JOSH GREEN, M.D.
GOVERNOR OF HAWAIʻI
KE KIAʻĀINA O KA MOKUʻĀINA ʻO HAWAIʻI

KENNETH S. FINK, M.D., M.G.A., M.P.H.
DIRECTOR OF HEALTH
KA LUNA HOʻOKELE

STATE OF HAWAII
DEPARTMENT OF HEALTH
P. O. Box 3378
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Testimony COMMENTING on HB952 HD1
RELATING TO PARKINSON'S DISEASE RESEARCH.

SENATOR JOY A. SAN BUENAVENTURA, CHAIR
SENATE COMMITTEE ON HEALTH AND HUMAN SERVICES

Hearing Date: March 17, 2025 Room Number: 229

Fiscal Impact: Ongoing general fund appropriation of $750,000 for start-up and operational costs, and 7.25 FTE to administer.

Department Testimony: The prevalence of Parkinson's disease in Hawaii varies among different racial and ethnic groups. According to a study conducted between 2016 and 2020, the prevalence of hospitalized Parkinson's disease patients among all case hospitalizations was 2.3% for Japanese and Chinese populations, 1.7% for White populations, 1.2% for Filipino populations, and 0.9% for Native Hawaiian or Other Pacific Islander (NHPI) populations.

The prevalence also increases with age, with the highest rates observed in the 80-84 age group. For example, 4.3% of Chinese, 4.0% of Japanese, 3.7% of White, 2.5% of Filipino, and 2.3% of NHPI populations in this age group were diagnosed with Parkinson's disease.

Parkinson's disease research in Hawaii is world-class, in part thanks to entities like the Hawaii Pacific Neuroscience and the University of Hawaii John A Burns School of Medicine, the latter having conducted research focused on the progression of dopaminergic therapy changes in Parkinson's disease among Asian and Native Hawaiian and Pacific Islander populations.

State support for local Parkinson's disease research will undoubtedly add value, however, significant investment will be required. Basic infrastructure include:

- A robust modern and secure IT system that meets human subject research standards needs to be procured,
- Consultants familiar with Parkinson's disease will need to be contracted with to guide the strategic development of the program,

The services proposed by this measure are generally provided by research universities or the private sector. Since DOH does not have the infrastructure, personnel, or experience to operate these functions, additional FTE are required:

- 1.0 FTE Research Manager (SR-N/A) to provide overall leadership and scientific expertise to the evaluation of clinical research proposals and human-subject research protocols, oversee the multiple data use and reciprocal sharing agreements, and serve as the principal investigator
- 1.0 FTE Administrative Assistant (SR-14) to provide general administrative and logistical support
- 0.25 Medical Director (SR-N/A) to provide clinical expertise for interventional studies or observational studies and co-manage the Institutional Review Board
- 1.0 FTE Data Manager (IT Band C) to provide data governance to the program and its participants and partners, ensure secure storage and transmission of confidential data, and ensure data integrity
- 1.0 FTE Compliance Officer (SR-26) to assure compliance to laws, regulations, and best practices of human subject-research, privacy, security, and risk management
- 1.0 FTE Patient Ombudsman (SR-24) to serve as a direct contact for patients participating in clinical trials with concerns and to advocate on their or their family's behalf, e.g., informed consent, trail withdrawal, patient safety, etc.
- 1.0 FTE Epidemiologist (SR-N/A) to review and validate clinical research
- 1.0 Research Statistician (SR-24) to provide statistical expertise

Due to the scope of this bill, including the human subject research function, DOH will likely need to create a new branch or office since there is no existing division into which the proposed Parkinson's disease research collection database can be placed. Additional resources are required to meet the intent of this bill.

Thank you for the opportunity to testify.

HAWAIʻI
PARKINSON
ASSOCIATION

Written Testimony to the Senate Committee on Health & Human Services

Monday, March 17, 2025 at 1 p.m.

Hawaii State Capitol, Conference Room 225

SUBJECT: HB952 HD1 - Establishes the Parkinson's Disease Research Collection Database to be administered by the Department of Health

Aloha Chair San Buenaventura and Vice-Chair Aquino,

My name is Glen Higa, President of the Hawai'i Parkinson Association and I have been living with Young Onset Parkinson's disease since 2018. Hawaii Parkinson Association (HPA) is a 501(c)(3) all-volunteer non-profit charitable organization comprised of community members with Parkinson's disease, care partners, family members, health care professionals, and educators. HPA was established in 1996 with the mission to positively impact the lives of those affected by Parkinson's disease through education, support, programs and other services.

HPA strongly supports HB952 HD1 which establishes the Parkinson's Disease Research Collection Database to be administered by the Dept. of Health. The intent of this bill is to accurately determine how many people in Hawaii have Parkinson's disease to ensure the necessary healthcare resources are available for the proper treatment of those afflicted by this growing condition.

This bill, as it is written, is a prime example of the need for this database. The bill cites a 2018 study by the Michael J Fox Foundation and Parkinson's Foundation which estimated about 4,000 Parkinson's patients in Hawaii. The bill also cites an estimated 7,000 diagnosed Parkinson's patients as provided by our former president and chairman of the board, Jerry Boster, who unfortunately passed away in 2023. Furthermore, the Queen's Medical Center's Parkinson's and Movement Disorders Clinic has estimated 8,000 people diagnosed with Parkinson's and projects that number will double by the year 2030. Globally, Parkinson's is now considered the fastest growing neurological condition in the world. An exact number is needed to determine the full impact Parkinson's disease has in Hawaii now.

The last estimate on the economic burden in Hawaii due to Parkinson's disease through direct and indirect medical costs is $250 million per a study conducted by the Michael J. Fox Foundation in 2019, a number that is surely higher today.

The creation of a Hawaii Parkinson's Disease Research Collection Database will provide de-identified patient information to the State of Hawaii Department of Health. The purpose of this database is to improve the lives of those affected, determine incidence and prevalence of Parkinson's disease more accurately by county and improve services needed in underserved communities.

Anecdotally, Hawaii's lower income populations are seemingly underserved in healthcare, therapeutic options and support programs. In addition, there is a perceived negative stigma in the Asian, native Hawaiian, Polynesian communities among others, along with those who are considered "Young Onset" or diagnosed under the age of 50 of the disclosure of a Parkinson's disease diagnosis. This stigma leads to people "hiding their condition", seeking medical care or not seeking proven therapies such as exercise or joining a support group.

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, educational resources and outreach services to where they are needed. Specifically:

- The data will help identify high-risk groups, support patient contact studies, and serve as a valuable resource to enable patients to effectively manage Parkinson's disease.

- The data will help researchers study patterns of incidences and prevalence of Parkinson's disease.

- Help determine if certain regions of the state have higher incidents of Parkinson's disease. Studies have shown a correlation between environmental factors such as higher pesticide use and increases in Parkinson's disease cases.

In 2024, HPA administered 15 support groups statewide, reaching 1,500 people. We conducted or participated in 21 outreach and educational events about exercise, medication, diet and other topics to help people live well with Parkinson's disease. And over 21,000 people receive our e-newsletter here in Hawaii and beyond. But no initiative will have the impact of this bill on the community of over 50,000 people impacted by Parkinson's disease.

HPA strongly urges your favorable consideration of this important measure. Should you have any questions, please feel free to contact me at president@parkinsonshawaii.org or (808) 348-2767. Mahalo for the opportunity to testify on behalf of Hawai'i Parkinson Association.

Glen M. Higa
President, Hawai'i Parkinson Association

THE QUEEN'S
HEALTH SYSTEMS

To: The Honorable Joy San Buenaventura, Chair
The Honorable Henry Aquino, Vice Chair
Members, Senate Committee on Health & Human Services

From: Dr. Michiko K. Bruno, Medical Director, Parkinson's and Movement Disorder Center, The Queen's Medical Center

Jacce Mikulanec, Director, Government Relations, The Queen's Health Systems

Date: March 17, 2025

Re: In Support of HB952 HD1 - Relating to Parkinson's Disease Research

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The Queen's Health Systems (Queen's) is a nonprofit corporation that provides expanded health care capabilities to the people of Hawai'i and the Pacific Basin. Since the founding of the first Queen's hospital in 1859 by Queen Emma and King Kamehameha IV, it has been our mission to provide quality health care services in perpetuity for Native Hawaiians and all of the people of Hawai'i. Over the years, the organization has grown to five hospitals, and more than 10,000 affiliated physicians, caregivers, and dedicated medical staff statewide. As the preeminent health care system in Hawai'i, Queen's strives to provide superior patient care that is constantly advancing through education and research.

Queen's appreciates the opportunity to provide testimony in support of HB952 HD1, which establishes the Parkinson's Disease Research Collection Database to be administered by the Department of Health (DOH), to house a collection of data on the incidence of Parkinson's disease in the State and establishes the Parkinson's Disease Research Collection Database Advisory Committee.

Parkinson's Disease (PD) is the second most common neurodegenerative disease after Alzheimer's disease. Its prevalence is likely underestimated and is expected to rise with an aging population. As a chronic neurological disorder affecting motor and non-motor functions, PD leads to significant disability, reduced quality of life, and increased economic and caregiving burdens on communities.

Medical registries have proven valuable in-patient care, public health, and research. Hawai'i's geographic isolation and relatively stable population provide an ideal setting for the successful development and maintenance of a statewide PD registry. To date, California, Nebraska, Utah, and Washington have created registries to help track incidence of the disease and support ongoing research and clinical trials.

For Hawai'i, Queen's is particularly interested in the impact registry will have in identifying and understanding ethnic and geographic disparities and its relation to access to care. Preliminary research from the Parkinson's and Movement Disorders Center has already highlighted disparities in health care access across racial and ethnic subgroups, as well as between urban (Oʻahu) and rural (neighbor island) communities. A registry would provide critical data to help shape policies for more equitable care. In addition, a registry of this sort can be critical for provider education, a, improve understanding of PD’s natural history in Hawaiʻi, and assess treatment effectiveness over time. Epidemiological data provided by a disease registry is critical in advancing research, understanding the environmental risk factors and facilitating clinical trial recruitment.

Hawai‘i Family
Caregiver Coalition

Testimony to the Senate Committee on Health and Human Services
Monday, March 17, 2025
1:00 p. m.
State Capitol Conference Room 225 and via videoconference

Re: HB 952 HD 1 Relating to Parkinson’s Disease Research

Dear Chair San Buenaventura, Vice Chair Aquino, and Honorable Members of the Senate Committee on Health and Human Services:

I am Gary Simon, a member of the board of the Hawai‘i Family Caregiver Coalition, whose mission is to improve the quality of life of those who give and receive care by increasing community awareness of caregiver issues through continuing advocacy, education, and training. I am testifying as an individual who has worked in healthcare for over thirty-five years, and I am offering testimony on behalf of the Hawai‘i Family Caregiver Coalition.

The Hawai‘i Family Caregiver Coalition supports HB 952 HD 1, which establishes the Parkinson's Disease Research Collection Database to be administered by the Department of Health, to house a collection of data on the incidence of Parkinson's disease in the State; establishes the Parkinson's Disease Research Collection Database Advisory Committee; and requires the Department of Health to create a Parkinson's disease research collection database webpage by January 1, 2026 and submit annual reports to the Legislature.

Public health agencies have long recognized that population-based data registries are required to estimate the incidence and prevalence of non-communicable chronic diseases. Registries have been developed throughout the world for the purpose of surveillance of these diseases to inform public health agencies and the public on the extent of the disease and to identify trends amidst population centers to support the development of public health interventions. The more common registries are focused on those diseases with the highest mortality rates, such as cancer, but many registries have been built for other diseases such as amyotrophic lateral sclerosis (ALS). In the U.S., federal and state statutes call for the creation of cancer data registries in many states. States are beginning to also develop registries for Parkinson’s disease (PD).[1]

We urge you to support Parkinson’s disease research and HB 952 HD 1, and we urge you to recommend its passage.

Mahalo for seriously considering the bill.

Very sincerely,

Gary Simon

Gary Simon
Hawai'i Family Caregiver Coalition
Email garysimon@hawaii.rr.com

1. Proceedings of the Parkinson's Disease Registries Data Summit. *Consensus-Based Recommendations for Establishing Statewide Parkinson's Disease Registries*. February 11, 2023. https://www.michaeljfox.org/sites/default/files/media/document/MJFF%20PD%20Registry%20Data%20Summit%20Proceedings%20%281%29.pdf. Accessed March 11, 2025.

HB-952-HD-1
Submitted on: 3/14/2025 8:48:24 AM
Testimony for HHS on 3/17/2025 1:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Amy Kelley	Testifying for Brain Matters LLC	Support	Written Testimony Only

Comments:

Testimony on HB952 HD1

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

Monday, March 17, 1:00 PM

Conference Room 225 & Videoconference

State Capitol - 415 South Beretania Street

Aloha Chair San Buenaventura and Vice Chair Aquino,

My name is Amy Kelley, and I am a resident of East Honolulu, Hawaiʻi. I am also the founder of Brain Matters, which uses evidence-based lifestyle interventions to help the people of Hawaiʻi outsmart dementia and other neurological diseases, such as Parkinson's. Personally, I have seen how Parkinson's affects the person living with the disease, as well as those around them. I have lost an aunt, uncle, and friend to the disease. But, I have also seen how lifestyle interventions, such as exercise, restorative sleep, stress management and diet help to slow and even halt the progression of the disease.

That is why I strongly support the bill to establish the Parkinson's Disease Research Collection Database to be administered by the Dept. of Health. This database will help us improve the lives of those affected, determine incidence and prevalence of Parkinson's disease more accurately by county and improve services needed in underserved communities.

I urge the committee to support this legislation for the benefit of the more than 50,000 affected by Parkinson's disease in Hawaiʻi and join 14 other states in the country that have established a Parkinson's database.

Thank you for the opportunity to submit this testimony.

Sincerely,

Amy Kelley

Founder, Brain Matters LLC

amy@brainmattershawaii.com

THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

Monday, March 17, 2025
Hawai'i Senate Committee on Health & Human Services
H.B. 952 – Relating to Parkinson's Disease Research (SUPPORT)

Good afternoon, Chair Buenaventura, Vice Chair Aquino and members of the committee. My name is Zach Hardy, and I am a Senior Manager of State Government Relations for The Michael J. Fox Foundation for Parkinson's Research (MJFF). Thank you for the opportunity to submit testimony in support of **H.B. 952**, which would establish a Parkinson's disease data collection database in Hawai'i.

MJFF was founded in 2000 and has been singularly dedicated to finding a cure for Parkinson's disease through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with Parkinson's today. To date, MJFF has funded more than $2 billion in research programs worldwide.

MJFF believes that establishing statewide databases for Parkinson's is a critical step in broadening our understanding of the disease. A Hawai'i Parkinson's disease database will produce invaluable information for researchers while providing accurate statewide rates of incidence and prevalence.

This proposed database is necessary to generate the data that will help researchers, treatment providers and lawmakers determine the causes of the disease, evaluate the efficacy of treatment, uncover inequities in Parkinson's disease healthcare and make decisions about the allocation of resources for prevention and treatment. This data will help identify high-risk groups, support patient contact studies and serve as a valuable data resource to the research community. By passing this legislation, Hawai'i would be joining fourteen states in collecting health information on Parkinson's disease.

According to the Centers for Disease Control and Prevention, Parkinson's disease is the second-most common and the fastest-growing neurological disease in the world. There are an estimated more than one million Americans currently living with Parkinson's disease, with about 90,000 more diagnosed each year.[1] The national cost associated with Parkinson's is approximately $52 billion per year, with that cost projected to rise to nearly $80 billion by 2037.[2]

The direct and indirect costs to care for the more than 5,000 people, which we believe to be an undercount, living with Parkinson's in Hawai'i is estimated to be $250 million per year. The discovery of improved treatments and therapeutics, and ultimately a cure, for Parkinson's will not only change the lives of those living with Parkinson's and their families but would also be in the best economic interest of the state.

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[1] "New Study Shows the Incidence of Parkinson's in the U.S. Is Nearly 50 Percent Higher than Previous Estimates." The Michael J. Fox Foundation for Parkinson's Research | Parkinson's Disease, 15 Dec. 2022, https://www.michaeljfox.org/news/new-study-shows-incidence-parkinsons-us-nearly-50-percent-higher-previous-estimates.

[2] "Study Finds Parkinson's $52 Billion Economic Burden Double Previous Estimates." The Michael J. Fox Foundation for Parkinson's Research | Parkinson's Disease, 13 June 2019, https://www.michaeljfox.org/news/study-finds-parkinsons-52-billion-economic-burden-double-previous-estimates.

On behalf of The Michael J. Fox Foundation for Parkinson’s Research and the community that we are proud to support, we urge this committee to vote favorably on **H.B. 952**. Thank you for your consideration.

CONTACT:
Zach Hardy
Senior Manager, State Government Relations
The Michael J. Fox Foundation for Parkinson's Research
zhardy@michaeljfox.org — 202-638-4101, Ext. 225

Testimony on HB952 HD1

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

Monday, March 17, 1:00 PM

Conference Room 225 & Videoconference

State Capitol - 415 South Beretania Street

Aloha Chair San Buenaventura and Vice Chair Aquino,

My name is Drew Higashihara, and I am a resident of Kailua. Parkinson’s Disease has affected many of my parents’ friends as well as thousands of other residents in the State of Hawaii and beyond. I have volunteered for the Hawaii Parkinson Association and have seen the many stages of this disease and how difficult it is for patients and their caregivers.

I strongly support the bill to establish the Parkinson’s Disease Research Collection Database to be administered by the Dept. of Health. The purpose of this database is to improve the lives of those affected, determine incidence and prevalence of Parkinson’s disease more accurately by county and improve services needed in underserved communities.

The most recent estimate (2019/Michael J. Fox Foundation) of the direct and indirect medical costs of Parkinson’s Disease is $250 million. An amount sure to be higher today.

I urge the committee to support this legislation for the benefit of the more than 50,000 affected by Parkinson’s disease in Hawaii and join 14 other states in the country that have established a Parkinson’s database.

Thank you for the opportunity to testify.

Sincerely,

Drew Higashihara

drewhigashi@gmail.com

Testimony on HB952 HD1

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

Monday, March 17, 1:00 PM

Conference Room 225 & Videoconference

State Capitol - 415 South Beretania Street

Aloha Chair San Buenaventura and Vice Chair Aquino,

My name is Cheri Higashihara, and I am a resident of Kailua. Through the Hawaii Parkinson Association, I lead the Tremble Tones `Ohana, a singing and social support group at the St. Francis Senior Community Center. Besides meeting people affected with Parkinson's through HPA, I have come across many others in my personal interactions. Many of these individuals and caregivers are surprised to hear of what we do.

In an effort to reach as many people as possible, the Hawaii Parkinson Association runs a Resource Center and many support groups and activities. We also participate in many Expos (Young at Heart, for example) and other athletic events. Our Annual Walk is our major fundraiser and we rely on that for funding. We need to make bigger impacts so those with Parkinson's Disease can receive the support they need. A Parkinson's Database is a great start.

I strongly support the bill to establish the Parkinson's Disease Research Collection Database to be administered by the Dept. of Health. The purpose of this database is to improve the lives of those affected, determine incidence and prevalence of Parkinson's disease more accurately by county and improve services needed in underserved communities.

The most recent estimate (2019/Michael J. Fox Foundation) of the direct and indirect medical costs of Parkinson's Disease is $250 million. An amount sure to be higher today.

I urge the committee to support this legislation for the benefit of the more than 50,000 affected by Parkinson's disease in Hawaii and join 14 other states in the country that have established a Parkinson's database.

Thank you for the opportunity to testify.

Sincerely,

Cheri Higashihara

higgy@hawaiiantel.net

The Senate
The Thirty-Third Legislature
Committee on Health and Human Services
Monday, March 17, 2025
1:00 p.m.

To: Senator Joy A. San Buenaventura, Chair
Re: HB 952 HD 1, Relating to Parkinson's Disease Research

Aloha Chair Joy San Buenaventura, Vice-Chair Henry Aquino, and Members of the Committee,

Mahalo for the opportunity to testify in **strong support of HB 952 HD 1**.

I am the primary caregiver of a recently diagnosed Parkinson's Disease patient.

As noted in HB 952 HD 1, Parkinson's Disease (PD) is one of the world's fastest growing neurological disorders. It is a chronic and progressive disease for which there is no cure, and it only gets worse with time.

Parkinson's Disease has a unique progression for every patient, impacting people in diverse ways, so the earlier the illness is detected, the sooner measures may be taken to slow the disease.

The degenerative nature of PD is associated with extensive healthcare needs. Roughly one-third of the people who live with PD for more than five years will develop mild cognitive impairment. Roughly 75% of those who live with long term Parkinson's Disease will develop dementia. This dementia is characterized by a decline in thinking and reasoning skills including problem solving, difficulties in communicating, understanding abstract concepts and visual information, forgetfulness, and concentration.

Little is known about the epidemiology of PD in certain racial/ethnic groups in Hawaii and the economic burden of PD to our overall community, including caregivers and taxpayers. Patients with Parkinson's Disease have greater medical care needs, lose the ability to work, and require the assistance of caregivers. A study estimated that caregivers of patients with PD spend an average of 22 hours per week. "PD is associated with substantial excess costs in direct medical costs, indirect productivity losses, non-medical costs, and disability income."[1]

Most ethnic/racial studies about medical disparities have focused on African Americans and Latinos/Hispanics, however, in Hawaii, Native Hawaiian or Other Pacific Islanders (NHPI) or Asian Americans (AA) groups are more populous.

Social-economic disparities--including higher rates of poverty, unemployment, education, and homelessness--may cause limited access to care, which consequently contributes to health

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[1] https://www.nature.com/articles/s41531-020-0117-1

disparities. Minorities are often less likely to be diagnosed and, if diagnosed, often at a later state. They are also often underrepresented in research.

In 2023, the Parkinson's Progression Markers Initiative (PPMI) scientists validated a biological test for Parkinson's with an amazing 93 percent accuracy by detecting an abnormal alpha-synuclein protein that is the hallmark of Parkinson's Disease in brain and body cells.[2] This breakthrough was made possible by thousands of study participants. This test, called an assay, allows pathological identification of subgroups of people with Parkinson's Disease to establish bio-marker-defined at-risk cohorts--those who have not yet been diagnosed with the disease, but at elevated risk of developing it. "It is an advance that may soon be used to develop better diagnostics, but more importantly could rapidly accelerate the search for treatments for the disease."[3]

By examining the demographic and clinical characteristics of patients in the proposed Parkinson's Disease database, the undiagnosed, the underserved, and social-economic and ethnic-racial disparities in Parkinson's Disease care could be identified, leading to greater access to care and treatment for more. The database may also lead to a fuller understanding of the impact of Parkinson's Disease in Hawaii.

In 2024, the State of Hawaii won a lawsuit, *State ex rel. Shikada v. Bristol-Meyer Squibb Co*., and was awarded over $916 million. "'Once actually received by the state general fund, I anticipate that this award will provide greater health care services to the people of Hawaiʻi. The state has many needs and *these funds will help us improve delivery of expanded health care to our residents*,' said Governor Josh Green, M.D."[4]

In December of 2024, Governor Green was reported to say about his administration's proposed two-year general fund budget, "We are in a good place as a state. We have adequate resources to meet our priorities and needs."[5] That news article also reported, "The general fund financial plan presented by the administration for fiscal years 2026 and 2027 also shows *surpluses of more than $1 billion*...[and] more than $1.5 billion to be held in reserve for the next budget crisis."[6]

Funding for this proposed measure appears existent.

All of us who are impacted by Parkinson's Disease hope for the "*improve[d] delivery of expanded health care to our residents*," hope for improved therapies that alleviate the symptoms of PD, and hope for, ultimately, a cure for Parkinson's Disease.

Please pass this measure. Mahalo.

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[2] https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(23)00109-6/abstract

[3] https://www.statnews.com/2023/04/12/michael-j-fox-parkinsons-biomarker/

[4] https://governor.hawaii.gov/newsroom/2024-23-state-awarded-more-than-900-million-against-major-pharmaceutical-manufacturers-of-plavix/

[5] https://www.civilbeat.org/2024/12/green-says-budget-has-room-for-public-worker-pay-raises-even-with-tax-cuts/

[6] Ibid.

HB-952-HD-1
Submitted on: 3/14/2025 1:31:05 PM
Testimony for HHS on 3/17/2025 1:00:00 PM

Submitted By	Organization	Testifier Position	Testify
GEORGE ROSS	Individual	Support	Written Testimony Only

Comments:

Aloha Chair San Buenaventura and Vice Chair Aquino,

My name is George Ross and I am a resident of Kailua, Oahu.

As a practicing neurologist doing Parkinson's Disease research in Hawaiʻi for over 30 years, I strongly support HB952 to establish the Parkinson's Disease Research Collection Database to be administered by the Department of Health. This database will allow estimates of Parkinson's disease frequency in our community that can be used for public health planning and policy making in regards to improving access to care and services and enhancing quality of care for all people with Parkinson's Disease in our state.

Thank you for allowing me to testify.

Sincerely, George Ross

Aloha Chair San Buenaventura and Vice Chair Aquino,

My name is John Kojima, and I am a resident of Kaneohe, HI. I was diagnosed with early stage of Parkinson's disease two years ago in 2022, and appreciate the support of the Hawaii Parkinson Association through its educational programs, and various support groups, like HPA Windward Support Group and "Tremble Tones", a choir of members afflicted with PD to help with breathing and speech therapy.

I strongly support the bill to establish the Parkinson's Disease Research Collection Database to be administered by the Dept. of Health. The purpose of this database is to Identify those individuals who are living with the Parkinson's Disease diagnosis and improve the lives of those affected, determine incidence and prevalence of Parkinson's disease more accurately by county and improve services needed in underserved communities.

The most recent estimate (2019/Michael J. Fox Foundation) of the direct and indirect medical costs of Parkinson's Disease is $250 million. An amount sure to be higher today.

I urge the committee to support this legislation for the benefit of the more than 50,000 affected by Parkinson's disease in Hawaii and join 14 other states in the country that have established a Parkinson's database.

Thank you for the opportunity to testify.

Sincerely,

John Kojima
johnkojima@gmail.com

HB-952-HD-1
Submitted on: 3/13/2025 10:23:43 AM
Testimony for HHS on 3/17/2025 1:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Marshall Mower	Individual	Support	Written Testimony Only

Comments:

I strongly support this measure.

Statement of A. Kawasaki

Senate Committee on Health and Human Services

Monday, March 17, 2025, 1:00 p.m.

State Capitol - 415 South Beretania Street

Conference Room 225 & Videoconference

Testimony on

H. B. No. 952, H. D. 1 – Relating to Parkinson's Disease Research.

Aloha Chair San Buenaventura, Vice Chair Aquino and Members of the Senate Committee on Health and Human Services.

My name is A. Kawasaki, and I am a resident of Honolulu. I've been living with Parkinson's disease since November 2016. I'm still independent (i.e., living alone, driving, etc.). I keep my Parkinson's disease stable with medication and high-intensity exercise. I train with a Fitness Therapy Hawaii personal trainer who specializes in Parkinson disease training and also attend group exercise classes at the Kalihi YMCA.

I strongly support this bill to establish the Parkinson's Disease Research Collection Database to be administered by the Department of Health. The purpose of this database is to improve the lives of those affected, determine incidence and prevalence of Parkinson's disease more accurately by county and improve services needed in underserved communities.

The most recent estimate (2019/Michael J. Fox Foundation) of the direct and indirect medical costs of Parkinson's Disease is $250 million. An amount sure to be higher today.

I urge the committee to support this legislation for the benefit of the more than 50,000 affected by Parkinson's disease in Hawaii and join 14 other states in the country that have established a Parkinson's database.

Thank you for the opportunity to testify on H. B. No. 952, H. D. 1.

Testimony on HB952 HD1

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

Monday, March 17, 1:00 PM

Conference Room 225 & Videoconference

State Capitol - 415 South Beretania Street

Aloha Chair San Buenaventura and Vice Chair Aquino,

My name is Phyllis Aguiar, and I am a resident of Ninole, Hawaii. I was diagnosed with Parkinson's in July 2023. Since my diagnosis, my life has been completely changed. Basic daily functions like decision making, walking, showering, preparing meals at times became very difficult for me to do. My daughter and her husband moved in with me to care for my needs. She quit her job to be with me since I was stuck in a mental fog on random days and unable to care for myself. It has made a tremendous burden on my family to care for my needs as this disease progresses. The financial burden that we endured has been tough as well with monthly trips to Honolulu for occupational therapy and doctor visits as well as physical therapy to continue to be mobile.

I strongly support the bill to establish the Parkinson's Disease Research Collection Database to be administered by the Dept. of Health. The purpose of this database is to improve the lives of those affected, determine incidence and prevalence of Parkinson's disease more accurately by county and improve services needed in underserved communities.

The most recent estimate (2019/Michael J. Fox Foundation) of the direct and indirect medical costs of Parkinson's Disease is $250 million. An amount sure to be higher today.

I urge the committee to support this legislation for the benefit of the more than 50,000 affected by Parkinson's disease in Hawaii and join 14 other states in the country that have established a Parkinson's database.

Thank you for the opportunity to testify.

Sincerely,

Phyllis Aguiar

phyllisaguiar@gmail.com