

IMI HALE

MAKAHIKI 2009

2ND ANNUAL CANCER PATIENT NAVIGATION CONFERENCE

BY AMANDA ALLISON

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On September 24 & 25, 2009, 'Imi Hale held its 2nd Annual Ho'okele i ke Ola Cancer Patient Navigation Conference at the Queen's Conference Center in Honolulu.

Participants came from all over the state to learn more about cancer patient navigation, the resources available to navigators and techniques and technical information that can help navigators thrive in their jobs, cancer understanding and what patients experience. It was also a rich environment to network, reach out and learn from each other.

This year, the conference focused on breast cancer and was made possible through funding from the Hawai'i Affiliate of Susan G. Komen for the Cure as well as logistical and CME support from The Oueen's Medical Center.

Presenters included many old friends of 'Imi Hale's Ho'okele project who shared new and expanded information about their work as it relates to navigation. There were also many new faces working with us to provide a new range of experience from survivorship to disability rights.

Rev. Al Miles helps navigators practice establishing and maintaining professional boundaries.

organizations who

a success: Susan G.

Komen for the Cure -

Hawai'i Affiliate and

The keynote speaker was Lisa Harjo, a Native Sister patient navigator, curriculum developer and Native American Tobacco Education Project Director with the Native American Cancer Research (NACR) in Colorado. Lisa is a member of the Choctaw Nation. Her keynote address was "The Cultural Roots of Navigation." Lisa and her colleagues at NACR have supported the Ho'okele i ke Ola navigator project since its inception by sharing curriculum and technical assistance. We were honored to be able to share her expertise with conference participants.

In addition to regular conference sessions, there were two special highlights: the premiere screening of a new film "A Journey of Hope When a Young Woman Gets Breast Cancer", and presentation of the first Ho'okele i ke Ola Award.

"A Journey of Hope" shares the experiences of three young Native Hawaiian women, during their diagnoses and treatment of breast cancer. (See page 4 for a review of the film.) The presentation of the film was made even more poignant with the panel discussion that followed with the three young women (Tiare Agpaoa, Darci Ludington, and Roz Makaula) and two of their mothers (Joy S. Agpaoa and Detta Makaula). L. Kehau Matsumoto, conference participant and breast cancer survivor remarked that the film "...is truly a blessing of success."

The first Ho'okele i ke Ola Award was presented by Hardy Spoehr, Executive Director of Papa Ola Lokahi to The Queen's Cancer Center in recognition of their contributions to cancer patient navigation in Hawai'i, which has been a priority of the Queen's Cancer Center and which Queen's has helped to

> establish as a profession in Hawai'i.

Mahalo nui loa to the many individuals and made this conference

Debbie Ishihara Wong holding the Ho'okele i ke Ola award for the Queen's Cancer Center.

their wonderful volunteer staff, Queen's Cancer Center, Queen's Conference Center staff and catering department, 'Imi Hale staff, all the presenters who graciously shared their time and knowledge and conference participants. Rulan Waikiki, a young breast cancer survivor and presenter at the Conference stated she was glad to have made her (very moving and intensely) personal presentation on the visual reality of breast cancer treatment to "... such a warm crowd of passionate people."

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FEATURED NATIVE RESEARCHER JAMIE KAMAILANI BOYD

Jamie Kamailani Boyd, RN, MSN, FNP, PhD is an assistant professor and nurse researcher at the University of Hawai`i Windward Community College on O`ahu.

As the Employment Training Center (ETC) Health Program Coordinator, Dr. Boyd oversees the nursing-pathway program she designed to enable students who become certified nurses aides (CPN) to go on to become licensed practical nurses (LPN) and earn a "living wage" with health benefits. The program also offers students the opportunity to pursue a nursing degree (RN) and achieve even greater economic sustainability.

Students in the CNA-LPN-RN pathway program participate in various academic and lifestyle activities that are designed to improve their employability and wellbeing.

Jamie is no stranger to hard work and the challenges faced by local students who lack the training and skills to envision the possibility of an entry-level nurse aide becoming a doctoral nurse researcher. In fact, she has spent over 18 years balancing the roles

of wife, mother, student and health practitioner to overcome the same barriers she now helps students to overcome.

Prior to establishing herself as a respected educator and researcher, Jamie spent 15 years in nursing, 7 as a nurse practitioner in a junior-college health center, where she also designed and tested a college-based nutrition and physical fitness course targeting Native Hawaiian young adults.

Students enrolled in her study were viewed through a holistic lens whereby

"The students were designing didn't know it. They (students) must be included in programming intended for them."

their educational and health needs were simultaneously considered. They not only received academic instruction, but also fitness training (working in a lo`i - taro patch) the program, but and diet instruction (emphasizing a traditional, healthy diet).

> In the ETC Health Program, Jamie effectively incorporates Hawaiian culture into job-readiness training that naturally includes wellness promotion so students gain skills to overcome multiple barriers.

In designing these programs, student focus groups were purposely conducted. According to Dr. Boyd, "the students were designing the program, but didn't know it. They (students) must be included



Dr. Jamie Kamailani Boyd holding her APHA Best Paper Award with colleague Winston Tsang, PhD

in programming intended for them."

Students are currently being tracked over three years to make sure everything is being done to ensure their success.

Dr. Jamie K. Boyd's studies have been published in Preventing Chronic Disease, 2007. One of her manuscripts in that publication Supports for and Barriers to Healthy Living for Native Hawaiian Young Adults Enrolled in Community Colleges garnered the Best Paper Award at the 2008 American Public Health Association conference.

PRIORITIES FOR A TOBACCO-FREE HAWAI`I

Tobacco advocacy priorities for the 2009 legislative session were: 1) protect funds dedicated to tobacco prevention and control, especially from the Tobacco Settlement Special Fund; 2) keep the Smoke-Free Law intact (HRS Ch. 328L); 3) eliminate the sunset provision in Hawaii's Tobacco Retail Permit Law (HRS 245-2. 2.5, 2.6, and 2.7); and 4) educate our legislators and the community about new tobacco products.

The good news from this year's session is that Hawai`i now has the 5th highest cigarette tax in the nation, with a significant increase in tax on other tobacco products. The retail tobacco law that requires tobacco vendors to have a permit remains

in effect and the Smoke-Free Workplace Law was kept intact.

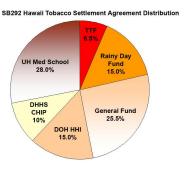
The bad news is, despite declining smoking rates among adults and youth, room-filled

hearings and overwhelming testimony, cessation and community advocates were not able to completely protect the tobacco settlement funds.

Sadly, the funds that were to be dedicated for tobacco prevention and control have been diverted to the State, citing the current financial crisis.

The result is a significant cut in monies (see

pie chart) and loss in funding to 30 community groups, who receive Tobacco Trust Funds (TTF) to provide needed cessation and prevention services.



So, at a time when the need for cessation services is at a critical high with more people quitting in response to tax increases on tobacco products, smoke-free laws and social norm pressures for a healthier lifestyle, there will be less

services available, 'AUWE no ho'i e!

A PERSONAL SMOKEFREE JOURNEY BY HEIDI VASPRA

I have struggled with tobacco dependence for 20 years. As a social worker who has been in the clinical and community health setting, I know all about the health implications of tobacco related illnesses. Quite frankly I hate the smell and all the behaviors that go with hiding and disguising my addiction. But my readiness to quit was a long journey.

I was once asked what the opposite of smoking is for me. I responded instantly — "The opposite of smoking is being healthy, disciplined, and professional." For me, being a smoker was counter-intuitive to being a healthy, disciplined and competent healthcare provider.

In 2007, I signed up for a tobacco cessation program. But, despite the behavior specialist being highly motivated and a former smoker, I did not feel a connection to her or that she was really listening to me and picking up on my fears. In her defense, I was on the lower end of the readiness scale because I was too afraid of failing.

The pressure of being the only health provider eligible for reimbursement of tobacco cessation services made me want to hide, because I did not feel like I could be a credible healthcare provider while still smoking.

In my journey for tobacco independence, I tried to find immediate cures and quick

fixes through NRTs (nicotine replacement therapies) and oral medication. I surfed the Internet in search of the "magic cure" with conflicting findings. I wanted something fast-acting and effective. A cure that would make me instantly tobacco- free with none of the withdrawal symptoms, weight gain, or cravings. It took me awhile to be ready to quit, and even longer to realize I was trying to quit without any work or effort on my part.

I finally called my primary care physician (PCP) and asked him about Chantix. He explained the side effects and discouraged me from using it. He patiently spent time with me and stressed the need to set a quit date that I could stick to, no matter what. I gave myself 15 days, unknowingly setting my quit date for Friday, March 13th. This has become an important date that has profound meaning in my life.

In preparation for my quit date, I set my mind to never smoke another cigarette, ever again.

I followed my PCP's advice to the letter. Several weeks after my quit date, my PCP contacted me to follow-up on my progress. I really felt like he was as committed to my quit attempt as I was.

I used Nicarettes as my nicotine replacement. It tastes terrible, like an ashtray in my throat. But, Nicarettes helped take the edge off.

My addiction to cigarettes was hand-to-mouth (that oral - hand fixation counselors caution you about), so I found myself snacking, and gained 12 pounds. But, in following the advice of my Tobacco Ouit Line coach, I replaced sweets, chocolates, and salty foods with healthy snacks. This was not easy and I do occasionally "reward" myself. My caffeine consumption has also increased. I drink two more cups of coffee every day.

On a positive note, my smell and taste are much more acute now. I've increased my exercise and sleep like a baby. Working and keeping my hands busy have been my replacement behaviors for smoking.

Smoking bans make it very hard to smoke in public. But, smoke-free laws are effective and necessary, and saves lives.

I know what the social pressures are for smokers.

Smoking is no longer "cool." "Being ready to quit, getting support from many sources, and having a provider follow up are critical components for a successful quit attempt."

TODAY, IT IS VERY DIFFICULT TO BE A SMOKER! The social stigmas can make one feel marginalized. I hope as a provider, that I come from a real understanding of the problems a smoker goes through in the quit process: the physical, psychological, and socio-cultural "Smoking is NOT a Hawaiian tradition."

Quitting takes a lot of work and self-determination. I think this process has added to my character, personally and professionally.



Hui No Ke Ola Pono posts reminders like this in their office to ensure a smoke-free place for their Healthy Cafe patrons, clients and workers.

www.imihale.org

'Imi Hale

NATIVE HAWAIIAN CANCER NETWORK

A program of Papa Ola Lokahi

894 Queen Street

Honolulu, Hawai`i 96813

Phone: 808-597-6558 Fax: 808-597-6552

E-mail: Isantos@papaolalokahi.org

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EVENTS

HPCA sponsored **Tobacco Cessation & Coding Training** for Community Health Centers Oct 14, 2009 Honolulu, HI

Komen Race for the Cure Oct 18, 2009 Kapi`olani Park Honolulu, HI

CTFH Alaka'i Awards Reception Oct 28, 2009 YWCA Richards Street, Honolulu, HI

CTFH Annual Meeting Oct 29, 2009 Japanese Cultural Center, Honolulu, HI

HPCA sponsored **Mayo Clinic TTS Training & Certification** for CHCs Nov 9-13, 2009 Honolulu, HI

'Imi Hale Combined Councils Meeting Nov 13, 2009 Honolulu, HI

Healing Our Spirits Worldwide Conference Sept 3-10, 2010 Honolulu, HI

A COMMUNITY'S RESPONSE TO CANCER PREVENTION AND CONTROL

A JOURNEY OF HOPE

WHEN A YOUNG WOMAN GETS BREAST CANCER

Five years ago, Tiare Agpaoa, then 30 years old discovered a lump under her arm and subsequently learned it was breast cancer. While the diagnosis was devastating, it was the lack of sensitivity for a young woman with breast cancer that left her feeling isolated and ignored. She channeled her frustration into documenting her personal cancer journey to develop a teaching DVD for others about the concerns specific to young women with breast cancer.

Her story is complemented

by two other young women experiencing similar and other concerns and testimonies from two of their mothers and a husband. Dr. Clayton Chong also shares information about breast cancer in young women and provides insight about being proactive in managing

one's cancer care.

A Journey of Hope – When a Young Woman gets Breast Cancer is just that, a story of hope poignantly told by three young women brave enough to share stories. They are as different as they are alike, one receiving her cancer diagnosis when she was 7 1/2 months pregnant, yet all share the same experience of self-discovery and a larger mission to help others who may find themselves in the



Survivors - Tiare Agpaoa, Darci Ludington and Roz Makaula

same situation. The DVD was premiered and well received on September 24, 2009 at the Patient Navigation conference at the Queen's Conference Center.

With the support of family, friends and partners, like 'Imi Hale; Papa Ola Lōkahi, HMSA

and many others, the DVD will be available in the coming months through Papa Ola Lōkahi (1-866–600-4253) at no cost. It will also be accessible for viewing on 'Imi Hale's website at www.imihale.org.