populations. This initiative includes three major pieces:

1. Identify & Locate

- The Queen's Medical Center's Parkinson's and Movement Disorder Center receiving a \$387K grant from The Michael J. Fox Foundation for Parkinson's Research to fund a research project to better understand the extent of disparities faced among Asian Americans (AA), Native Hawaiians, and Pacific Islanders (NHPI), and identify optimal strategies to ensure they have access to quality care.
- SB2029 combined with The Queen's PMDC research project will identify where we need resources.

2. Treatment

- We have some idea of the number of Parkinson patients in the higher income brackets. These are the people who are engaged in all aspects of their treatment including utilizing the information available at the HPA Resource Center.
- What we don't know is how many people with Parkinson's there is in the lower income. Each healthcare system has their own patient list which is confidential for HIPAA and business reasons.
- Doctors can talk in very general terms about patient numbers, but until we can get the actual numbers and locations of their Parkinson's patients, we won't be able to combine all the individual databases and come up with a comprehensive statewide picture. Only then will we be able to accurately plan and acquire the resources needed for the proper treatment of this terrible disease.

3. Partnerships

- The HPA has partnered with all the major healthcare systems in Hawai'i to provide educational and informational resources from the HPA Resource Center located at St. Francis Healthcare System of Hawai'i in Liliha. These resources are provided **free of charge** to the Parkinson's patient so they can have an informed discussion with their doctor to determine the most advantageous course of treatment leading to the best quality of life possible.

The HPA strongly urges your favorable consideration of this important measure. Should you have any questions, please do not hesitate to contact me at jboster@parkinsonshaawaii.org or 808-477-9460.

Thank you for the opportunity to testify.



February 2, 2022

The Honorable Jarrett Keohokalole, Chairman
Senate Health Committee
Hawaii State Capitol, Room 205

RE: S.B. 2029 – The Hawaii Parkinson's Disease Research Collection Database (SUPPORT)

Dear Chairman Keohokalole and members of the committee,

The Michael J. Fox Foundation for Parkinson's Research was founded in 2000 and has been singularly dedicated to finding a cure for Parkinson's Disease (PD) through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with PD today. S.B. 2029 would establish a much-needed state database for Parkinson's patients now and in the future to be part of a larger, global research efforts towards finding better therapies, and with hope one day, a cure.

A Hawaii Parkinson's Disease Research Database, along with those already established in California, Nebraska, Utah, and Massachusetts could truly power significant progress toward new treatments, and ultimately a cure for Parkinson's patients. The database would provide data on the incidence of the disease and its various patterns in the state, including potential geographic clusters and environmental exposures. Patient registries can provide a real-world view of clinical practice, patient outcomes, safety, and comparative effectiveness. The database can also inform policymakers about health care equity disparities and the influences of social determinants of health.

Parkinson's disease is the second most common and fastest growing neurological disease in the world and the number of people with PD is expected to double by 2040. According to the Centers for Disease Control and Prevention, PD is the nation's 14th leading cause of death. The annual cost of Parkinson's nationally is at least \$58 billion and that will rise to nearly \$80 billion by 2037.¹

The direct and indirect costs to care for the over 5,000 people living with PD in Hawaii is \$250 million per year – finding new treatments and ultimately a cure would save tens of millions of dollars each year.

Establishing a state research collection registry will feed into the Center for Disease Control's National Neurological Conditions Surveillance System which tracks the incidence and prevalence of many neurologic disorders, including Parkinson's.

Researchers around the globe will be able to take state-based data to:

- Help identify high-risk groups, support patient contact studies, and serve as a valuable data resource to prevent and optimally manage Parkinson's disease.
- To determine incidence and prevalence of Parkinson's disease more accurately by state.
- The data will help researchers study patterns of Parkinson's disease over time.
- Help determine if certain regions of the state that use more pesticides have higher a higher incidence of Parkinson's. Studies have shown a correlation between higher pesticide use and increases in Parkinson's cases.
- Improve our understanding of the link between Parkinson's and military service since a larger portion of the veteran's community has Parkinson's compared to the general population.
- Privacy of individual patients is protected rigorously within registries, compliant with the Health Insurance Portability and Accountability Act (HIPAA) and other federal and state privacy laws.

When properly designed, a Parkinson's registry can expand in the future to collect data on other neurological diseases. Given the known, and unknown, neurological impact of COVID-19, a state registry could provide data critical for treatments of future coronaviruses.

The registry data would also provide insight into Parkinson's 'clusters' in the state and would enable greater scientific understanding of exposure of firefighters and other first responders to chemicals, toxins, heavy metals, and other possible environmental factors that may be Parkinson's triggers.

On behalf of the foundation and the patients we support, **we urge a favorable vote on S.B. 2029.** Thank you for your time and consideration, please don't hesitate to contact me at jworchester@michaeljfox.org or 202-638-4101, ext. 441.

Sincerely,



Julia Worcester, JD
Director of State Government Relations

OFFICE OF INFORMATION PRACTICES

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To: Senate Committee on Health

From: Cheryl Kakazu Park, Director

Date: February 2, 2022, 1:00 p.m.
State Capitol, Via Videoconference

Re: Testimony on S.B. No. 2029
Relating to Parkinson's Disease Research

Thank you for the opportunity to submit testimony on this bill, which would establish a Parkinson's Disease Research Collection Database administered by the Department of Health. The Office of Information Practices (OIP) takes no position on the substance of this bill, but offers comments on a confidentiality provision in proposed section 321-C, HRS, beginning on page 10 of the bill.

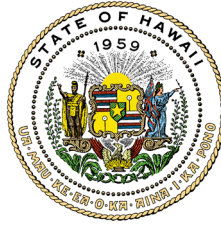
Subsection (a) of the provision provides for general confidentiality of all information collected pursuant to the newly created part “[e]xcept as otherwise provided,” while subsection (f) specifically allows the Department of Health to publish “reports and statistical compilations that do not identify individual cases or sources of information.” To clarify the apparent intent for the confidentiality requirement to apply to individually identifiable information rather than to aggregated statistical information, OIP recommends that subsection (a) be amended to make information confidential that is " identifiable by individual case or source." **Specifically, OIP recommends that subsection (a) be amended to read:**

(a) Except as otherwise provided in this section, all information collected pursuant to this part shall be confidential to the extent it is identifiable by individual case or source.

Thank you for considering OIP's testimony.

DAVID Y. IGE
GOVERNOR OF HAWAII

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**Testimony in SUPPORT of SB2029
Relating to Parkinson's Disease Research**

COMMITTEE ON HEALTH
SENATOR JARRETT KEOHOKALO, CHAIR
SENATOR ROSALYN H. BAKER, VICE CHAIR

Testimony of Caroline Cadirao
Director, Executive Office on Aging
Attached Agency to the Department of Health

Hearing Date: February 2, 2022
1:00 p.m.

Room Number:
Via Videoconference

1 **EOA's Position:** The Executive Office on Aging (EOA), an attached agency to the Department
2 of Health, supports SB2029, Relating to Parkinson's Disease Research.

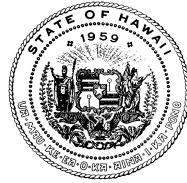
3 **Purpose and Justification:** The purpose of this bill is to establish the Parkinson's Disease
4 Research Collection Database to be administered by the Department of Health and an advisory
5 committee appointed by the director.

6 A Parkinson's Disease Research Collection Database will expand the State's understanding of
7 Parkinson's disease or related Parkinsonism, including Parkinson's disease dementia. Individuals
8 with Parkinson's disease may also develop problems with thinking and reasoning. According to
9 the Alzheimer's Association, Parkinson's disease also affects the brain and there is an "*overlap in*
10 *symptoms and other evidence suggest that Lewy body dementia, Parkinson's disease and*
11 *Parkinson's disease dementia may be linked to the same underlying abnormalities in how the*
12 *brain processes the protein alpha-synuclein. Many people with both Lewy body dementia and*

1 *Parkinson’s dementia also have plaques and tangles—the hallmark brain changes linked to*
2 *Alzheimer’s disease”* ([https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-](https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/lewy-body-dementia)
3 [dementia/lewy-body-dementia](https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/lewy-body-dementia)). Since both diseases currently have no cure, the more
4 information and data we can collect would be helpful in understanding the disease, developing
5 possible treatments and hopefully a cure for these diseases.

6 **Recommendation:** EOA supports this measure.

7 Thank you for the opportunity to testify.



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LATE

**Testimony COMMENTING on SB2029
RELATING TO PARKINSON'S DISEASE RESEARCH.**

SENATOR JARRETT KEOHOKALOOLE, CHAIR
SENATE COMMITTEE ON HEALTH

Hearing Date: February 2, 2022

Room Number: Videoconference

- 1 **Fiscal Implications:** A general fund appropriation is required to implement this measure.
- 2 **Department Testimony:** The purpose of this measure is to establish a Parkinson's disease
3 research collection database within the Department of Health, and related activities.
- 4 Parkinson's disease touches many families, and the Department of Health (DOH) sees value in
5 understanding how Hawaii's unique ethnic demographics factor into detecting, treating, living,
6 unfortunately dying from complications of the disease. Currently, DOH has no program or staff
7 focused on Parkinson's disease and would require an appropriation and new positions to
8 implement the systems, governance, and planning required to manage this complex set of tasks.
- 9 There have been recent private sector grants to study the disease's impact to Asian Americans,
10 Pacific Islanders, and Native Hawaiians; additionally, there is research activity in the community
11 but the consensus is that a registry may not be a priority nor a high value tool at the moment.
- 12 **Offered Amendments:** The Legislature may appropriate funds to DOH for subgrants, otherwise
13 additional resources are required to implement the purpose of this measure. A minimum of one
14 FTE is required, though a program with the scope as proposed likely will need an additional two
15 or three FTE over time.

16 SECTION . There is established within the department of
17 health a full-time Parkinson's disease coordinator to implement
18 the purposes of this Act. The Parkinson's disease coordinator

1 shall be equivalent to a program specialist VI and shall be
2 selected by the director of health or the director's designee.

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

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

12