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
doh.testimony@doh.hawaii.gov

Testimony COMMENTING on HB952
RELATING TO PARKINSON'S DISEASE RESEARCH.

REP. GREGG TAKAYAMA, CHAIR
HOUSE COMMITTEE ON HEALTH

Hearing Date: February 12, 2025 Room Number: 329

Department Testimony: Department Testimony: The Department of Health (DOH) provides comments recommending appropriations and new positions to implement HB952.

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.

Hawaiʻi Family
Caregiver Coalition

Testimony to the House Committee on Health
Wednesday, February 12, 2025
10:00 a. m.
State Capitol Conference Room 329 and via videoconference

Re: HB 952 Relating to Parkinson's Disease Research

Dear Chair Takayama, Vice Chair Keohokapu-Lee Loy, and Honorable Members of the House Committee on Health:

I am Gary Simon, a member of the board of the Hawaiʻi 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 Hawaiʻi Family Caregiver Coalition.

The Hawaiʻi Family Caregiver Coalition supports HB 952, 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.

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, 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 7, 2025.

HB-952
Submitted on: 2/10/2025 7:33:20 AM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Fran Calvert	Hawaii Parkinson's Association	Support	Written Testimony Only

Comments:

Aloha Chair Takayama and Vice Chair Keohokapu-Lee Loy

My name is Frances Calvert, and I am a resident of Keaau, Hawaii. My husband, Glen Calvert has advanced Parkinson's Disease. I have facilitated the Parkinson's Support Group in Hilo for the past 8 years. We send out a newsletter to 60 people but we think there are more than 300 people with PD on our island .

I urge you to join me in favorably supporting 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.

I urge the committee to support this legislation for the benefit of the Parkinson’s disease community 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,

Frances Calvert

HB-952
Submitted on: 2/10/2025 11:07:16 AM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Terry Kennedy	Speech, Swallowing, & Voice Specialists of Hawaii	Support	Written Testimony Only

Comments:

Please see attached pdf testimony on HB952

Testimony on HB952

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

Wednesday, February 12, 9:30 AM

Conference Room 329 & Videoconference

State Capitol - 415 South Beretania Street

Aloha Chair Takayama and Vice Chair Keohokapu-Lee Loy,

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 instances of others in my own 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 urge you to join me in favorably supporting 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.

I urge the committee to support this legislation for the benefit of the Parkinson's disease community 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

HB-952
Submitted on: 2/10/2025 5:47:39 PM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Stephanie Dumas	Speech, Swallowing, & Voice Specialists of Hawaii	Support	Written Testimony Only

Comments:

Aloha Chair Takayama and Vice Chair Keohokapu-Lee Loy

My name is Stephanie Dumas and I am a resident of Ewa Beach, Hawai‘i on Oahu. I am a Speech Therapist on the island who primarily works with the geriatric population many whom have been diagnosed with Parkinson's disease. The opportunity to serve these individuals and provide treatment methods to help preserve their speech, swallowing, voice, and cognition have been beyond rewarding and it is my hope that we can continue to serve the people in our community and to improve their quality of life for as long as possible.

I urge you to join me in favorably supporting 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.

I urge the committee to support this legislation for the benefit of the Parkinson’s disease community in Hawai‘i and join 14 other states in the country that have established a Parkinson’s database.

Thank you for the opportunity to testify.

Sincerely,

Stephanie Dumas

Stephanie.Dumas308@gmail.com

HAWAIʻI PARKINSON ASSOCIATION

Written Testimony to the House Committee on Health

Wednesday, February 12, 2025 at 10 A.M.

Hawaii State Capitol, Conference Room 329

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

Aloha Chair Takayama and Vice-Chair Keohokapu-Lee Loy,

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 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.

A prime example of the need for this database is this bill itself. The bill cites a study by the Michael J Fox Foundation and Parkinson's Foundation in 2018 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. 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. Whatever the number, the undeniable fact is Parkinson's disease is the fastest growing neurological condition in the world, surpassing Alzheimer's disease.

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 data 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 other 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 MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

Wednesday, February 12, 2025
Hawai'i House Committee on Health
H.B. 952 – Relating to Parkinson's Disease Research (SUPPORT)

Good morning, Chair Takayama, Vice-Chair Lee Joy, and members of the committee. My name is Zach Hardy, and I am a State Government Relations Manager 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 California, Connecticut, Maryland, Massachusetts, Missouri, Nebraska, Nevada, New York, Ohio, South Carolina, Utah, Virginia, Washington and West Virginia 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

---

[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.

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.

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

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

HB-952
Submitted on: 2/11/2025 7:46:38 AM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Quintin E. Lawrence	Hawaii Parkinson's Association	Support	Written Testimony Only

Comments:

Aloha Chair Takayama and Vice Chair Keohokapu-Lee Loy,

My name is Quintin E. Lawrence, Sr. and I am a resident of Ewa Beach, Hawaiʻi. I am a retired Army veteran of 24 years and was diagnosed with Young Onset Parkinson's Disease (YOPD) at the age of 41. Once diagnosed, I immediately went into a deep depression because I didn't completely understand the condition and impact. It took me a while to fully accept the condition as the new normal and faced multiple challenges with my family and society. I lacked energy and motivation to conduct basic tasks such as hygiene and chores. I didn't have time to process the condition after retirement because I immediately had to obtain employment to maintain the household. The added stress put a serious strain on my finances and ultimately, my marriage. I have been working tirelessly to regain a sense of 'normalcy' since the diagnosis. I exercise regularly, eat healthier, and use all available resources such as massage therapy, acupuncture, and therapy to work through mental health and physical symptoms. The Hawaiʻi Parkinson's Association (HPA) has been a great place to educate the community, share stories with similar affected people, gain insight on latest developments, and provide valuable resources.

I urge you to join me in favorably supporting 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.

I urge the committee to support this legislation for the benefit of the Parkinson's disease community in Hawaiʻi and join 14 other states in the country that have established a Parkinson's database.

Thank you for the opportunity to testify.

Sincerely,

Quintin E. Lawrence, Sr.

quel28@hotmail.com

HB-952

Submitted on: 2/11/2025 8:50:21 AM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
peter n	hawaii pacific neuroscience	Support	Written Testimony Only

Comments:

To the Honorable Members of the Legislature,

I am here today to give voice in strong support of the bill that establishes the Parkinson's Disease Research Collection Database, to be administered by the Department of Health of Hawai'i. This initiative is of vital importance in advancing the understanding of Parkinson's disease, improving healthcare outcomes, and supporting the many individuals and families affected by this debilitating condition.

Parkinson's Disease, being the progressive neurological disorder as it is, affects millions of people worldwide, especially those of the older generation. It is important to take the essential steps to comprehend the scope and nature of this disease. Creating a centralized database will not only track the people who suffer from this ailment, but to improve the reception of data collection to be analyzed and shared to the people of Hawai'i. This, in turn, will allow the public to be informed and strategize and improve the public health for Parkinson's. For those who will be considered into the database. different providers from the state can access this and ensure collaboration and provide revolutionary research to those who can. Working a neuroscience center in research, my co-workers and I have endlessly looked for patients who suffer from this disease, and want to provide other options. As of now, there are no medications that can stop the progression -- just barely treating the symptoms. Our team work with companies and sponsors to provide studies that patients can participate in that could revolutionize the way we treat Parkinson's.

This bill represents a significant step forward in the state’s commitment to combating Parkinson’s disease and improving the lives of individuals living with this condition. By investing in data collection, research, and collaboration, we are positioning ourselves to make meaningful progress in understanding Parkinson’s disease, advancing treatment options, and ultimately improving quality of life for those affected.

I urge you to support the establishment of the Parkinson's Disease Research Collection Database and the creation of its advisory committee. Not only is it an investment in the health and well-being of our citizens, but an essential step in addressing one of the most challenging neurological diseases of our time.

Thank you for your time and consideration.

Sincerely,
Peter Nguyen

Hawaii Pacific Neuroscience

HSHA
HAWAI'I SPEECH-LANGUAGE-HEARING ASSOCIATION

Testimony of the Hawaii Speech-Language-Hearing Association
Before the
House Committee on Health

Wednesday, February 12, 2025
10:00am

On the following Measure:
HB952 RELATING TO PARKINSON'S DISEASE RESEARCH

Chair Takayama and Members of the Committee:

On behalf of the Hawaii Speech-Language-Hearing Association (HSHA), I am writing in strong support of the bill to establish the Parkinson's Disease Research Collection Database, to be administered by the Department of Health. Our organization, which is dedicated to advancing the science and practice of speech-language pathology, recognizes the significant impact that Parkinson's Disease (PD) has on individuals and families, as well as the critical need for better data and services in Hawaii.

Parkinson's Disease affects not only the physical health of individuals but also their ability to communicate, which is a core focus of our association. The challenges faced by those living with Parkinson's disease, particularly in terms of speech and language difficulties, require effective, evidence-based interventions. In addition to these challenges, the financial and emotional burdens on families and caregivers can be overwhelming.

The proposed Parkinson's Disease Research Collection Database will provide a valuable tool to better understand the incidence and prevalence of PD in Hawaii, particularly in underserved communities. By collecting and analyzing this data, we will be able to tailor services and support to those most in need, and improve the quality of life for all individuals affected by Parkinson's Disease.

HSHA strongly supports this important legislation, which aligns with our mission to improve the lives of individuals with speech, language, and hearing disorders. Establishing a Parkinson's Disease database will not only benefit the local community but also put Hawaii in line with the 14 other states across the nation that have already established similar databases.

We urge you to support this bill and help ensure that individuals with Parkinson's Disease and their families receive the support and resources they deserve.

Thank you for your time and consideration.

Kristina Fuentes, MS, CCC-SLP
HSHA President
808-651-5766
info@hsha.org

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

Parkinson's
Foundation

February 11, 2025

Hawai'i House of Representatives
415 South Beretania Street
Honolulu, HI 96813

Dear Representatives;

On behalf of the Parkinson's Foundation, I am writing in support of House Bill 952, which would establish a Parkinson's disease (PD) research database in Hawai'i. This database will help expand our understanding of Parkinson's and accelerate research towards prevention, treatment, and an eventual cure.

Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience, and passion of the global Parkinson's community. Since 1957, the Parkinson's Foundation has invested more than $400 million in Parkinson's research and clinical care.

There are estimated to be more than one million Americans currently living with PD, with about 90,000 more diagnosed each year. According to the Centers for Disease Control and Prevention, PD is the second most common and the fastest-growing neurological disorder in the world.

Nationally, the cost of treating and caring for individuals living with PD is at least $52 billion annually – a total expected to eclipse $80 billion by 2037. This database will facilitate the collection and utilization of PD data to measure the incidence and prevalence of the disease and provide vital contributions towards research efforts.

Establishing a PD research database will provide critical information on the progression of the disease, help identify high-risk groups, support patient contact studies and serve as a valuable data resource for researchers and health care practitioners engaged in the prevention, management and treatment of PD. In addition, the database will enable researchers to effectively study patterns over time and support scientific efforts to discover additional treatments and therapeutics, and ultimately, a cure for PD.

The Parkinson's Foundation is proud to support this critically important piece of legislation. We urge you to pass HB 952. Please contact me at cevers@parkinson.org if I can be of further assistance.

Very truly yours,

Christiana Evers

Christiana Evers
Chief Community Engagement Officer

200 SE 1ST STREET, SUITE 800
MIAMI, FLORIDA 33131

1359 BROADWAY, SUITE 1509
NEW YORK, NEW YORK 10018

PARKINSON.ORG
HELPLINE: 800.473.4636

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

THE QUEEN'S HEALTH SYSTEMS

To: The Honorable Greg Takayama, Chair
The Honorable Sue L. Keohokapu-Lee Loy, Vice Chair
Members, House Committee on Health

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 12, 2025

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

---

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, 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 Hawaiʻi, 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. Epidemiologial data provided by a disease registry is critical in advancing research, understanding the environmental risk factors and facilitating clinical trial recruitment.

HB-952
Submitted on: 2/8/2025 7:30:04 AM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Kaiulani McDurmin	Individual	Support	Written Testimony Only

Comments:

I urge you to support this bill to create a Hawaii Parkinson's Database. Parkinson's is the fastest growing neurological disease and thousands of Hawaii families are impacted by Parkinson's each year. Creating a database will help with research, funding, and ultimately to help to find a cure.

Let Hawaii lead the way in creating the best healthcare system for our residents.

Mahalo.

House of Representatives
The Thirty-Third Legislature
Committee on Health
Wednesday, February 12, 2025
10:00 a.m.

To: Representative Gregg Takayama, Chair
Re: HB 952, Relating to Parkinson's Disease Research

Aloha Chair Takayama, Vice-Chair Keohokapu-Lee Loy, and Members of the Committee,

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

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

As noted in HB 952, 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 disparities. Minorities are often less likely to be diagnosed and, if diagnosed, often at a later state. They are also often underrepresented in research.

---

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

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 Hawai'i. 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]

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.

---

[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
Submitted on: 2/9/2025 2:49:25 PM
Testimony for HLT on 2/12/2025 10:00:00 AM

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

Comments:

Thank you for the opportunity to testify in support of this bill.

Parkinson's Disease (PD) is the second most common neurodegenerative disease after Alzheimer's disease. Both are chronic and progressive degenerative conditions that affect the central nervous system. Neither have a cure yet.

According to information from the Queen's Medical Center and other resources, an estimated 6,500 to 8,000 people in Hawaii are diagnosed with PD. This number is likely to increase as our population ages. The actual numbers are likely much higher given the fact that many individuals go undiagnosed or are misdiagnosed.

Artificial Intelligence (AI) offers new hope to those afflicted by Parkinson’s Disease and other chronic diseases. AI enhances the work of medical researchers as they continue their quest to improve therapies that help to alleviate the symptoms of these diseases. Whether it be AI or human ingenuity and innovation, quantifiable and verifiable data is needed.

Please support the passage of this bill to contribute to the development of a cure.

HB-952
Submitted on: 2/10/2025 7:38:51 AM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Natasha Gentry-Heath	Individual	Support	Written Testimony Only

Comments:

Aloha Chair Takayama and Vice Chair Keohokapu-Lee Loy

My name is Natasha Gentry-Heath, and I am a resident of Honolulu, Hawaiʻi. I have been living with Parkinson's Disease for over 8 year. It has been very challenging to navigate this neuro-degenerative disease. I've had to retire from a 20+ teaching career and face a dismal future.

I urge you to join me in favorably supporting 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.

I urge the committee to support this legislation for the benefit of the Parkinson's disease community in Hawaiʻi and join 14 other states in the country that have established a Parkinson's database.

Thank you for the opportunity to testify.

Sincerely,

Natasha Gentry-Heath

natashagentryheath@gmail.com

HB-952
Submitted on: 2/10/2025 7:43:43 AM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Glen Calvert	Individual	Support	Written Testimony Only

Comments:

Aloha Chair Takayama and Vice Chair Keohokapu-Lee Loy

My name is Glen Calvert, and I am a resident of Keaau, Hawaii. I have advanced Parkinson's Disease. I have participated in the Parkinson's Support Group in Hilo for the past 8 years and have been helped by them. There are many people on the island that don't know about us and I support having a data base so that we can reach out to them.

I urge you to join me in favorably supporting 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.

I urge the committee to support this legislation for the benefit of the Parkinson’s disease community 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

Aloha, Chair Takayama and Vice Chair Keohokapu-Lee Loy!

My name is Charol Takahashi, and I am a resident of Ewa Beach. This year will be 18 years since being diagnosed with Parkinson's disease. Having Parkinson’s has not only affected me, but my family as well.

I urge you to join me in favorably supporting 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.

I urge the committee to support this legislation for the benefit of the Parkinson’s disease community 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,
Charol Takahashi
charolt@hotmail.com

HB-952
Submitted on: 2/10/2025 4:03:58 PM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Debra Michels	Individual	Support	Written Testimony Only

Comments:

please support this bill. it affects so many good people.

HB-952
Submitted on: 2/10/2025 4:53:05 PM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Lurline k. Fujii	Individual	Support	Written Testimony Only

Comments:

Testimony on HB952

my name is Lurline Fujii from Hon. HI. I have Parkinsons.

I support the bill to establish the Parkinsons disease research collection data base.

Lurline Fujii

HB-952
Submitted on: 2/10/2025 6:05:43 PM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Mickey Norvell	Individual	Support	Written Testimony Only

Comments:

I have Parkingson s

HB-952
Submitted on: 2/10/2025 8:11:35 PM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Gordon Hirano	Individual	Support	Written Testimony Only

Comments:

Aloha Chair Takayama and Vice Chair Keohokapu-LeeLoy,

My name is Gordon Hirano, I am a resident of Kahului, Maui. I have Parkinson Disease. It's been about 15 yrs. I use to be a Math teacher at Maui High School . I had a heart attack went w/o oxygen it affected my brain, was in a coma . Long story short , I came out of the coma but had to do rehabilitation. Long story short , I had to take early retirement . Then I also found out I had Parkinson Disease. I had to stop driving my car , it only got worst ,financial and emotional and challenging impact for caregiver-my sister and brother. I am residing at Roselani Place . Thank goodness for YMCA and their Parkinson Disease boxing program ,which has helped me a lot . We need more services and support .

I urge you to join me in favorably supporting 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.
I urge the committee to support this legislation for the benefit of of the Parkinson's Disease community in Hawaiʻi and join 14 other states in the country that have established a Parkinson's database.
Thank you for your attention in this matter!
Sincerely ,

Gordon Hirano

House Committee on Health

Wednesday, February 12, 2025, 10:00 a.m.

State Capitol - 415 South Beretania Street

Conference Room 329 & Videoconference

Testimony on

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

Aloha Chair Takayama and Vice Chair Keohokapu-Lee Loy and Members of the House Committee on Health.

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 urge you to join me in favorably supporting this bill to establish the Parkinson's Disease Research Collection Database (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.

I urge the committee to support this legislation for the benefit of the Parkinson's disease community 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.

Sincerely,
A. Kawasaki

Testimony on HB952

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

Wednesday, February 12, 10:00 AM

Conference Room 329 & Videoconference

State Capitol - 415 South Beretania Street

Aloha Chair Takayama and Vice Chair Keohokapu-Lee Loy,

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 am supporting 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.

I urge the committee to support this legislation for the benefit of the Parkinson's disease community 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

HB-952
Submitted on: 2/10/2025 10:06:47 PM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Marylene Chun	Individual	Support	Written Testimony Only

Comments:

My name is Marylene Chun and I live in Volcano Village on Hawaii island. I had a close relative with Parkinson's who suffered greatly for many years before passing. The relative's primary caregiver suffered as well. This brutal disease can strip all those affected of their dignity and their physical, mental and financial health.

I am in support of this bill which will aid in Parkinson's research specifically in Hawai'i. As Hawai'i's population grows older the rates of occurrence of Parkinson's will only increase. We should be proactive in gaining as much insight as possible that will aid in the detection of causation and further treatment of this disease.

Thank you for your consideration,

Marylene Chun

Testimony on HB952

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

Wednesday, February 12, 9:30 AM

Conference Room 329 & Videoconference

State Capitol - 415 South Beretania Street

Aloha Chair Takayama and Vice Chair Keohokapu-Lee Loy

My name is Lyn Hew, and I am a resident of Manoa in Honolulu.

Since December 2013, when I was diagnosed with Parkinson's Disease I've had a drastic decline in my overall wellbeing. I used to be able to play tennis, help my husband in the yard, do household chores, including cooking and baking, enjoy quality time with family and friends, and be active in my church. But most humbling of all, it's not being able to be self-reliant. Now, I can't do anything safely by myself. Because of lack of balance, I must use a walker at home and be pushed in a wheelchair when I go out. It's very draining on my husband, my sole caregiver. I am an invalid. All activities have been cancelled.

I urge you to join me in favorably supporting 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.

I urge the committee to support this legislation for the benefit of the Parkinson's disease community 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,

Lyn Hew

Email – lthew@hawaiiantel.net

Testimony on HB952

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

Wednesday, February 12, 9:30 AM

Conference Room 329 & Videoconference

State Capitol - 415 South Beretania Street

Aloha Chair Takayama and Vice Chair Keohokapu-Lee Loy

My name is John Kojima, and I am a resident of Kaneohe, Oahu. I have been diagnosed with Parkinson's Disease since 2023 and am continuing to learn about my diagnosis and how best I can address treating my diagnosis. Information is critical in learning about tendencies of the disease and development of treatment protocols.

I urge you to join me in favorably supporting 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.

I urge the committee to support this legislation for the benefit of the Parkinson's disease community 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 A. Kojima

johnkojima@gmail.com

HB-952
Submitted on: 2/11/2025 7:47:53 AM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Stephanie Mullin	Individual	Support	Written Testimony Only

Comments:

Aloha, and thank you for all that you do to responsibly steward resources for the people of Hawaii.

Please support the Parkinson's Disease database to get better statistics for our community in Hawaii in order to secure future funding and attract more health care professionals specializing in this field for all of the Hawaiian Islands. The more we know, the better chance we have to get more state or federal assistance. Additionally, a database would provide a pool of individuals to consider for diagnostic, preventative and treatment research.

I am a speech language pathologist with specialized training in Parkinson's Disease. My work and volunteering reveals the deep and wide needs of this community, especially in the population of Parkinson's Disease. A database would provide some unification for further advocacy efforts.

Kindly consider the long term positive impact of this decision, and I encourage you to vote in favor. May God bless you and protect you.

HB-952
Submitted on: 2/11/2025 7:59:32 AM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Samantha Heath	Individual	Support	Written Testimony Only

Comments:

My name is Samantha Heath, and I am a resident of Honolulu, Hawaii. My mother, Natasha, has been suffering from Parkinson's for many years now. She is early onset and suffers from dyskinesia and stiffness. It has been a difficult journey because there is no one test that can confirm she has Parkinson's. I can't count how many doctor visits she has had to the limited amount of Parkinson's specialists Hawaii has. She has paid her own way to the Mayo clinic to get more help. Every medical professional has a different opinion on how to help her. But besides diagnosing her the only way to get relief is with exercise and massage therapies. All of which is paid by her!!!!!!!!!!! It's not as easy to exercise when your body does not work and it requires help and guidance which costs money. My mom can't get any relief from this disease so whatever research can be done to help these people who suffer from Parkinson's is absolutely necessary.

I urge you to join me in favorably supporting 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.

I urge the committee to support this legislation for the benefit of the Parkinson’s disease community 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,

Samantha Heath

Samantha.s.heath@gmail.com

Aloha Chair Takayama and Vice Chair Keohokapu-Lee Loy

My name is Lloyd Nakao, and I am a resident of Honolulu. I was diagnosed with Parkinson's Disease in 2023.

I urge you to join me in favorably supporting 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.

I urge the committee to support this legislation for the benefit of the Parkinson's disease community 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,

Lloyd Nakao

coldandagi@verizon.net

HB-952
Submitted on: 2/11/2025 9:46:12 AM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Jack Suyderhoud	Individual	Support	Written Testimony Only

Comments:

Aloha ChairTakayama and Vice-Chair Keopokapu-Lee Loy,

My name is Jack Suyderhoud and I live in East Honolulu.

I strongly urge that HB 952, relating to Parkinson's disease in Hawaii, be approved by the Legislature.

I am a former UHM business professor. After my retirement I was diagnosed with Parkinson's Disease (PD). Fortunately my diagnosis occurred early in the progression of the disease, and my symptoms are relatively mild.

The incidence of PD in Hawaii is increasing rapidly. The causes of the disease are unknown, and there is no cure. However, tremendous progress has been made in treating the symptoms of PD and in slowing its progression.

Still, more needs to be done. Research into the disease and developing policies to mitigate its effects requires more knowledge. The purpose of HB 952 is to:

- establish 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 (much like the cancer tumor registry);
- establish the Parkinson's Disease Research Collection Database Advisory Committee;
- require the Department to create a Parkinson's disease research collection database webpage by 1/1/2026; and
- submit annual reports to the Legislature.

I know that the Legislature faces many complex issues that require attention and resources. HB 952 would have significant positive impacts while requiring minimal resources. By passing this legislation, Hawaii would join at least 14 other states in advancing research on PD through better knowledge of the incidence, causes and impacts of PD, especially in the context of our racially diverse population.

Thank you for your consideration.

Jack Suyderhoud, Hawaii Kai

Jack P. Suyderhoud, PhD
Economic Consultant (Ret.)
7149 Kukii Street
Honolulu, Hawaii 96825
T: 808-342-6226
jsuyderhoud@icloud.com

HB-952

Submitted on: 2/11/2025 9:50:26 AM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Ana Ribeiro	Individual	Support	Written Testimony Only

Comments:

Testimony on HB952

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

Wednesday, February 12, 9:30 AM

Conference Room 329 & Videoconference

State Capitol - 415 South Beretania Street

Aloha Chair Takayama and Vice Chair Keohokapu-Lee Loy

My name is Ana Ribeiro, and I am a resident of Honolulu, HI.

As a Speech-Language Pathologist, I closely work with people with Parkison's Disease and their families. I have seen first hand the financial and emotional impact this disease has on them. As a progressive disease, it tends to not receive much attention due to lack of proper information and funding for the necessary therapy this population require.

I urge you to join me in favorably supporting 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.

I urge the committee to support this legislation for the benefit of the Parkinson’s disease community 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,

Ana Ribeiro

anajmribeiro@gmail.com

HB-952
Submitted on: 2/11/2025 9:53:33 AM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Matt Johnston	Individual	Support	Written Testimony Only

Comments:

I have worked as a healthcare provider in both facility and community based settings in this state and others. In Hawai’i I have seen a higher prevalence of patients with Parkinson's Disease, fewer available community resources, and reduced health literacy among patients and caregivers regarding the etiology and management of Parkinson's Disease. Understanding Parkinson's in Hawai’i is the first step in overcoming these challenges. Establishing this database would serve as a precious resource in helping to better learn and understand the impact of Parkinson's Disease on our population, and be able to measure and observe efficacy of interventions with management. Understanding Parkinson's in Hawai’i is the first step in overcoming these challenges.

HB-952
Submitted on: 2/11/2025 10:24:38 AM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Marie Cruz	Individual	Support	Written Testimony Only

Comments:

Testimony on HB952

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

Wednesday, February 12, 9:30 AM

Conference Room 329 & Videoconference

State Capitol - 415 South Beretania Street

Aloha Chair Takayama and Vice Chair Keohokapu-Lee Loy

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

I was a caregiver for my husband. He had

Parkinson for 21 years before he passed away in 2021. Establishing a Parkinson data base for

people with Parkinson’s disease will assist in them having access to all the medical care, equipment, etc for them to continue to enjoy the quality of life they deserve while living with the disease.

I urge you to join me in favorably supporting 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.

I urge the committee to support this legislation for the benefit of the Parkinson's disease community 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

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

HB-952
Submitted on: 2/11/2025 10:37:43 AM
Testimony for HLT on 2/12/2025 10:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Vern Heath	Individual	Support	Written Testimony Only

Comments:

Aloha Chair Takayama and Vice Chair Keohokapu-Lee Loy

My name is Vern Heath, and I am a resident of Honolulu, Hawaii. As a caregiver for my wife, who has Parkinson's, I witness firsthand the daily challenges that come with this progressive disease. From mobility issues to medication management, caregiving is physically, financially and emotionally demanding. Despite the hardships, my commitment to her well-being is unwavering.

I urge you to join me in favorably supporting 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.

I urge the committee to support this legislation for the benefit of the Parkinson's disease community 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,
Vern Heath
vernheath@gmail.com

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

February 11, 2025

Testimony in SUPPORT of HB952
RELATING TO PARKINSON'S DISEASE RESEARCH

COMMITTEE ON HEALTH
Rep. Gregg Takayama, Chair
Rep. Sue L. Keohokapu-Lee Loy, Vice Chair

Aloha Chair Takayama, Vice Chair Keohokapu-Lee Loy, and Honorable Members of the Committee,

My name is Tani Kalei Salazar and I'm a Social Worker, born and raised in Honolulu. My grandfather lived with Parkinson's disease and later developed dementia. As an ʻohana, we cared for him in every stage and in various care settings. I saw the way it changed him over the years. I wish we knew more. Parkinson's disease has impacted many of my patients in the past as well. I am testifying in support of HB952 and I affirm the need for significant resources in order to meet the intent of this bill.

Mahalo for this opportunity to testify.

Sincerely,

Tani K. Salazar

Tani Kalei Salazar, LSW, MSW