DAVID Y. IGE
GOVERNOR OF HAWAII

BRUCE S. ANDERSON, PHD
DIRECTOR OF HEALTH

STATE OF HAWAII
DEPARTMENT OF HEALTH
P. O. Box 3378
Honolulu, HI 96801-3378
doh.testimony@doh.hawaii.gov

Testimony in SUPPORT of SB804 SD1 HD1
RELATING TO PALLIATIVE CARE.

REP. SYLVIA LUKE, CHAIR
HOUSE COMMITTEE ON FINANCE

Hearing Date: March 28, 2019 Room Number: 308

Fiscal Implications: Unspecified general fund appropriation request. The Department of Health respectfully recommends $350,000.

Department Testimony: The Department of Health (DOH) supports SB804 SD1 HD1 provided that any appropriations do not displace any Executive Budget requests. The purpose of this measure is to adopt recommendations from the palliative care working group, including testing the hypotheses of recent local research on culturally competent approaches to staff and patient engagement.

Palliative care is a recent medical specialty focused on comfort care and quality of life for patients, including their family, suffering from serious health conditions. Palliative care may be employed while the patient is continuing active treatment through different phases of their life limiting condition. All hospice care is palliative in nature, but not all palliative care is hospice.

The "Our Care, Our Choice" Act, Act 2, Session Laws of Hawaii 2018, which authorized medical aid in dying, was a major driver of the community conversation on palliative care. The advisory group which guided DOH's implementation urged a focus on all available end-of-life care options and not just a singular focus on obtaining a prescription of life-ending medication. Palliative care was thus identified as a major gap in the care of Hawaii's patients enduring serious illnesses.

Concurrently, in 2018, the department convened a working group pursuant to SCR142 HD1 SLH 2018 which tasked the community to recommend strategies to expand palliative care in Hawaii. In partnership with the American Cancer Society Cancer Action Network and Kokua Mau, as well as industry partners, the top recommendations were to:

1) Increase public and health care provider education;
2) Support with public funds demonstration projects in the State; and
3) Evaluate new and existing data sources to further establish community standards of care.

Mainland-based research reveals clear disparities such that "in every ethnic subgroup studied, Asian Americans and Pacific Islanders were less likely than whites to enroll in hospice" (Ngo-Metzger, et al. 2007). Local research from the University of Hawaii School of Nursing, "Culturally Competent Palliative and Hospice Care Training for Ethnically Diverse Staff in Long-Term Care Facilities," (Kataoka-Yahiro, et al. 2016) suggests that culturally competent approaches to Asian Americans and Pacific Islanders improve patient and staff knowledge and satisfaction with palliative and hospice care services.

This research is likely to have real-world implications since non-enrollment or late enrollment in palliative care, including but not limited to hospice, increases direct health care costs and like the emotional burden of patients and their families.

In short, Hawaii's families should have much earlier access to palliative care options than the current health environment provides, which is very inadequate. Thank you for the opportunity to testify in strong support of SB804 SD1 HD1.

Offered Amendments: N/A.

Committee on Finance

Representative Sylvia Luke, Chair
Representative Ty J.K. Cullen, Vice Chair

NOTICE OF HEARING

DATE: Thursday, March 28, 2019
TIME: 2:00 p.m.
PLACE: Conference Room 308
State Capitol – 415 South Beretania Street

Testimony in Support of SB804, SD1, HD1 (HSCR1589)

RELATING TO PALLIATIVE CARE

Establishes the culturally competent palliative care pilot program to promote palliative care, gather health care utilization data, and conduct bidding for at least two pilot programs for home or community based palliative care, one of which must be located in a county with less than two hundred thousand residents. Requires reports to the legislature. Establishes an advisory group to oversee implementation of the pilot program. Appropriates funds.

(Name/Title) ROY K. NAKAMOTO

Thank you for the opportunity to provide testimony in **support of SB804, SD1, HD1 (HSCR1589)** that establishes the culturally competent palliative care pilot program to promote palliative care. I am grateful for the support and unanimous passage by members of the CPH, WAM, HLT and CPC – recognizing the importance of palliative care as a vital healthcare issue, and the need for expansion of palliative care services statewide.

According to the Executive Office on Aging, Hawaii's high percentage of Japanese-American's have one of the longest life expectancies of any ethnic subgroup in the United States, contributing to a critical need for palliative and hospice care. In fact, when national data is broken down by race, Asian-Pacific Islanders make up only 2.6% of hospice patients nationwide. With the State of Hawaii's population self-identifying in the latest census as 74.3% non-white, we have a lot of opportunities to build community awareness and service acceptance.

The palliative care model addresses more than pain management; it also treats the physical, spiritual, and emotional needs of the seriously ill patient.

As our state's senior population continues to grow, and health care focus shifts from acute to chronic illnesses, the need to change from one-time interventions that correct a single problem to the ongoing management of multiple diseases, disabilities, and complex social issues increases.

SB804, SD1, HD1 (HSCR1589) goals are an essential step to providing more comprehensive, culturally competent care for the communities we serve, and I are in complete support of this initiative.

Again, mahalo for the opportunity to provide testimony on this important measure.

HAH
Healthcare Association
of Hawaii

March 28, 2019 at 2:00 pm
Conference Room 308

House Committee on Finance

To: Chair Sylvia Luke
Vice Chair Ty J.K. Cullen

From: Paige Heckathorn Choy
Director of Government Affairs
Healthcare Association of Hawaii

Re: Testimony in Support
SB 804 SD 1 HD 1, Relating to Palliative Care

The Healthcare Association of Hawaii (HAH), established in 1939, serves as the leading voice of healthcare on behalf of 170 member organizations who represent almost every aspect of the healthcare continuum in Hawaii. Members include acute care hospitals, skilled nursing facilities, home health agencies, hospices, assisted living facilities and durable medical equipment suppliers. In addition to providing access to appropriate, affordable, high quality care to all of Hawaii's residents, our members contribute significantly to Hawaii's economy by employing over 20,000 people statewide.

Thank you for the opportunity to testify in **support** of this measure, which would provide public education on palliative care, encourage earlier adoption of palliative care in a patient's course of treatment, and establish at least two culturally competent palliative care pilot programs. Palliative care provides a comprehensive treatment option for individuals battling serious illness to help alleviate physical and emotional pain that greatly improve these patients' quality of life.

This legislation will help to continue important discussions and actions to promote palliative care and help patients access this important type of care. We are grateful to the legislature for focusing on this important piece of the care continuum and hope your committee will view this legislation favorably.

Thank you for the opportunity to support this measure.

HAWAI‘I PACIFIC HEALTH
KAPI‘OLANI
PALI MOMI
STRAUB
WILCOX

Thursday, March 28, 2019 at 2:00 PM
Conference Room 308

House Committee on Finance

To: Representative Sylvia Luke, Chair
Representative Ty Cullen, Vice Chair

From: Michael Robinson
Vice President, Government Relations & Community Affairs

Re: Testimony in Support of SB 804, SD1, HD1
Relating to Palliative Care

My name is Michael Robinson, Vice President, Government Relations & Community Affairs at Hawai‘i Pacific Health. Hawai‘i Pacific Health is a not-for-profit health care system comprised of its four medical centers – Kapi‘olani, Pali Momi, Straub and Wilcox and over 70 locations statewide with a mission of creating a healthier Hawai‘i.

I write in support of SB 804, SD1, HD1 establishing the culturally competent palliative care program to promote palliative care through education and two pilot projects, as well as establishing an advisory group to oversee implementation.

Hawai‘i Pacific Health in collaboration with Kokua Mau and the hospice provider community provides access to palliative care to our patients. Our palliative care programs provide interdisciplinary services that seek to prevent or relieve the physical, psychological, social and spiritual distress produced by a life-threatening medical condition or its treatment, to help patients with such conditions and their families live as normally as possible, and to provide them with timely and accurate information and support in decision-making.

Unfortunately most patients only become knowledgeable about palliative care options when confronted with serious illness or serious life threatening conditions. Therefore, the opportunity to provide greater awareness of palliative care options across the general population through access to program services would be to the benefit to all patients in our State.

Thank you for the opportunity to testify.

THE QUEEN'S HEALTH SYSTEMS

To: The Honorable Sylvia Luke, Chair
The Honorable Ty J.K. Cullen, Vice Chair
Members, Committee on Finance

From: Paula Yoshioka, Vice President, Government Relations and External Affairs, The Queen's Health Systems
Date: March 27, 2019
Hrg: House Committee on Finance Hearing; Thursday, March 28, 2019 at 2:00 PM in Room 308

Re: Support for S.B. 804, S.D.1, H.D.1, Relating to Palliative Care

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The Queen's Health Systems (Queen's) is a not-for-profit corporation that provides expanded health care capabilities to the people of Hawai‘i and the Pacific Basin. Since the founding of the first Queen's hospital in 1859 by Queen Emma and King Kamehameha IV, it has been our mission to provide quality health care services in perpetuity for Native Hawaiians and all of the people of Hawai‘i. Over the years, the organization has grown to four hospitals, 66 health care centers and labs, and more than 1,600 physicians statewide. As the preeminent health care system in Hawai‘i, Queen's strives to provide superior patient care that is constantly advancing through education and research.

Queen's appreciates the opportunity to testify in support of S.B. 804, S.D. 1, H.D. 1 Relating to Palliative Care, which establishes a culturally competent palliative care pilot program. Palliative care is a proven approach that improves the quality of life of our patients and their families facing challenges associated with life-threatening illness. Through prevention and relief of suffering, palliative care address and manages the physical symptoms, as well as the emotional and spiritual hardship our patients face due to their serious, chronic, and/or terminal conditions.

Thank you for your time and attention to this important issue.

SB-804-HD-1
Submitted on: 3/27/2019 1:45:20 AM
Testimony for FIN on 3/28/2019 2:00:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
GARY SIMON	ST. FRANCIS HEALTHCARE SYSTEM	Support	No

Comments:

Dear Chair Luke, Vice Chair Cullen, and Honorable Members of the House Committee on Finance:

I am Gary Simon, Director of Corporate Affairs and Advocacy for St. Francis Healthcare System.

I am testifying as an individual who has worked in healthcare for over thirty years, and I am offering testimony on behalf of St. Francis Healthcare System.

St. Francis Healthcare System wholeheartedly supports SB 804 SD 1 HD 1.

Our St. Francis Palliative Care Program has demonstrated positive results in assisting patients with managing their pain and symptoms as well as assisting patients and their families with psychosocial and spiritual support.

Furthermore, our Palliative Care Program has been effective in helping patients and their families with the burdensome details in their daily lives, including, but not limited to, coordinating transitions of care from hospitals and care facilities to their homes, navigating the healthcare system, advocating for patients and their families, educating caregivers, assisting with health insurance (including Medicaid), and securing transportation.

St. Francis Healthcare System is pleased that the Legislature is developing a policy and program to expand palliative care and to enhance access to palliative care for those facing serious illness and for their loved ones to reduce their unnecessary suffering and to find the support and care they need.

We urge you to support SB 804 SD 1 HD 1, and we urge you to recommend its passage.

We thank you for seriously considering the bill.

Very sincerely,

Gary Simon

Director of Corporate Affairs and Advocacy

St. Francis Healthcare System

SB-804-HD-1
Submitted on: 3/27/2019 8:40:57 AM
Testimony for FIN on 3/28/2019 2:00:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Elena Cabatu	East Hawaii Region of Hawaii Health Systems Corporation	Support	No

Comments:

hawaii family forum

ONLINE SUBMITTAL
Submitted on March 27, 2019

HEARING DATE: March 28, 2019 2:00 p.m. in room #308

TO: Committee on Finance
Rep. Sylvia Luke, Chair
Rep. Ty Cullen, Vice Chair

FROM: Eva Andrade, President

RE: **Strong Support for SB 804 SD1 HD1 Relating to Palliative Care**

Hawaii Family Forum is a non-profit, pro-family education organization committed to preserving and strengthening life, family and religious freedom in Hawaii. We support this bill that establishes a culturally competent palliative care pilot program to promote palliative care, gather health care utilization data, and conduct bidding for at least two pilot programs for home or community based palliative care.

When someone we love faces the fear of a terminal diagnosis—and all the emotions and decisions that come with it—more than ever, they need to know that we believe their life is worth fighting for.

The National Hospice and Palliative Care Organization describes palliative care as "patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs to facilitate patient autonomy, access to information and choices." Palliative care focuses on treating the ***person***, as well as the disease, and helps provide support and inclusion for family members.

Palliative care improves quality of life and survival and creates care efficiencies that curb costs. Although we believe that Hawai'i leads the way in many aspects because of the hard work of groups like Hospice Hawai'i, St. Francis Hospice, Kokua Mau, and others, there are often barriers to getting patients with serious illness access to palliative care. These include:

- Lack of knowledge and understanding about palliative care;
- Variability in access based on geographic location, physician training, and services offered;
- Inadequate workforce to meet the needs of patients and families especially in some of our local cultural groups;
- Insufficient research to guide and measure quality of care.

We strongly support activities that increase public education and the development of practices that will specifically address the cultural norms of Hawaii's patients and families. The effort will ensure that comprehensive and accurate information about palliative care is available to the wider public, and that benefits the entire community. By passing this bill, Hawai'i legislators will be taking a significant step towards helping our sickest patients get access to the best care for them and their families.

Let's work together to make sure those with the most serious illnesses in our community know we're not giving up on them. Mahalo for the opportunity to testify.

HAWAI'I
CARECHOICES
Where Quality of Life Matters

Formerly
HOSPICE *of* HILO

1011 Waiānuenue Avenue
Hilo, HI, 96720-2019
P: (808) 969-1733
F: (808) 961-7397

care@hawaiicarechoices.org
www.hawaiicarechoices.org

Committee on Finance
The Honorable Sylvia Luke, Chair
The Honorable Ty J.K. Cullen, Vice Chair

RE: TESTIMONY IN SUPPORT OF SB804 SD1, HD1 (HSCR1589)
RELATING TO PALLIATIVE CARE
Hearing: March 28, 2019 at 2:00 p.m.

Dear Chair Luke and Members of the Committee:

Thank you for the opportunity to provide testimony in **support of SB 804 SD1, HD1 (HSCR 1589)** that establishes the culturally competent palliative care pilot program to promote palliative care. I am grateful for the support and unanimous passage by members of the CPH, WAM, HLT, and CPC – recognizing the importance of palliative care as a vital healthcare issue, and the need for expansion of palliative care services statewide.

According to the Executive Office on Aging, Hawaii's high percentage of Japanese-American's have one of the longest life expectancies of any ethnic subgroup in the United States, contributing to a critical need for palliative and hospice care. In fact, when national data is broken down by race, Asian-Pacific Islanders make up only 2.6% of hospice patients nationwide. With the State of Hawaii's population self-identifying in the latest census as 74.3% non-white, we have a lot of opportunities to build community awareness and service acceptance.

With 35 years serving the palliative, hospice, and bereavement needs of East Hawai'i, we can attest to the power of palliative care through the example of our community-based palliative care program started in 2016. As our state's senior population continues to grow, and health care focus shifts from acute to chronic illnesses, the need to change from one-time interventions that correct a single problem to the ongoing management of multiple diseases, disabilities, and complex social issues increases. The palliative care model addresses more than pain management; it also treats the physical, spiritual, and emotional needs of the seriously ill patient. **We at Hawai'i Care Choices can confirm that the models and cost-savings found in palliative care are the solutions for the future.**

SB804 SD1, HD1 (HSCR1589) goals are an essential step to providing more comprehensive, culturally competent care for the communities we serve, and we are in complete support of this initiative. Again, mahalo for the opportunity to provide testimony on this important measure.

Respectfully,

Brenda S. Ho

Brenda S. Ho, MS, RN
Chief Executive Officer

SB-804-HD-1
Submitted on: 3/26/2019 2:16:44 PM
Testimony for FIN on 3/28/2019 2:00:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Karen Maedo	HawaiiCareChoices	Support	No

Comments:

Headquarters **HONPA HONGWANJI MISSION OF HAWAII**
1727 PALI HIGHWAY / HONOLULU, HAWAII 96813 / PH: 522-9200 / FAX: 522-9209

Date: March 28, 2019

To: The Honorable Sylvia Luke, Chair
The Honorable Ty Cullen, Vice Chair
Members, House Committee on Finance

From: Bishop Eric Matsumoto
Honpa Hongwanji Mission of Hawaii

RE: **Support for SB 804, SD1 HD1 Relating to Palliative Care**

The Honpa Hongwanji Mission of Hawaii is a Shin Buddhist community that is celebrating its 130th Anniversary in 2019. We are the largest Buddhist denomination in Hawaii with over thirty temples across the state. Our mission is to share the living Teachings of Jodo Shinshu Buddhism so that all beings may enjoy lives of harmony, peace, and gratitude.

I appreciate the opportunity to offer testimony in support of SB 804, SD1 HD1 Relating to Palliative Care which seeks to establish a culturally competent palliative care pilot program. Palliative care has been proven to improve the quality of life for patients and their families facing chronic and/or life-limiting illness. With the goal of preventing or relieving suffering, palliative care addresses not only physical symptoms but also emotional and spiritual distress.

Increasing public education and the development of culturally appropriate practices will help ensure that comprehensive and accurate information about the benefits of palliative care is available to a wider population. Increasing access to palliative care is beneficial for our entire community.

Mahalo for your consideration and attention to this important issue.

American Cancer Society
Cancer Action Network
2370 Nu`uanu Avenue
Honolulu, Hawai`i 96817
808.432.9149
www.acscan.org

House Committee on Finance
Representative Sylvia Luke, Chair
Representative Ty Cullen, Vice Chair

SB 804, SD1, HD1 – RELATING TO PALLIATIVE CARE

Cory Chun, Government Relations Director – Hawaii Pacific
American Cancer Society Cancer Action Network

Thank you for the opportunity to provide testimony in support of SB 804, SD1, HD1, which appropriates unspecified funds for palliative care education and establish a culturally competent palliative care pilot program. Measure effective on July 1, 2050.

Palliative care is specialized medical care for people with serious illness. This type of care is focused on providing patients with relief from the symptoms, pain and stress of a serious illness - from point of diagnosis onward. The goal is to improve quality of life for both the patient and the family.

SB 804, SD1, is based on research of cultural competency in palliative care conducted by the University of Hawaii in 2016. As a first step to increasing palliative care in Hawaii, people facing chronic diseases and life-threatening conditions need to know what palliative care is and how it can increase their quality of life as they go through recovery or face an end-of-life situation.

In 2018, the Legislature adopted SCR 142, HD1, which created the palliative care working group in partnership with the Department of Health, Kokua Mau, and the American Cancer Society Cancer Action Network. SB 804 is a continuation of the working group and will allow for further discussions by increasing public awareness, gathering more information, and creating a pilot program to focus on cultural competency. We are committed to continue working with the palliative care community on this important issue for cancer patients and others facing serious illnesses.

Thank you for the opportunity to provide testimony on this important matter.

Committee on Finance

Representative Sylvia Luke, Chair
Representative Ty J.K. Cullen, Vice Chair

NOTICE OF HEARING

DATE: Thursday, March 28, 2019
TIME: 2:00 p.m.
PLACE: Conference Room 308
State Capitol – 415 South Beretania Street

Testimony in Support of SB804, SD1, HD1 (HSCR1589)

RELATING TO PALLIATIVE CARE

Establishes the culturally competent palliative care pilot program to promote palliative care, gather health care utilization data, and conduct bidding for at least two pilot programs for home or community based palliative care, one of which must be located in a county with less than two hundred thousand residents. Requires reports to the legislature. Establishes an advisory group to oversee implementation of the pilot program. Appropriates funds.

(Name/Title) Kim Kobayashi, Program Manager for **Community First**

Thank you for the opportunity to provide testimony in **support of SB804, SD1, HD1 (HSCR1589)** that establishes the culturally competent palliative care pilot program to promote palliative care. I am grateful for the support and unanimous passage by members of the CPH, WAM, HLT and CPC – recognizing the importance of palliative care as a vital healthcare issue, and the need for expansion of palliative care services statewide.

According to the Executive Office on Aging, Hawaii's high percentage of Japanese-American's have one of the longest life expectancies of any ethnic subgroup in the United States, contributing to a critical need for palliative and hospice care. In fact, when national data is broken down by race, Asian-Pacific Islanders make up only 2.6% of hospice patients nationwide. With the State of Hawaii's population self-identifying in the latest census as 74.3% non-white, we have a lot of opportunities to build community awareness and service acceptance.

The palliative care model addresses more than pain management; it also treats the physical, spiritual, and emotional needs of the seriously ill patient.

As our state's senior population continues to grow, and health care focus shifts from acute to chronic illnesses, the need to change from one-time interventions that correct a single problem to the ongoing management of multiple diseases, disabilities, and complex social issues increases.

SB804, SD1, HD1 (HSCR1589) goals are an essential step to providing more comprehensive, culturally competent care for the communities we serve, and I are in complete support of this initiative.

Again, mahalo for the opportunity to provide testimony on this important measure.

KŌKUA MAU
Continuous Care
A Movement to Improve Care

March 27, 2019

Testimony in Support of SB 804, SD1, HD1

Dear Representative Luke and other members of the House Committee on Finance,

With this testimony for SB804, I would like to express my strong support for this bill to strengthen and expand Palliative Care in Hawaii. This bill from recommendations from the Palliative Care Task Force, created last year by resolution, and provides next steps in increasing palliative care awareness and usage in Hawaii.

I currently have the honor to serve as Executive Director of Kōkua Mau, which is the Hospice and Palliative Care Organization for Hawaii. As a network of organizations and individuals around the state, we are committed to increasing palliative care as it is seen as best practice for caring well for people with serious illness. This support includes hospice care, which is a type of palliative care for those at the very end of life. Kōkua Mau is committed to creating a continuum of care for those with serious illness, including their loved ones and those who care for them, and is very encouraged by the increase interest in the opportunities that palliative care offers.

We support all part of the bill, which include:

1. Education for the public and professionals
2. Pilot studies to show the efficacy of palliative care
3. Establish data points to best determine standards of care and determine unmet need

Studies show that palliative care increases patient and family satisfaction, decreases patients suffering, increases advance care planning and decreases unnecessary hospital stays. Palliative care can therefore improve patient care, support caregivers, and reduce unnecessary treatments and save money. We see this bill as an important next step in increasing our palliative care capacity statewide. Unfortunately, although palliative care is known as best practice, it is not yet available to all that need it. My personal experiences with palliative care have inspired my professional commitment and I believe that more palliative care will help those in Hawaii to be getting the best care possible.

Please let me know if you have any further questions. We are supportive of the proposed amendments. I will be attending the hearing on March 28.

Best wishes,

Jeannette G. Koijane, MPH
Executive Director
Kōkua Mau
jkoijane@kokuamau.org

Kōkua Mau, Hawaiʻi Hospice and Palliative Care Organization
P.O. Box 62155 • Honolulu, HI 96839 • Tel: 808-585-9977 • www.kokuamau.org

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HOUSE COMMITTEE ON FINANCE

Thursday, March 28, 2019, 2 pm, Conference Room 308
SB 804, SD 1, HD 1 Relating to Palliative Care

TESTIMONY

Douglas Meller, Legislative Committee, League of Women Voters of Hawaii

Chair Luke and Committee Members:

The League of Women Voters of Hawaii requests amendment of SB 804, SD 1, HD 1.

The League has no expertise or position concerning palliative care. However, we request amendment of SB 804, SD 1, HD 1 so that the "advisory group" which would "**oversee**" implementation of the palliative care pilot program is subject to Chapter 92, Hawaii Revised Statutes. There is no compelling justification to totally exempt the proposed "advisory group" from the Sunshine Law.

Thank you for the opportunity to submit testimony.

SB-804-HD-1
Submitted on: 3/27/2019 10:26:03 AM
Testimony for FIN on 3/28/2019 2:00:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Douglass Adams	Individual	Support	No

Comments:

My name is Charlene Iboshi from Hawaii Island. I currently serve our community through many civic organizations and am on the Board of Community First, a non-profit organization established in 2014. We are a grassroots effort to care for our community's health. I am a committee member on the State's PABEA Legislative Committee.

One of the Grass-roots Initiatives of Community First is to educate the community regarding Advance Health Care Directives, the need for the end-of-life "conversations. and have community members complete their AHCDs. As part of this effort, we have educated ourselves of the growing needs of the elders and those who have life-threatening conditions. We have worked with Hawaii Care Choices on Hawaii Island and Kokua Mau on Oahu. In the past couple of years, we have monthly sessions at our Aging Disability Resource for the AHCDs Workshops.

What we have learned is that we have a "diverse" community, but many people here culturally are challenged by "barriers" to discuss death, end-of-life conversations and having community conversations about "palliative care" as part of the continuum of care before death. Fear through culturally appropriate strategies can overcome cultural barriers for engagement, including—"if we talk about it, illness and death will come to those who discuss it." It's like "jinxing" a healthy life. I don't need help because my "family" will take care of the me, because it's their duty. Our island has one of the most diverse ethnic groups, including the Hawaiian and Micronesian communities, who do not engage the palliative and hospice care until crises care needs arise.

The need to discuss providing meaningful discussions for palliative and hospice care is more critical now with the "Silver Tsunami." In my life journey as a caretaker for several people and professional career prosecuting cases of "untimely" deaths and serious injuries, I recognize the need for a data-driven, culturally sensitive-discussions and strategies to engage our community and provide the available "palliative care and hospice" services.

Please pass **SB 804, SSCR 106** for more comprehensive, culturally competent care for our communities. I would eliminate the 200,000 population-restriction, otherwise, Hawaii Island may not qualify as a pilot-site. Thank you for the opportunity to testify.

SB-804-HD-1
Submitted on: 3/26/2019 2:30:46 PM
Testimony for FIN on 3/28/2019 2:00:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Clarysse Kami Nunokawa	Individual	Support	No

Comments:

SB-804-HD-1
Submitted on: 3/26/2019 9:45:10 AM
Testimony for FIN on 3/28/2019 2:00:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Junshin Miyazaki	Individual	Support	No

Comments:

Committee on Finance

Representative Sylvia Luke, Chair

Representative Ty J.K. Cullen, Vice Chair

NOTICE OF HEARING

DATE:	Thursday, March 28, 2019
TIME:	2:00 p.m.
	Conference Room 308
PLACE:	
	State Capitol – 415 South Beretania Street

Testimony in Support of SB804, SD1, HD1 (HSCR1589)

RELATING TO PALLIATIVE CARE

Establishes the culturally competent palliative care pilot program to promote palliative care, gather health care utilization data, and conduct bidding for at least two pilot programs for home or community based palliative care, one of which must be located in a county with less than two hundred thousand residents. Requires reports to the legislature. Establishes an advisory group to oversee implementation of the pilot program. Appropriates funds.

(Name/Title) Junshin Miyazaki, resident minister of Hilo Meishoin

Thank you for the opportunity to provide testimony in **support of SB804, SD1, HD1 (HSCR1589)** that establishes the culturally competent palliative care pilot program to promote palliative care. I am grateful for the support and unanimous passage by members of the CPH, WAM, HLT and CPC – recognizing the importance of palliative care as a vital healthcare issue, and the need for expansion of palliative care services statewide.

According to the Executive Office on Aging, Hawaii's high percentage of Japanese-American's have one of the longest life expectancies of any ethnic subgroup in the United States, contributing to a critical need for palliative and hospice care. In fact, when national data is broken down by race, Asian-Pacific Islanders make up only 2.6% of hospice patients nationwide. With the State of Hawaii's population self-identifying in the latest census as 74.3% non-white, we have a lot of opportunities to build community awareness and service acceptance.

The palliative care model addresses more than pain management; it also treats the physical, spiritual, and emotional needs of the seriously ill patient.

As our state's senior population continues to grow, and health care focus shifts from acute to chronic illnesses, the need to change from one-time interventions that correct a single problem to the ongoing management of multiple diseases, disabilities, and complex social issues increases.

SB804, SD1, HD1 (HSCR1589) goals are an essential step to providing more comprehensive, culturally competent care for the communities we serve, and I are in complete support of this initiative.

Again, thank you for the opportunity to provide testimony on this important measure.

SB-804-HD-1
Submitted on: 3/25/2019 5:57:10 PM
Testimony for FIN on 3/28/2019 2:00:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Christine	Individual	Support	No

Comments:

SB-804-HD-1
Submitted on: 3/26/2019 12:11:06 PM
Testimony for FIN on 3/28/2019 2:00:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Virginia Hinshaw	Individual	Support	No

Comments:

This bill is a move forward for Hawaii’s citizens.. Please support this bill.

SB-804-HD-1
Submitted on: 3/27/2019 11:20:11 AM
Testimony for FIN on 3/28/2019 2:00:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Daniel H Belcher	Individual	Support	No

Comments:

SB-804-HD-1
Submitted on: 3/27/2019 1:27:43 PM
Testimony for FIN on 3/28/2019 2:00:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Hope Young	Individual	Support	No

Comments:

Palliative Care is a critical need in our community. This bill will benefit many people faced with serious illness, providing an extra layer of support people need when dealing with an illness. When palliative care is used, better care is provided and people are supported in times of a healthcare crisis. Education and implementation are crucial for the people of Hawaii.

House Committee on Finance
Rep. Sylvia Luke, Chair
Rep. Ty J.K. Cullen, Vice Chair

RE: SB804, RELATING TO PALLIATIVE CARE

Dear Chair Luke, Vice-Chair Cullen and Other Members of this Committee,

My name is Uri Martos, and I am writing to express my support for SB804, which would create a pilot program that would increase the utilization of palliative care through public education and the development of practices specific to the cultural norms of Hawaii's patients and families.

As a recent breast cancer survivor, I can tell you firsthand how important palliative care is. SB804will make palliative care more available to people like me who need this special care to help them through their health conditions.

Palliative care was essential to my success in completing treatment with a more positive state of mind. The special care that I received made such a difference and I want all cancer & those suffering chronic illnesses to also have this special care.

Please support SB804 and help others in our community receive this same care. The pilot program formed under SB804 would aim toward allowing palliative care to be accessible for all Hawaii residents by promoting cultural competency among our health professionals. A consistent finding of various studies on palliative care show that culturally competent palliative and hospice training is a promising practice to increase patient, family, and provider engagement with end-oflife conversations.

I urge you to support SB804. Thank you for the consideration of my testimony.

Mahalo,
Uri Martos

House Committee on Finance
Rep. Sylvia Luke, Chair
Rep. Ty J.K. Cullen, Vice Chair

RE: SB804, RELATING TO PALLIATIVE CARE

Dear Chair Luke, Vice-Chair Cullen and Other Members of this Committee,

My name is Gary Tanimitsu, and I am writing to express my support for SB804. I believe this bill and the pilot program it supports is one big step in allowing the general public and those touched by a chronic or terminal disease to learn more about palliative care, regardless of their socio-economic status or ethnicity.

I am reminded of my uncle, my father’s oldest brother, who successfully lived with cancer in the 1980’s and 1990’s. When he got older he eventually needed to be hospitalized and languished in Queen’s Medical Center, suffering painfully every day. When my father and I went to visit him, he spoke to my father and said “Shinitai”, which is Japanese for “I want to die.”

As soon as a bed opened up at a Skilled Nursing Facility, he was transferred and remained there until he finally and mercifully passed away.

SB804 is a step in the right direction in ensuring that any patient, regardless of their ethnicity, knows that palliative care is an option that they can pursue in the course of their treatment. In my uncle’s case, a conversation about palliative care could have been made with cultural competency taking into account his Japanese American ancestry.

There is also a personal stake in this for me. I'm a Boomer, a member of the largest demographic group in the United States. I'm no longer the bullet proof, invincible young man who thought he would outrun pain and suffering to live forever. I'm older now and facing my mortality with a sober realization that I, too, could have an experience similar to that of my uncle.

SB804 is a step in the right direction for many reasons. We all deserve to have our need for balanced, compassionate care addressed, but for too many individuals, palliative care is a foreign concept that they may be unfamiliar with. With this bill, we can move forward in promoting education around palliative care in our communities.

Sincerely,
Gary Tanimitsu

House Committee on Finance
Rep. Sylvia Luke, Chair

SB804, RELATING TO PALLIATIVE CARE

Dear Chair Luke and Members of the Committee,

My name is Natalie Nimmer, and I strongly support SB804, which would establish a culturally competent palliative care pilot program to promote palliative care, gather health care utilization data, and conduct bidding for at least two pilot programs for home or community based palliative care. All cancer patients—regardless of financial status, age, or any other factor—should have access to palliative care; this pilot project could lead greater awareness and access.

When we rang in the new year in 2015, I was a 36-year-old vegan marathon runner. Then in March, I was diagnosed with Stage 3 breast cancer. In addition to pointing out the shock of the news, just about everyone around me said that I needed to get used to a "new normal."

I endured 7 different chemo drugs over two separate multi-month periods of treatment, as well as 1 minor and 2 major surgeries, and 33 rounds of radiation. In the midst of this, I suffered from debilitating nausea, extreme fatigue, and neutropenic fever (a condition sparked by a compromised immune system in when everything goes wrong—rash from head to toe, high fever, and a range of other maladies). There were many days during the year and a half of treatment when I could not stay awake for more than 2 hours a day and could not walk without assistance to the bathroom.

But I was self-employed and a doctoral candidate at UH-Mānoa, so I did not have the option to drop out of life for 18 months. My nurse practitioner Christa Braun-Ingles and oncologist Keola Beale, performed magic through the use of palliative care treatments. I was able to continue working and attend classes on my good days—even if it meant bringing a pillow and blanket to camp out on the floor when I didn't have the energy to sit up. In fact, I completed the Hibiscus Half-Marathon between my 3rd and 4th rounds of chemo and presented my graduate research at a conference in the Marshall Islands 2 weeks after my 6th round of chemo. I was bald and weak, but I was still *living* life. Without palliative care treatments, none of this would have been possible. It was a "new normal", but could still easily be classified as "normal."

SB804 would raise awareness about palliative care and increase access to these options. Palliative care is about dignity, but it is also about ensuring that anyone with serious, chronic, or terminal conditions can still *live* while they are on this earth. Please support this "new normal" for Hawai'i, by supporting SB804.

Thank you for considering my testimony.

Mahalo,
Natalie Nimmer

House Committee on Finance
Rep. Sylvia Luke, Chair
Rep. Ty J.K. Cullen, Vice Chair

RE: SB804, RELATING TO PALLIATIVE CARE

Dear Chair Luke, Vice-Chair Cullen and Other Members of this Committee,

My name is Misty Figuera, and I am writing to express my support for SB804, which would create a pilot program that would increase the utilization of palliative care through public education and the development of practices specific to the cultural norms of Hawaii's patients and families.

As a young twenty one year old student who has a chronic disease and has been caregiver for the father figure in my life who has cancer, I see the benefits of Palliative care clearly.

Life doesn't stop when cancer and chronic illness comes knocking on the door. Bills still need to be paid, children still have volleyball games that need to be attended, and term papers still need to be written by a due date. Life is stressful in the first place – being sick only makes it worse. For those of us with busy schedules struggling to make it financially, being sick is just not the icing of the top of stress made cake; Suddenly, your schedule becomes filled by trying to find the write doctors, paying to see the wrong ones, and being exhausted physically and mentally. This is why palliative care is so important.

Palliative care is about improving life for cancer patients and those who live with chronic illnesses. When you are given the news that you are very sick, your life Cullenes. Life becomes harder – for you AND especially your loved ones – after all, they are the ones who watch over you and take care of you. It becomes easy to give up to want to die, because that would be easier.

Palliative care is not only needed and extremely beneficial, but it is NECESSARY. It makes life easier, better, and makes it enjoyable again. What makes Hawaii a great state is the aloha we share – through our daily interactions, through giving our time, and through palliative care. The pilot program formed under SB804 would be the first step in allowing palliative care to be accessible for all Hawaii residents by promoting cultural competency among our health professionals. A consistent finding of various studies on palliative care show that culturally competent palliative and hospice training is a promising practice to increase patient, family, and provider engagement with quality of life conversations.

I urge you to support SB804. Thank you for the consideration of my testimony.

Mahalo,
Misty Figuera

House Committee on Finance
Rep. Sylvia Luke, Chair
Rep. Ty J.K. Cullen, Vice Chair

RE: SB804, RELATING TO PALLIATIVE CARE

Dear Chair Luke, Vice-Chair Cullen and Other Members of this Committee,

My name is Jenny Hausler, and I am writing to express my support for SB804, which would create a pilot program that would increase the utilization of palliative care through public education and the development of practices specific to the cultural norms of Hawaii's patients and families.

My sister Lucy was diagnosed with Stage 4 breast cancer at 58 and passed away at age 63. During the course of her disease she suffered much pain and stress and at the end of her life, especially fear. Had coordinated palliative care been available at the time, her cancer journey and passing would have been eased so much.

Her one wish would be that no one would ever have to go through the pain and suffering she did. This is one of the main reasons I support SB804.

The pilot program formed under SB804 would be the first step in allowing palliative care to be accessible for all Hawaii residents by promoting cultural competency among our health professionals. A consistent finding of various studies on palliative care show that culturally competent palliative and hospice training is a promising practice to increase patient, family, and provider engagement with quality of life conversations.

I urge you to support SB804. Thank you for the consideration of my testimony.

Mahalo,
Jenny Hausler

House Committee on Finance
Rep. Sylvia Luke, Chair
Rep. Ty J.K. Cullen, Vice Chair

RE: SB804, RELATING TO PALLIATIVE CARE

Dear Chair Luke, Vice-Chair Cullen and Other Members of this Committee,

My name is Molly Pierce, and I serve as a volunteer for the American Cancer Society, Cancer Action Network. I would like to submit my testimony in support of SB804, which would create a pilot program that would increase the utilization of palliative care through public education and the development of practices specific to the cultural norms of Hawaii's patients and families.

Palliative care involves treating the whole patient, not just their disease. Ensuring that someone's mental health is as closely monitored as their physical health or treating pain conditions that arise from the treatment of chronic illness can make all the difference in quality of life. It is not solely reserved for those who are at the end of their lives. Palliative care can improve health outcomes for all patients fighting life threatening or chronic illnesses.

Having seen many family members go through cancer treatments, I can attest that those who were fortunate enough to have doctors who fought for them to receive palliative care were far better prepared to fight their cancer battle. Treating the cancer alone didn't treat the pain, the shortness of breath, or the fragility of mental health that come along with facing a life threatening illness. Access to holistic palliative care helped give my mother the strength and peace of mind I truly believe allowed her to survive. Treating her lack of appetite, helping her regain physical strength, and caring for her mental state instead of just focusing on killing her cancer helped give her the motivation to fight.

Please pass SB804, which would aim toward allowing palliative care to be accessible for all Hawaii residents by promoting cultural competency among our health professionals.. Give Hawaii the chance to improve quality of life for our loved ones fighting life threatening or chronic illnesses.

Mahalo,
Molly Pierce

House Committee on Finance
Rep. Sylvia Luke, Chair
Rep. Ty J.K. Cullen, Vice Chair

RE: SB804, RELATING TO PALLIATIVE CARE

Dear Chair Luke, Vice-Chair Cullen and Other Members of this Committee,

My name is Gay Okada, and I am writing to express my support for SB804, which would create a pilot program that would increase the utilization of palliative care through public education and the development of practices specific to the cultural norms of Hawaii's patients and families.

Living in Kona, on the island of Hawaii, health care and palliative care is at the none existence level in some areas.

To form a palliative care work group would help my friends with rheumatoid arthritis and bone cancer. One friend with rheumatoid arthritis (severe) had moved to Kentucky to live with her brother and passed away already. We desperately need your help with this situation.

I urge you to support SB804. Thank you for the consideration of my testimony.

Mahalo,
Gay Okada

House Committee on Finance
Rep. Sylvia Luke, Chair
Rep. Ty J.K. Cullen, Vice Chair

RE: SB804, RELATING TO PALLIATIVE CARE

Dear Chair Luke, Vice-Chair Cullen and Other Members of this Committee,

My name is Alberto Rodriguez, and I am writing to express my support for SB804, which would create a pilot program that would increase the utilization of palliative care through public education and the development of practices specific to the cultural norms of Hawaii's patients and families.

I have witnessed a loved one's fight against cancer and I want to make sure that others that go through this fight are able to access the holistic care provided by palliative care.

My aunty passed away from cancer and lacked access to palliative care services that would have allowed for a higher level of care for both herself and our family. I now want to make sure that we do everything we can to promote awareness about palliative care services in our state.

In 2014, my aunt was diagnosed with kidney cancer. At the time, she wasn't sure where to turn to and who we could talk to about the services and care as her disease progressed. We often were forced to travel two hours to see a doctor. The appointment was on a firstcome/first-served basis. Long lines outside the doctor's office starting at 4 o'clock in the morning, waiting for the secretary to open the door at 8 o'clock and waiting for the doctor to arrive at 12 o'clock or later.

My aunt's health deteriorated quickly and we were a prisoner of the process and health access. She passed away in less than 6 months after diagnosis.

The pilot program formed under SB804 would be the first step in allowing palliative care to be accessible for all Hawaii residents by promoting cultural competency among our health professionals. A consistent finding of various studies on palliative care show that culturally competent palliative and hospice training is a promising practice to increase patient, family, and provider engagement with quality of life conversations.

I urge you to support SB804. Thank you for the consideration of my testimony.

Mahalo,
Alberto Rodriguez

House Committee on Finance
Rep. Sylvia Luke, Chair
Rep. Ty J.K. Cullen, Vice Chair

RE: SB804, RELATING TO PALLIATIVE CARE

Dear Chair Luke, Vice-Chair Cullen and Other Members of this Committee,

My name is Kyle Loui, and I am writing to express my support for SB804, which would create a pilot program that would increase the utilization of palliative care through public education and the development of practices specific to the cultural norms of Hawaii's patients and families.

My family has been personally been affected by cancer and I wish that we could do more palliative care. My mother has been personally been affected by breast cancer. I personally witnessed her go through chemotherapy, and felt her pain as she struggled to go about doing day to day tasks.

All the Doctors were allowed to do was give her pain relief drugs and advice on what to do. Which was insufficient to help her get through the tough process of chemotherapy. I feel she could have benefited from palliative care when going through Chemotherapy. Besides looking up what other people are helping people through those time. She went through a near-death situation, was going through continuous pain, and was extremely depressed.

The pilot program formed under SB804 would be the first step in allowing palliative care to be accessible for all Hawaii residents by promoting cultural competency among our health professionals. A consistent finding of various studies on palliative care show that culturally competent palliative and hospice training is a promising practice to increase patient, family, and provider engagement with quality of life conversations.

I want this bill to achieve a more personal and effective type of care. It would help to focus palliative care coverage on chronic diseases, hopefully, we can incorporate new stakeholders on this important issue.

Mahalo,
Kyle Loui

TESTIMONY RE: SB 804 by Rae Seitz, MD

I wish to submit this testimony in support of SB 804 regarding Palliative Care.

There is perhaps no single subspecialty of medicine more impactful than palliative medicine on the quality of care, degree of engagement of patients and their loved ones, and degree of shared decision-making regarding the care a person receives when faced with serious or life-threatening conditions. The activities of palliative medicine are basically four-fold:

1. Conduct a comprehensive, holistic review of an individual's medical condition and options for care, assess the capacity and literacy of the individual to integrate information so as to enable true shared decision-making between patients, families, and providers.
2. Conduct conversations with patients and loved ones to ensure their understanding, concerns, anxieties, and goals are fully understood. Enabling an individual to "find his or her voice" and to be able to effectively express themselves is something that requires skill and patience to be able to accomplish. Palliative medicine specialists have these skills as a cornerstone of their training and experience.
3. Conduct open and honest conversations with all the providers of care to an individual so as to obtain the most complete and comprehensive understanding of what each provider understands and has learned about the individual. It is critical to assess, from each of their perspectives, what they believe an individual's options for care are, the risks and benefits, and the prospects for achieving those benefits. In this way palliative care can improve coordination of care, clarify goals of care so as to enable all providers to better work towards the same goals, and to make more efficient the care rendered to the individual.
4. Provide a plan of care which is centered on the patient's understanding of his/her condition and options, his/her wishes and goals. This plan of care often is updated by the palliative care team which, optimally, maintains a longitudinal relationship with the patient. At this point this is program-dependent but should be aspired to by all palliative care programs. This continuity of care and adjustments to care plans based on changing conditions, understanding, and goals is especially valuable when an individual faces serious or life-threatening situations.

It is important to recognize the foundation upon which palliative medicine is conducted: skillful, values-neutral communication facilitated by experienced and skilled interdisciplinary teams. When done well the result is a safer, more cohesive plan of care which places the individual squarely in the driver's seat. These skills can be acquired and palliative medicine specialists have a specific responsibility to help build those skills and knowledge with others who may touch these individuals. This is why most palliative medicine specialists regularly participate in workshops, lectures, and development of materials to build better capacity of our healthcare providers to themselves conduct more skillful and productive conversations with their patients and families. I would suggest that the bill be strengthened by adding clear language that palliative care builds upon a foundation of true shared decision-making and that this effort needs to be supported and enabled.

I am a palliative medicine specialist and a founding board member of Kokua Mau, Hawaii's hospice and palliative care organization. I have been the major architect and developer of palliative care programs state-wide, including home-based and hospital-based programs. I have taught at JABSOM, in the community widely, nationally, and internationally. I have published in the field. Most recently I was appointed to the Department of Health Advisory Panel to help organize the implementation of the Our Care Our Choice Act.

Thank you for your kind consideration of this testimony.

I may be reached at (808)285-3102 for any additional information.

Rae S. Seitz, MD
5710 Haleola Street
Honolulu, HI 96821

House Committee on Finance
Rep. Sylvia Luke, Chair
Rep. Ty J.K. Cullen, Vice Chair

RE: SB804, RELATING TO PALLIATIVE CARE

Dear Chair Luke, Vice-Chair Cullen and Other Members of this Committee,

My name is Mimi Demura-Devore, and I am writing to express my support for SB804, which would create a pilot program that would increase the utilization of palliative care through public education and the development of practices specific to the cultural norms of Hawaii's patients and families.

I am a Licensed Clinical Social Worker in Hawaii. Over the past 20 years, I have worked with people who are HIV-positive as a case manager, terminally-ill and their families as a hospice social worker, and currently, I am working with many seniors, seriously ill people and their caregivers as a psychotherapist. I see many people dealing with serious illnesses and their loved ones face many challenges daily that affect their physical, psychosocial and spiritual wellbeing. It is a very difficult journey to go through on your own, and no one should go through such suffering alone. From my experience, I strongly believe that the early involvement of palliative care support that is comprehensive and culturally competent greatly improves the quality of life of seriously ill people and their loved ones.

I am also a member of the Kokua Mau's Let's Talk Story Program, and I volunteer to provide education on Advance Health Care Directives and End-of-life care to the Japanese-speaking community. Many people are not aware of the options for palliative care and hospice care due to the language barrier that limits their access to such information. With our diverse population in Hawaii, it is important to ensure that all people are aware of their options and have access to palliative care services. In order to do so, putting more efforts into educating health care professionals to increase their knowledge and competency in palliative and hospice care is crucial. Since I have seen many compassionate and dedicated palliative care and hospice care teams help improve people's quality of life, I'd like to see increased and easier access to and utilization of those services throughout the communities in the state of Hawaii.

I ask you for your support of SB804 to help improve the quality of life of people in Hawaii.

I am not able to appear in person today, but if you have any question, please feel free to contact me. Thank you for the opportunity to express my support for SB804 relating to Palliative Care.

Respectfully submitted,

Mimi Demura-Devore, LCSW

From: Peggy McIntaggart <peggymcintaggart@gmail.com>
Sent: Wednesday, March 27, 2019 2:23 PM
To: FINtestimony
Subject: Lexis Law SB804

We are all in favor of Lexis Law SB804

Peggy Seagren
McKenzie Seagren
GARY Busey
Mika Seagren
KAREN McDougle

Sent from my iPhone

LATE

RE: HB 1447/SB804 RELATING TO PALLIATIVE CARE

My name is Melissa C Bojorquez and I am writing to express my support for B1447/SB804, appropriates funds for palliative care education and establish a culturally competent palliative care pilot program.

Palliative care is crucial to the quality of life during the most difficult times of a person's life. Many don't understand how this is a critical and necessary service and I hope to explain just how important this is for a large group of constituents and family members.

The importance of palliative care has touched my life through my personal and professional experiences.

Professionally, I am a social worker and longtime case management professional. Having worked for the largest health plan for almost 20 years - managing a case management department serving members who were facing serious and life limiting conditions - I had been instrumentally involved in piloting projects that focus on removing barriers and access to valuable benefits such as Hospice and Home Health Care who are vital conduits in delivering palliative care services. The challenges to adopt palliative care were often hindered by policies that limit access due to stringent language and patients/caregivers/families lack of understanding of what palliative care is and when should someone receive palliative care.

The reality is palliative care is more that comfort care and end of life. It is a seamless service that should be woven in all aspects of care - from acute and aggressive cancer treatments fighting for cure to the ebb and tides of aging gracefully or through the course of a good death.

Personally I have been a caregiver for my parents for almost 15 years. I am of Filipino ancestry and strong asian - traditional Catholic belief systems. It was when my father was diagnosed with lung CA in 2008 at age 84. It took all my professional years of experience as a social worker and case manager as well as familial values/belief - to be the best advocate and case manager for my parents. I navigated and coordinated care for my father from initial diagnosis that started with seeking palliative oncology treatment and working with St. Francis Healthcare's Outpatient Palliative Care team. I helped coordinated his care that involved multidisciplinary team consults to discern what would be the best course to live the kind of quality of life we wanted in the final year. After a 2 hours consultation with the Palliative Care team and specialists -the only critical team member that was not at that meeting was my father's primary care of over 40 years. After the 2 hour consultation with several options presented - my father insisted we go see his primary care PCP. Tired and on oxygen - we arrived at the PCP office to find that the elevator to his office was out of order. My father insisted to walk up 3 flights. It was the meeting with his PCP that my father asked -" What should I do? " His PCP said "do nothing" and " go and enjoy your time with your family." It was then - he opted to proceed with Home Hospice Care which allowed him 6 months of quality time - that he was able to spend with his family - seeing his 1st grandchild graduate from high school. He passed away surrounded by his entire family and peaceful death - a good death.

Since my father's passing in 2009, I have been my mother's caregiver - and she is now 88 years old. We have experienced the ebbs and tides of caregiving over the 10 years - and I would call it palliative care. Last years was the most difficult as it was marked with multiple falls, changes in cognition/increase confusion/Dementia, ER visits and hospitalizations. Having had friends and colleagues who are Palliative Care clinicians - I consulted them and they suggested Hospice care. I was in denial - I didn't not think it was time for Hospice - but we enrolled in hospice care. After 3 months on home hospice - she improved with Hospice Care and graduated to Palliative Care. I was able to take her to the mainland to see her 1st grandson graduate from high school. That is what palliative care is - its that extra layer of support that helps the whole person - medically, physically, spiritually - mind body & spirit. Palliative care allows individuals with their entire support system (friends, family, ohana) live their best life.

My experiences validates that palliative care can assist those with transitioning towards health and recovery or towards the end of options/treatment phase before hospice enters that picture. There is a huge gap and palliative care can help fill that gap in care.

My concern is that I am a caregiver who has the expertise and knowledge to navigate this complex healthcare system. What about all those who lack the knowledge, lack the family support, who are isolated and at risk to fall through so many gaps in the system. It is critical that Palliative care is part of our healthcare ecosystem to look out and connect those to the supportive care that is missing today.

In 2018, the Legislature adopted SCR 142, HD1, which the palliative care working group in partnership with the Department of Health, Kokua Mau, and the working group and will allow further discussions by increasing public awareness, gathering more information, and creating a pilot program to focus on cultural competency.

I urge you to support HB 1447/SB804. Thank you for the consideration of my testimony.

Mahalo,

Melissa C Bojorquez

Melissa C. Bojorquez