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
Honolulu, HI 96801-3378
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Testimony COMMENTING on HB952 HD1
RELATING TO PARKINSON'S DISEASE RESEARCH.

REP. KYLE T. YAMASHITA, CHAIR
HOUSE COMMITTEE ON FINANCE

Hearing Date: February 21, 2025 Room Number: 308

Fiscal Impact: General fund appropriation request for $750,000 for start-up and operational costs.

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,
- Several FTE need to be authorized to
    - Manage the contracts
    - Develop and monitor data use and reciprocal sharing agreements
    - Conduct provider education
    - Collect, store, scrub, and share repored data,
    - Provide epidemiological services,
    - Manage the Institutional Review Board,
    - Manage adiminstrative processes related to procurement, reimbursement for travel expenses, and various personnel transactions, and
    - Assure compliance with the Health Information Portability and Accountability Act for privacy and information security.

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.

Hawai‘i Family Caregiver Coalition

Testimony to the House Committee on Finance
Friday, February 21, 2025
2:00 p. m.
State Capitol Conference Room 308 and via videoconference

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

Dear Chair Yamashita, Vice Chair Takenouchi, and Honorable Members of the House Committee on Finance:

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 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 February 19, 2025.

HAWAIʻI PARKINSON ASSOCIATION

Written Testimony to the House Committee on Finance

Friday, February 21, 2025 at 2 P.M.

Hawaii State Capitol, Conference Room 308

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

Aloha Chair Yamashita and Vice-Chair Takenouchi,

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. An exact number is needed now to determine the impact Parkinson's disease has in Hawaii as globally, Parkinson's is now considered the fastest growing neurological condition in the world.

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.

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. Anecdotally, Hawaii is like the mainland with lower income populations being underserved. 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 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 Kyle T. Yamashita, Chair
The Honorable Jenna Takenouchi, Vice Chair
Members, House Committee on Finance

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: February 21, 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 Hawaiʻi 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 Hawaiʻi. 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 Hawaiʻi, 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. Hawaiʻi'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 (O‘ahu) 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 Hawai‘i, and assess treatment effectiveness over time. Epidemiologial data provided by a disease registry is critical in advancing research, understanding the environmental risk factors and facilitating clinical trial recruitment.

HB-952-HD-1
Submitted on: 2/20/2025 10:12:19 AM
Testimony for FIN on 2/21/2025 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Fran Calvert	Hawaii Parkinson's Association	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

Friday, February 21, 2:00 PM

Conference Room 308 & Videoconference

State Capitol - 415 South Beretania Street

Aloha Chair Yamashita and Vice Chair Takenouchi,

My name is Fran Calvert, and I am a resident of Keaau, Hawaii.. I am a caretaker for my husband with Parkinson’s Disease which has affected him and me and our loved ones. I facilitate the Parkinson's support group in Hilo and there are many in our community struggling with this condition.

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,

Fran Calvert

francalvert46@gmail.com

HB-952-HD-1
Submitted on: 2/19/2025 3:15:37 PM
Testimony for FIN on 2/21/2025 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
John Bickel	Individual	Support	Written Testimony Only

Comments:

As one who was diagnosed with Parkinson's seven years ago, I know all too well how debilitating this disease is. This bill would not eliminate the disease but it would house a collection of data on the incidence of Parkinson's disease ande establish the Parkinson's Disease Research Collection Database Advisory Committee. These would be positive steps for the Parkisonson's community. I encourage your favorable vote on this bill. Thank you.

TESTIMONY BY D. H. Wilson
CAPT, USN (Retired)
1212 Punahou St., #3108, Honolulu, HI 96826

Friday, February 28, 2025
(18 copies required; one for each member)

RE: HB 952 – THE PARKINSON'S DISEASE RESEARCH DATABASE

Chair Yamashita, Vice Chair Takenouchi, and Members of the Finance Committee:

As a 37+ year U.S. Navy veteran, and 64 year Hawaii resident, I strongly support this bill, which – if enacted – may provide definitive causation factors and hopefully, cure(s), which disproportionately impact military veterans. I, fortunately, do not fall within that category, but know veterans who suffer from this today. With sufficient funding, researchers might identify the cause(s), and develop viable medical protocol to either eliminate the disease in total, or mitigate its effects. This bill is similar to others in life-sciences, to include the University of Hawaii John A. Burns School of Medicine research efforts.

Throughout my residency, I voluntarily donated to Blood Bank of Hawaii, and enrolled in various U.S. Department of Defense, and JABSOM research efforts to address tropical and other diseases adversely impacting Asian and Polynesian ethnicities in particular. The greater – and broader – the research database, the more accurate the study. Given Hawaii's unique geolocation, and diverse ethnic population, the research has application beyond our shores, and could either prolong the lives of those impacted, or possibly eliminate the disease via routine inoculations, like polio. Hawaii has on-going medical research now, albeit focused on other diseases. Given the projected impact on future generations, those would number in the tens of millions. This bill, if approved as written, reinforces Hawaii's commitment to viable medical research, and addresses a malady which prematurely terminates individuals well before actuarial tables project, and greatly and adversely, impacts quality of life prior to the end. Without denigrating other projects seeking financial backing, this particular effort if successful, puts people ahead of civil engineering projects, for example, and will have a lasting, positive impact for future generations.

This bill also keeps the money here, within the state, and may attract researchers from other locales if made aware of it – confident it will be perpetuated until a cure is found. Hawaii's relatively high per capita military population, both active duty and retirees, affords researchers a "captive" source of those who are disproportionately impacted – just what is needed to validate the research. That is good for those suffering from the disease, and the State, as it attracts highly qualified researchers who, once here, tend to stay for all the reasons residents have known for generations.

I strongly support this bill, confident it will benefit many. Thank you for the opportunity to provide comment.

HB-952-HD-1
Submitted on: 2/19/2025 5:29:06 PM
Testimony for FIN on 2/21/2025 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Agnes Tauyan	Individual	Support	Written Testimony Only

Comments:

I strongly support this bill which would be of great benefit to eventually finding a cure to those who suffer from this terrible disease.

House of Representatives
The Thirty-Third Legislature
Committee on Finance
Friday, February 21, 2025
2:00 p.m.

To: Representative Kyle T. Yamashita, Chair
Re: HB 952 HD 1, Relating to Parkinson's Disease Research

Aloha Chair Kyle Yamashita, Vice-Chair Jenna Takenouchi, 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: 2/19/2025 7:41:46 PM
Testimony for FIN on 2/21/2025 2:00:00 PM

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

Comments:

I strongly support this measure.

Testimony on HB952 HD1

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

Friday, February 21, 2:00 PM

Conference Room 308 & Videoconference

State Capitol - 415 South Beretania Street

Aloha Chair Yamashita and Vice Chair Takenouchi,

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. Participants include those with Parkinsons as well as their caregivers. Luckily this `Ohana came together by word of mouth through HPA's main events such as the Symposium in April and Walk in Nov. We also attend community expos like the Senior Expo and Young at Heart Expo. HPA runs support groups across Oahu and on some of the neighbor islands. However, there are many others who could benefit from a support group but perhaps haven't received the information yet.

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

[redacted]

House Committee on Finance

Friday, February 21, 2025, 2:00 p.m.

State Capitol - 415 South Beretania Street

Conference Room 308 via Videoconference

Testimony on

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

Aloha Chair Yamashita and Vice Chair Takenouchi and Members of the House Committee on Finance.

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.

Sincerely,
A. Kawasaki

HB-952-HD-1
Submitted on: 2/20/2025 9:29:52 AM
Testimony for FIN on 2/21/2025 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Michael hill	Individual	Support	Written Testimony Only

Comments:

The importance of this bill is significant for the Parkinson’s community. It will have wide reaching impact in Hawaii. Enabling the Parkinson’s community to establish data which will go towards funding of research, potential causes and determining what areas Hawaii need help and assistance the most. Without this Data of the overall community, the Parkinson’s community is somewhat helpless in Hawaii in many areas.

Testimony on HB952 HD1

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

Friday, February 21, 2:00 PM

Conference Room 308 & Videoconference

State Capitol - 415 South Beretania Street

Aloha Chair Yamashita and Vice Chair Takenouchi,

My name is Andrea Bender, and I am a resident of Honolulu. I have been diagnosed with Parkinson's Disease. Luckily, my medication is currently working, and my life has not been significantly affected. Since being diagnosed, I have met many others in Hawaii who have Parkinson's Disease. I see the difficulties they face daily. Every day I wonder how much longer I can work, walk, and take care of myself.

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. The amount is 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 fourteen other states in the country that have established a Parkinson's database.

Thank you for the opportunity to testify.

Sincerely

Andrea Bender

andreaapo@hotmail.com

HB-952-HD-1
Submitted on: 2/20/2025 9:59:09 AM
Testimony for FIN on 2/21/2025 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Marie Cruz	Individual	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

Friday, February 21, 2:00 PM

Conference Room 308 & Videoconference

State Capitol - 415 South Beretania Street

Aloha Chair Yamashita and Vice Chair Takenouchi,

My name is Marie Cruz, and I am a resident of Honolulu,Hawaii .

I support the Parkinson Disease database collection for research. My husband Norman had Parkinson’s for twenty one years. Having the database will greatly assist everyone with PD to receive help and have access to resources that will enhance their quality of life as they face the challenges of the disease.

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,

Marie Cruz

fungo3756@gmail.com

HB-952-HD-1
Submitted on: 2/20/2025 10:07:09 AM
Testimony for FIN on 2/21/2025 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Glen Calvert	Individual	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

Friday, February 21, 2:00 PM

Conference Room 308 & Videoconference

State Capitol - 415 South Beretania Street

Aloha Chair Yamashita and Vice Chair Takenouchi,

My name is Glen Calvert, and I am a resident of Keaau.I have advanced Parkinson’s Disease which has affected and me and my loved ones. Many challenges faced every day with mobility.

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,

Glen Calvert

glencalvert22@gmail.com

HB-952-HD-1
Submitted on: 2/20/2025 2:16:50 PM
Testimony for FIN on 2/21/2025 2:00:00 PM

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

Comments:

As a Hawaiʻi Neurologist who has been performing Parkinson's disease research for over 30 years, I strongly support HB 952 relating to Parkinson's disease research. This bill will establish a system for collecting and disseminating data on Parkinson's disease in Hawaiʻi by requiring diagnosis reporting to the Department of Health. One immediate public health benefit of this information will be to allow estimates of incidence and prevalence of Parkinson's disease and related disorders in our community. As an age related disorder, Parkinson's disease will become more common as the proportion of Hawaiʻi's elderly increases. Knowing incidence and prevalence will help to plan future healthcare policy and to direct resources to the appropriate areas for the best management and care.

LATE *Testimony submitted late may not be considered by the Committee for decision making purposes.

HB-952-HD-1
Submitted on: 2/20/2025 2:31:58 PM
Testimony for FIN on 2/21/2025 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Helen Petrovitch	Individual	Support	Written Testimony Only

Comments:

As a Parkinson's Disease researcher in Hawaii for the past 30 years I support HB952 that 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. It also establishes the Parkinson's Disease Research Collection Database Advisory Committee, and Requires the Department to create a Parkinson's disease research collection database webpage by 1/1/2026, and submit annual reports to the Legislature. Thank you.

HB-952-HD-1
Submitted on: 2/20/2025 3:36:22 PM
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Submitted By	Organization	Testifier Position	Testify
Kaiulani McDurmin	Individual	Support	Written Testimony Only

Comments:

Aloha Chair Yamashita and Vice Chair Takenouchi,

I am in support of 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 the many families in Hawaii affected by the fastest growing neurological disease, determine incidence and prevalence of Parkinson’s disease more accurately, help procure funding for research and ultimately find a cure.

I urge the committee to support this legislation and join 14 other states that are leading the way for better healthcare to their communities.

Thank you for the opportunity to testify.

Sincerely,

Kaiulani McDurmin

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