



COMMUNITY PROFILE REPORT

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2011

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Executive Summary

Introduction and Affiliate History

The *Susan G. Komen for the Cure promise* is to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to discover the cures ®. Our goal through an effectively developed statewide presence is to fulfill the *promise* and save lives in Hawai'i. Based on our commitment to serving Hawai'i's people affected or potentially affected by breast cancer, our *Community Profile* has a statewide focus. It is designed to serve as our basis for strategic planning, development and grant funding.

Our history dates back to 1995, when the first Komen Hawai'i Race for the Cure® was held in Honolulu with 800 participants. A small group of women gathered on O'ahu with a single purpose – raise money to make a difference in the many lives of women and men affected by breast cancer. Their intent was to raise awareness across the state and to have their voices heard in the Hawai'i Legislature and eventually in Washington, DC.

The Hawai'i Affiliate was established in Honolulu in 1999 and has since been actively raising funds and public awareness about breast cancer and breast health. By 2010, the 16th Annual Komen Race for the Cure® grew to over 7000 registered participants. In 2011, the Komen Hawai'i Affiliate granted over \$325,000 to local programs throughout the islands. Recipients of the funds included Bay Clinic; Hamakua Health Center; Hui Malama Ola Na 'Oiwi; Kokua Kalihi Valley Comprehensive Family Services; Molokai General Hospital; Na Pu 'uwai/Ke Ola Hou O Lana'; Queen's Medical Center - Cancer Center (Acupuncture); Queen's Medical Center (Genetics); Queen's Medical Center (NCI); Waikiki Health Center; Waimanalo Health Center; Kalihi-Palama Health Center; Ko'olauloa Community Health and Wellness Center; Turning Point Cancer Center and Pacific Cancer Center.

The Affiliate's vision is to assist the women of Hawai'i to take responsibility and participate in the highest level of breast health care, regardless of their ethnicity and/or socioeconomic status. To accomplish this goal, the Affiliate supports and collaborates with Hawai'i healthcare providers and Affiliate grantees in the implementation of culturally sensitive education, screening, and treatment programs.

Our Profile includes a review of current population and breast cancer statistics. We provide an overview of available services, a spotlight on key statewide programs, and a more in-depth focus on the neighbor islands. Based on interviews by provider groups, gaps and opportunities for service improvements are explored.

Overview of Demographic and Breast Cancer Statistics Key Findings¹

Hawai'i is unique due to the diversity of its population. Major racial groups include Asian (38.6%), Caucasian (24.7%), and Native Hawaiian/Pacific Islander (10%), with 23.6% of the population reporting two or more races. Among Asians, the most common ethnic groups are Chinese, Japanese, and Filipinos. Native Hawaiians are the most common ethnic group within the Pacific Islander population.

Breast cancer is the most common cancer among women in Hawai'i with approximately 860 cases of female invasive breast cancer diagnosed in the state each year². Breast cancer is the second leading cause of cancer deaths for Hawai'i women in all racial/ethnic groups, with the exception of the Japanese population. The rural and more sparsely populated islands showed considerably higher incidence and mortality rates than the urban center of Honolulu.

Not unlike in the rest of the county, women who are underserved (i.e. low-income, unemployed, uninsured) face the greatest barriers to breast cancer screening. Hawai'i is also unique in its abundance of transportation and language barriers to screening, due to the geographic and culturally diverse landscape. The data shows a clear need for more education and better access to care, including better transportation in the rural and remote areas of the islands. Breast cancer mortality rates decrease with early detection and screening. Advocacy programs are imperative to our success.

Overview of Programs and Services Key Findings

Hawai'i's major hospitals, facilities, and resources are concentrated in the urban areas of O'ahu. Mammography providers and resources are limited on the neighbor islands. The largest island, Hawai'i Island, is served by three mammography units, Maui is served by five mammography providers, and Kaua'i and Moloka'i each have one mammography provider. Residents of Lana'i and Ni'ihau must travel to another island for both screening and diagnostic mammograms.

To access screening services, rural women must drive for several hours, fly, or take a ferry. These areas are also home to the poorest and most ethnically diverse populations in the state who are at the highest risk for suboptimal breast health. Transportation is a major barrier to screening, diagnosis, treatment, aftercare, and support within isolated populations, especially areas such as Lana'i, Moloka'i, and Ni'ihau.

For uninsured and underinsured women, the Hawaii Department of Health's Breast and Cervical Cancer Control Program (BCCCP) partners with nine community clinics,

¹ U.S Census Bureau. <http://quickfacts.census.gov>

² American Cancer Society

hospitals, and organizations to provide breast and cervical screening services.³ Additional eligibility requirements include being with 50 to 64 years old and having an income at or below 250% of the federal poverty level.

Narrative of Affiliate Priorities

Given the findings of our 2011 Community Profile, we have set the following priorities:

- **To collaborate and partner with other cancer organizations to increase available breast cancer screening, diagnosis, treatment and follow-up care services throughout the Hawaiian Islands to the low income, uninsured and underinsured and increase access to these services.** This approach will provide an opportunity to leverage the resources and knowledge gained from these individual organizations' efforts to create a more comprehensive and interconnected approach to the breast cancer problem in Hawai'i. Address the transportation issue which is a major barrier to screening, diagnosis, treatment, aftercare, and support within isolated populations, especially areas such as Lana'i, Moloka'i, and Ni'ihau.
- **Provide education on the importance of breast self-awareness and screening tests to all individuals throughout the Hawaiian Islands by focusing on the underserved racial/ethnic minorities.** Remove cultural and linguistic barriers to regular mammography. Provide language and literacy sensitive education and resources to low-income, uninsured and underserved women.
- **Expand Hawai'i Affiliate's presence throughout the Hawaiian Islands with a new focus on the Neighbor Islands.** Expand our volunteer base and improve volunteer training through conferences, events and educational opportunities. Create liaison positions on the Neighbor Islands to increase networking on behalf of Komen. Increase Partners and Advocates throughout the Islands.

Marketing/Fund-Raising Priorities

The Hawai'i Affiliate has one primary fundraiser, the Race for the Cure®, a special event. They are also in the process of starting other fundraising events (i.e. a signature Golf tournament; Susan G. Komen Marathon for the Cure in partnership with the Kona Marathon; and Pink Tie Ball) as additional revenue generating sources. The Affiliate continues to aspire to:

- Raise funds with integrity, honesty and truthfulness;
- Act according to the highest standards and visions of the Komen organization;
- Put philanthropic mission above personal gain;

³ Hawaii Breast and Cervical Health Program – <http://hawaii.gov/health/family-child-health/chronic-disease/bcccp/bcccp/eligibility.html>

- Value the privacy and interests of all those affected by our actions;
- Inspire others through a sense of dedication and high purpose;
- Demonstrate concern for the interests and well-being of those affected by our actions;
- Affirm, through personal giving, a commitment to philanthropy and its role in society;
- Foster cultural diversity and treat all people with dignity and respect; and
- Adhere to the spirit as well as the letter of all applicable laws and regulations.
- Transparency and accountability and communicating to the community, which consists of potential donors, about how funds are being used

Public Policy Efforts

The Hawai'i Affiliate needs to become more involved at the local level with legislation and advocating for disparate populations. By developing relationships with key legislators at the local level the affiliate will be able to:

- Protect state funding for BCCCP screening at the present level.
- Ensure that access to health care continues to be available for indigent and other disparate population identified as high risk for cancer.
- Support legislation that may be introduced by other organizations containing an association to breast cancer prevention and treatment that can be aligned with Komen's overall goals.

Developing these relationships can be accomplished through several methods:

- Organizing patients, survivors, and volunteers from Komen to write, email or phone their local and Congressional representatives.
- Organizing Affiliate members contact the key legislators via phone, email, or fax to introduce themselves.
- Create Champions for the Cure Community Day at the State Capital.
- Continue to participate with the Susan G. Komen for the Cure Advocacy Alliance.

Introduction: Hawai'i Affiliate

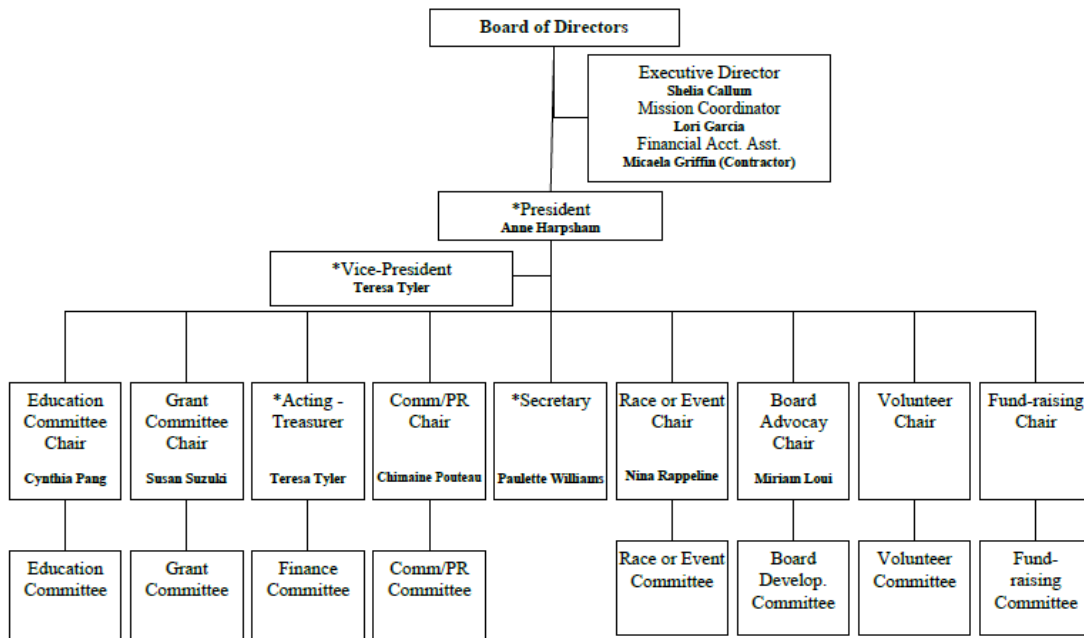
The Hawai'i Affiliate is committed to the *Susan G. Komen for the Cure promise* is to save lives and end breast cancer forever by empowering people, ensuring quality care for all, and energizing science to discover the cures ®. In our 12 years since becoming an Affiliate, our Hawai'i team has worked tirelessly to raise money, support, and awareness to help prevent and cure breast cancer.

Our Community Profile includes relevant statistics regarding the burden of breast cancer in our communities. We will use this information to guide and shape our priorities with regard to Affiliate activities and target areas. We aim to use evidence-based strategies in the communities that need it most, thus increasing the effectiveness of our Affiliate's work.

Organizational Structure

As seen in our Affiliate Organizational Chart below, our Board of Directors is staffed entirely by volunteers. The Executive Director, the Mission Coordinator, and a contract Financial Accounting Assistant are the only compensated positions in the Affiliate.

Affiliate Organizational Chart



*Denotes a required Board position

Description of Service Area

Hawai'i's population of 1,400,000⁴ is distributed across 7 islands separated by hundreds of miles of ocean. O'ahu is the most densely populated island with 72% of the state's population. The remaining 28% of the population lives on the islands of Kaua'i, Ni'i'hau, Moloka'i, Lana'i, Maui, and Hawai'i (also called the Big Island). Most of these islands are serviced by hospitals and clinics, however; the majority of hospitals, facilities, and resources are concentrated in the urban centers of O'ahu.

Outside the main urban areas of O'ahu; many Hawai'i's residents live in rural areas that are sometimes difficult to access except via long car rides, airplane, or in Lanai's case, ferry. These areas are often home to the poorest and most ethnically diverse populations whose access to appropriate healthcare services are limited due to language barriers, low-income, and lack of care that is culturally-acceptable to them. As a result, residents in these areas are at higher risk for many chronic diseases, including breast cancer.



⁴ US Census, 2010

Demographic and Breast Cancer Statistics

Data Source and Methodology

Demographic information was gathered from the United States Census Bureau. Information regarding breast cancer incidence, breast cancer mortality, and mammography was gathered from several sources, including the National Cancer Institute’s State Cancer Profiles and the Hawai’i State Department of Health’s 2010 Behavioral Risk Factor Surveillance Survey (BRFSS). Information on late state diagnosis was gathered from PubMed searches of the scientific literature.

Cancer incidence, mammography, and late stage diagnosis data were carefully reviewed to discover patterns within our community, particularly in regard to demographics. Of particular importance are the patterns that highlight target areas with the greatest need for certain services, such as health care access or breast health education. Reviewing the current statistics in our community allows our Affiliate to define and focus on our main priorities.

Overview of Key Demographic & Breast Cancer Statistics at State and County Level

Population Demographics

Per 2010 U.S. Census Bureau estimates, the following table represents Hawaii’s population by race.

Table 1. Percent of Population by Race, State of Hawai’i ⁵

Race	% of Population
Caucasian	24.7
African American	1.6
American Indian/Alaska Native	0.3
Asian	38.6
Native Hawaiian/Pacific Islander	10.0
Mixed (2 or more ethnicities reported)	23.6

While the Asian population in Hawai’i is large, it is important to note that this group is made up of a number of specific Asian ethnicities, including Japanese, Chinese, Korean, Filipino, and others. Many of these groups immigrated to Hawai’i at

⁵ www.census.gov

different times; therefore, their levels of acculturation (including English proficiency) vary widely.

Breast Cancer Incidence and Mortality Rates by State and County

Breast cancer is the most common cancer among women in Hawai‘i⁶. As shown in Table 2, Hawai‘i State has a breast cancer incidence rate similar to that of the United States. However, urban Honolulu County has an even higher incidence rate. Though the incidence rate in the other more rural counties is lower than that of Honolulu County, the breast cancer death rate is higher.

One likely explanation for the higher death rate in the more rural counties is lack of proper breast cancer screening, which is discussed in more detail in Tables 5 & 6. It is understood that mortality decreases with early detection, so early detection programs are key to our Affiliate’s success.

Table 2. Breast Cancer Incidence and Mortality Rates for State and Counties of Hawai‘i, as compared to the U.S.⁷

Location	Annual Incidence Rate (cases per 100,000)*	Average Breast Cancer Cases Per Year*	Annual Death Rate (deaths per 100,000)**	Average Deaths Per Year**
United States	121.1 (120.8, 121.3)	***	24.0 (23.9, 24.1)	41,021
Hawai‘i State	122.4 (118.8 - 126.1)	886	17.9 (16.5, 19.3)	134
Hawai‘i County	117.0 (107.6 – 127.1)	118	22.2 (18.2, 26.9)	22
Honolulu County	127.1 (122.7 – 131.7)	643	16.3 (14.8, 17.9)	88
Maui County	111.6 (101.3 – 122.6)	88	20.9 (16.5, 26.1)	16
Kaua‘i County	98.5 (84.6 - 114.1)	37	23.3 (16.9, 31.5)	9
Kalawao County	****	3 or fewer	***	3 or fewer

*Rate period 2004-2008

**Rate period 2003-2007

***Data has been suppressed due to data consistency issues.

****Data has been suppressed to ensure confidentiality and stability of rate estimates. Counts are suppressed if fewer than 16 cases were reported in a specific area-sex-race category.

⁶ American Cancer Society

⁷ www.statecancerprofiles.cancer.gov

Breast Cancer Incidence and Mortality Rates by Race

Incidence of breast cancer is not evenly distributed throughout the state. Tables 3 and 4 show the incidence rates for females with breast cancer in Hawai'i by race and ethnicity.

Table 3. Breast cancer incidence rates by race for Hawaii, 2000-2005⁸

Race	Annual Incidence Rate (Cases per 100,000)	Annual Death Rate (Cases per 100,000)
Native Hawaiian	157.5	27.1
Caucasian	127.5	21.1
Chinese	98.7	12.2
Filipino	96.5	13.9
Japanese	140.1	15.0

As seen from the data, Asian, Native Hawaiian, and Pacific Islander women make up the majority of breast cancer cases in Hawai'i. Table 4 shows that Native Hawaiian women have a considerably higher incidence and mortality rate, making this population an important target for our Affiliate's work.

Breast Cancer Screening Statistics

Keeping in mind the United States Preventive Services Task Force's recent recommendations for biennial mammography for women ages 50-74⁹, we focus our data on women ages 40 and older.

In Tables 4 and 5 below, data on clinical breast exam and mammography screening among Hawaiian women age 40+ are presented. The screening data are broken down by several variables, including:

- geographic area
- race
- age group
- marital status
- education level
- employment status
- household income

⁸ Tumor Registry, Cancer Research Center of Hawai'i University of Hawai'i. Hawai'i Cancer Facts and Figures 2010.

⁹ <http://www.uspreventiveservicestaskforce.org/uspstf/uspsbrca.htm>

Table 4. Clinical breast exams among Hawaiian women age 40+¹⁰

		% Ever Had a Clinical Breast Exam	% Had a Clinical Breast Exam <1 year ago
Geographic Area	Hawai'i State	88.5	53.3
	Honolulu County	87.7	53.6
	Hawai'i County	91.1	54.3
	Kaua'i County	88.9	50.9
	Maui County	90.0	51.3
Race	Caucasian	95.9	54.3
	Hawaiian	89.1	49.1
	Filipino	74.4	47.2
	Japanese	88.4	56.0
	Other	86.0	55.7
Age Group	40-44 Years	89.2	55.0
	45-54 Years	91.0	57.0
	55-64 Years	91.9	57.1
	65+ Years	83.8	47.0
Marital Status	Married	88.9	56.0
	Unmarried	87.7	48.9
Education Level	<High School	72.6	35.2
	High School	80.4	41.0
	Some College	90.1	55.3
	College	95.2	63.1
Employment Status	Employed	91.1	57.7
	Unemployed	82.7	47.9
	Student/Homemaker	89.1	43.8
	Retired/Can't work	85.1	50.2
Household Income	<\$15,000	73.0	34.7
	\$15,000-24,999	80.1	41.0
	\$25,000-49,999	88.3	50.1
	\$50,000-74,999	93.9	61.4
	\$75,000+	95.5	63.3

¹⁰ Hawaii BRFSS 2010; <http://hawaii.gov/health/statistics/brfss/brfss2010>

Table 5. Mammography screening among Hawaiian women age 40+¹¹

		% Ever Had a Mammogram	% Had a Mammogram <2 year ago
Geographic Area	Hawai'i State	93.6	76.1
	Honolulu County	94.3	77.6
	Hawai'i County	90.7	72.0
	Kaua'i County	92.3	72.0
	Maui County	93.5	73.3
Race	Caucasian	93.0	72.9
	Hawaiian	95.0	73.1
	Filipino	89.7	74.5
	Japanese	95.7	79.9
	Other	93.9	80.4
Age Group	40-44 Years	80.5	66.0
	45-54 Years	93.9	77.7
	55-64 Years	96.5	81.0
	65+ Years	96.3	75.2
Marital Status	Married	93.1	78.3
	Unmarried	94.4	72.7
Education Level	<High School	90.9	61.5
	High School	94.4	74.6
	Some College	92.7	74.2
	College	94.2	80.8
Employment Status	Employed	93.0	78.0
	Unemployed	88.5	67.6
	Student/Homemaker	91.1	70.5
	Retired/Can't work	96.0	76.0
Household Income	<\$15,000	86.6	61.7
	\$15,000-24,999	90.1	67.2
	\$25,000-49,999	94.5	75.3
	\$50,000-74,999	94.2	79.6
	\$75,000+	96.1	82.4

¹¹ Hawaii BRFSS 2010; <http://hawaii.gov/health/statistics/brfss/brfss2010>

The data above shows several disparities among Hawaiian women in regard to rates of clinical breast exam (CBE) and mammography screening.

Although Hawai'i's rates of ever having a CBE or mammogram are relatively high, the more rural counties have a lower rate of having a CBE or mammogram within the last 2 years. This suggests that most Hawaiian women are familiar with breast cancer screenings, but that those in more rural counties may have trouble accessing these health services.

Rates of screening are also relatively consistent among different races, although over 10% of Hawai'i's Filipino women have never had a mammogram, which may also point to a lack of accessible health services. Women aged 65 and older (who are also the most likely to be diagnosed with breast cancer¹²) lag behind in rates of CBE and of recent mammograms.

The most staggering disparities we see in Hawai'i (which mirrors national statistics) are the substantially lower rates of CBE and mammography screening among women who are unemployed and who have lower levels of education and household income. This unfortunate disparity is seen throughout our country and our state, and our Affiliate aims to confront this social determinant of health in our work.

Late stage Diagnosis

The earlier that breast cancer can be found, the more likely it is to be effectively treated and cured. Given this, it is of the utmost importance that our Affiliate works to help women get routinely screened for breast cancer and avoid the dangers of a late stage diagnosis. National data show that certain women are more likely to have a late stage diagnosis due to lack of screening, including women who are low-income, elderly, less educated, and unmarried.¹³ In addition, women aged 55-74 years who are uninsured or on Medicaid or Medicare are more likely to have a later stage diagnosis of breast cancer than those with private insurance.¹⁴ In particular, Hawaiian and Filipino women are more likely to be diagnosed at later stages than their Caucasian, Japanese, and Chinese counterparts.¹⁵

Target Areas and Populations

From this data, it is clear that our Affiliate should focus on women who live in more rural counties and who are under or uninsured, have lower levels of education, have

¹² <http://seer.cancer.gov/statistics/>

¹³ Taplin SH, et al. Reason for late-stage breast cancer: absence of screening or detection, or breakdown in follow-up? *J Natl_Cancer_Inst.* 2004 Oct 20;96(20):1518-27.

¹⁴ Ward EM et al. The association of insurance and stage at diagnosis among patients aged 55 to 74 years in the national cancer database. *Cancer J.* 2010 Nov-Dec;16 (6):614-21.

¹⁵ Hawai'i Cancer Facts & Figures (2010)

lower income, and who are unemployed. This target group is likely going to need assistance accessing screening resources, both regarding transportation and cost of services. Some of our Affiliate's work should also focus on women older than 65 as well as all Filipino women, as an effort should be made to help increase the breast cancer screening rates among these populations. It is essential that our programs and services address the disparities across the state.

Programs and Services



Health Systems Analysis

Presented here is an analysis of the Hawaiian health systems as they relate to breast cancer screening and care. Consistent with the Susan G. Komen Continuum of Care Model, our Affiliate recognizes that being an advocate for breast cancer extends before and beyond cancer diagnosis. The Susan G. Komen Continuum of Care Model includes a broader perspective, including breast health education, screening, diagnosis, treatment, and post-diagnosis recovery and survivorship. Below you will find an analysis of the strengths and gaps of the current health systems available in Hawai'i and the impact that has on various levels of the Continuum of Care.

Data Source and Methodology Overview

Breast health key informants were identified by cross-referencing information provided in the previous Hawai'i Affiliate Community Profile, the grant awards file, and a list of community contacts generated from various community resource lists. A provider survey was created on Survey Monkey (www.surveymonkey.com) and distributed via e-mail and fax. The survey included open-ended and multiple-choice questions intended to assess barriers to care and community resources. Information was supplemented by telephone interviews.

Key Informant Interview Findings

Many neighbor island patients requiring advanced care/services (i.e. radiation, chemotherapy, surgical procedures) are referred to O'ahu. The predominant services being provided to patients are limited to educational materials and client management. Responses suggest that these communities could benefit from additional educational services/resources, funding through grants, and support services such as counseling support groups, and travel and housing assistance.

Respondents indicated that women were likely to obtain breast health information from a variety of sources, including their medical doctor, nurses or clinical staff, a pharmacist, and/or friends and family members for breast health information. Community health centers, physicians, and local hospitals also indicated that breast health information may be obtained in the form of brochures, pamphlets, and fliers.

Key informants noted that clinical breast exams and mammography services are provided at major clinics and local hospitals on Maui, Moloka'i, and Kaua'i. Two of the islands in these counties do not have access to mammograms on-island. Residents of Lana'i (Maui County) and Ni'ihau (Kaua'i County) are required to go to Kaua'i, Maui or O'ahu for mammogram services. Patients from Moloka'i in need of diagnostic mammography must also travel to the larger islands for this service.

Key informants from Kaua'i County indicated that services they provide beyond breast health education include screening and diagnostic mammography, and chemotherapy. Patients are also referred to Kapi'olani Medical Center for Women & Children on O'ahu or the American Cancer Society for support services. Respondents from Maui County stated they provide both screening and diagnostic mammography, chemotherapy, and radiation services. Maui County patients are also referred to their primary care providers, O'ahu hospitals, or their local hospital's outpatient women's health centers for additional services.

Additional Resources for Healthcare Professionals

Respondents to the survey listed Susan G. Komen, American Cancer Society, American Congress of Obstetricians and Gynecologists, 'Imi Hale, Hui No Ke Ola Pono, Ho'ola Lahui Hawai'i, Na Pu'u Wai, Queen's Medical Center, and Kapi'olani Medical Center for Women and Children as additional resources for breast health information and cancer education. Respondents from Maui County indicated that they provide translation services for those whose first language is not English. These respondents utilize Hui No Ke Ola Pono (an organization targeting the Native Hawaiian population) and verbal translators based on patient needs. Maui County respondents also indicated a need for educational materials in Ilocano, Tagalog, and Visyan.

Barriers to Healthcare

Uninsured and non-Caucasian women were highlighted to be least likely to receive regular breast health screening. Many providers and community agencies stated that outreach activities are used to target these underserved populations, and include free cancer screening events, letters, fliers, educational seminars, and festivals. Key informants noted that newspapers, brochures/pamphlets, radio, church bulletins, and public seminars are the best ways to disseminate breast health information to these communities. Providers responded that barriers to getting regular breast health screening include fear, high cost of higher level services, being required to leave their island for treatment, and lack of understanding about the need for these services. Some providers/agencies offer gift incentives for breast health screening that can include bracelets, cell phone charms, and rice. Respondents indicated that delivery of breast health services could be improved by providing funding for travel expenses as well as on-island mammography services.

Financial Resources for Care

Key informants indicated that there are a number of ways in which women can pay for their breast health care. These include private and public (MedQUEST) insurance, free services (BCCCP/BCCTP), and federally qualified health centers that accept patients regardless of insurance status. Women who are uninsured can also go to their local community health centers, Wilcox Memorial Hospital, or Kaua'i Veterans Memorial Hospital. Maui key informants indicated that financial assistance is provided through Charity Care from Maui Memorial Medical Center and sliding fee scales. Key informants from Maui County also specified that various grants provide travel assistance to O'ahu (one time use per patient) for those requiring additional services not provided in their counties. Other organizations that patients can utilize for financial assistance include Moloka'i Outpatient Clinic, Kukui Ahi Cancer Navigation Program located at Moloka'i General Hospital (aimed at helping patients through their screening processes and other treatments), Na Pu'u Wai and Hui No Ke Ola Pono.

Educational Partnerships

Breast cancer coalitions to which key informants belong include the Lana'i Cancer Group and the American Cancer Society. Several informants were unaware of any coalition affiliation and other respondents indicated they are not affiliated with a coalition. All key informants acknowledged that they partner with local organizations in providing health services to women in their communities, including community health centers for women, the American Cancer Society, Hui No Ke Ola Pono, and Ke Ola O Lana'i, and Susan G. Komen.

Health Systems Analysis Overview

Resource Asset Maps

Please refer to Appendices A and B for geographical asset maps of the programs and services listed below.

Kaua'i County

Kaua'i County consists of the islands of Kaua'i and Ni'ihau.

Island of Kaua'i

Screening and diagnostic mammography is available on-island through Wilcox Memorial Hospital. Three oncologists from O'ahu visit the island on a rotating basis and see patients in Lihue. Outpatient chemotherapy is provided at Wilcox Memorial Hospital, with the exception of home-based services provided by Hawai'i Home Infusion Associates. Home-based chemotherapy is not currently covered by insurance. Radiation therapy is currently unavailable on-island, therefore Kaua'i patients in need of radiation treatment must travel to O'ahu, Maui, or the mainland.

The Hawai'i Breast and Cervical Cancer Control Program (BCCCP) clinics provide clinical breast exams, financial support and referral for mammograms for the uninsured population over 50 years of age. BCCCP patients seeking mammography services are referred to the Kaua'i Veterans Memorial Hospital or Kaua'i Medical Clinic within Wilcox Memorial Medical Center.

Oncology services are generally not available for Kaiser Permanente patients on Kaua'i, therefore Kaiser patients also travel to O'ahu for cancer treatment. Ho'ola Lahui Hawai'i is the branch of the Native Hawaiian Health Care System on Kaua'i. The American Cancer Society operates a field office in Lihue.

Island of Ni'ihau

Ni'ihau, a privately owned island, has a population of 130 (Census 2009) people. No oncologic services are available on island, so cancer patients either travel to Kaua'i for treatment or receive some treatment when public health nurses travel to Ni'ihau from Kaua'i.

City & County of Honolulu

O'ahu is home to the most comprehensive cancer screening, imaging, and treatment in the state of Hawai'i. Medical facilities include the Kapi'olani Medical Center for Women & Children, Straub Clinic & Hospital, The Queen's Medical Center, Hawai'i Medical Centers East and West, the Kaiser Foundation Hospital, Wahiawa General Hospital, Kahuku Hospital, Castle Medical Center, the Rehabilitation Hospital of the Pacific, and Tripler Army Medical Center, as well as many medical clinics.

In addition to mammography, breast ultrasound, MRI, and PET scanning are available. Breast cancer treatment, both chemotherapy and radiation, are available at a number of facilities. Some of these facilities also host patient navigator programs, which help guide patients through their diagnosis and treatment.

Several key cancer-related organizations that serve Hawai'i and the Pacific region are based on O'ahu:

The University of Hawai'i's Cancer Research Center of Hawai'i (CRCH) is one of 64 National Cancer Institute-designated cancer centers in the U.S. It is also home to a Minority-Based Community Clinical Oncology Program, which enrolls patients into and monitors patients on cancer clinical trials. Both basic and population-based research is conducted at CRCH. The mission of CRCH is to reduce the burden of cancer through research, education, and service with an emphasis on the unique ethnic, cultural, and environmental characteristics of Hawai'i.

The American Cancer Society Hawai'i (ACS) Pacific, Inc., has its headquarters in Honolulu. The Hawai'i Pacific Office is part of the High Plains Division of ACS and offers many of the services provided by ACS nationwide, including community outreach and patient services such as the Cancer Survivors Network and Reach to Recovery. ACS also provides financial assistance to cancer patients traveling to O'ahu for oncologic services, including airfare vouchers and discounted lodging. ACS maintains field offices on Maui and Kaua'i, as well as in East and West Hawai'i on the Big Island.

'Imi Hale is the Native Hawaiian Cancer Network. Launched in 2000, 'Imi Hale is a program of Papa Ola Lōkahi, a nonprofit consortium of Native Hawaiian health organizations, and serves as one of the National Cancer Institute's 25 Community Networks Program sites. Per their website, the organization "collaborates with local, state, national, and international partners to reduce cancer incidence and mortality among Native Hawaiians and Pacific Islanders through the establishment of a core organizational infrastructure that 1) promotes cancer education and awareness; 2) supports cancer research and training, and the development of indigenous researchers; and 3) facilitates policy development and implementation of evidence-based information into cancer prevention and control practices to reduce cancer health disparities" (www.imihale.org, accessed March 2, 2009). In addition to maintaining core staff on O'ahu, 'Imi Hale provides funding for positions in the Native Hawaiian Health Care Systems offices on the neighbor islands.

Maui County

Maui County consists of the islands of Maui, Moloka'i, and Lana'i.

Island of Maui

One full-time oncologist provides services out of Maui Medical Group. Two medical oncologists visit from O'ahu and provide services out of Maui Memorial Medical Center on a rotating basis. Maui County is also serviced by three on-island radiation

oncologists. Chemotherapy is available at Maui Memorial Hospital for non-Kaiser members. Radiation therapy is available in Wailuku at Maui Memorial Hospital, Island Radiology, Maui Medical Group, and Maui Clinic. Diagnostic and screening radiology services are also available.

Kaiser Permanente members have one medical oncologist. Mammography, radiation, surgery, and chemotherapy are provided out of Kaiser's Wailuku clinic.

Care coordination for some uninsured and under-insured patients is handled by Hui No Ke Ola Pono, Maui's Native Hawaiian Health Care System. In terms of cancer screening and prevention, Hui No Ke Ola Pono assists women who are eligible to receive services through the CDC-funded, DOH administered Breast and Cervical Cancer Control Program (BCCCP). Unfortunately, Maui still has a significant proportion of non-U.S. citizens, mostly Hispanics and Filipinas, who do not qualify for MedQuest or BCCCP services.

The American Cancer Society operates a field office in Wailuku.

Island of Moloka'i

Screening mammograms are available at Moloka'i General Hospital (MGH), but patients must travel to O'ahu for diagnostic screening. There are no oncologists practicing on Moloka'i; however, chemotherapy is available at a clinic operated by MGH, which is part of The Queen's Health Systems. Most Moloka'i patients travel to Honolulu for treatment at The Queen's Medical Center because they must initially be seen by an oncologist. Patients who are doing well can continue to receive ongoing treatments on-island. Follow-up appointments are sometimes conducted with off-island oncologists through teleconference. Radiation therapy and surgery for breast cancer is not available on Moloka'i, and patients must travel to O'ahu or Maui for this treatment. There is only one direct flight (to O'ahu) in and one direct flight out of Moloka'i each day.

Several organizations coordinate cancer care on Moloka'i. Patient navigators from Kukui Ahi (MGH's patient navigations service for cancer patients) and Na Pu'uwai (Molokai's Native Hawaiian Health Care System) work with patients at MGH. In addition to coordinating some air and ground transportation and lodging, these support agencies refer patients to the Moloka'i Cancer Fund and the American Cancer Society for financial assistance and other support services.

Island of Lana'i

Clinical breast exams are available on island; however, women must take a 45 to 55-minute ferry to Maui for mammography or other treatment services. Treatment is also available on O'ahu, and requires a 30-minute plane ride at a cost of approximately \$150 (round trip).

Each year, Ke Ola Hou 'O Lana'i (the Lana'i unit of Na Pu'uwai) hosts a cancer screening day where patients receive free clinical breast exams, Pap smears, fecal

occult blood testing, digital rectal exams, prostate specific antigen testing, and oral cancer screening. An educational component related to cancer is also offered at this event. The majority of services provided by Ke Ola Hou 'O Lana'i come from community donations. Ke Ola Hou 'O Lana'i also works together with Straub Lana'i Family Health Center and Hui No Ke Ola Pono to coordinate care for women receiving mammograms on Maui by transporting them via car and interisland ferry. Ke Ola Hou 'O Lana'i sets up appointments and takes care of ground transportation once women obtain their ferry tickets from Straub, and Hui No Ke Ola Pono takes care of the financial aspect of the medical services obtained. Women are eligible for free transportation if their medical insurance does not cover it.

Hawai'i County

Hawai'i County encompasses the island of Hawai'i, the largest island in the Hawaiian Archipelago, and referred to by Hawai'i residents as the Big Island. Because East, North, and West Hawai'i are geographically separated from each other by volcanoes, the sections of this island will be analyzed separately.

West Hawai'i

A medical oncologist sees non-Kaiser patients at Kona Community Hospital (KCH) three days a week. Chemotherapy is also available through the outpatient infusion center here, as well as through West Hawai'i Home Health Services. Two radiation oncologists split their time between Hilo in East Hawai'i and Kona in West Hawai'i, and radiation therapy services are available through a clinic affiliated with KCH. Kaiser Permanente operates an outpatient clinic in Kona, where a medical oncologist visits twice a month, but this medical oncologist is scheduled to retire in 2009. Chemotherapy services are available at this clinic, and radiation therapy is available locally through a contract Kaiser has with another company. Hui Mālama Ola Nā 'Ōiwi, the Big Island's Native Hawaiian Health Care System, has 11 patient navigators who service Native Hawaiian cancer patients island wide. However, as of 2008, only one patient navigator was committed to serving West Hawai'i. The American Cancer Society operates their West Hawai'i field office in Kona.

North Hawai'i

A medical oncologist services non-Kaiser patients through another physician's office in Waimea about once a week. Chemotherapy and radiation are not available in Waimea; patients usually travel to Kona, a 40-mile trip one way, for these treatments. Kaiser Permanente has a clinic in Waimea, but no oncologic services are offered there.

East Hawai'i

East Hawai'i is serviced by a full-time medical oncologist who operates out of the Hawai'i Pacific Oncology Center (HPOC), which is affiliated with Hilo Medical Center. Two radiation oncologists are also affiliated with HPOC, and two radiation oncologists visit from The Queen's Medical Center on O'ahu, as well. Chemotherapy and radiation therapy are available through HPOC. Kaiser Permanente operates an outpatient clinic in Hilo, where the same medical oncologist who visits the Kona clinic also sees patients twice a month; again, however, this oncologist is planning to retire in 2009.

Chemotherapy services are available at this clinic, and radiation therapy is available through a contract that Kaiser has with HPOC. 23 Mammography services are available at the Women's Imaging Center, which is operated by Hawai'i Radiologic Associates, Ltd., in Hilo. Hui Mālama Ola Nā 'Ōiwi has patient navigators who service Native Hawaiian cancer patients in this region. The American Cancer Society also operates their East Hawai'i field office in Hilo.

Public Policy Perspectives

BCCCP

The Hawai'i Breast and Cervical Cancer Control Program (BCCCP) was established in 1993 through a cooperative agreement with the Centers for Disease Control and Prevention (CDC) to provide breast and cervical cancer screening services under the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). The mission of the BCCCP is to provide:

- Breast and cervical cancer screening services to medically under-served women
- Appropriate referrals, and when necessary, appropriate diagnostic follow-up, case management and assurances for medical treatment
- Public information and education programs to increase the use of breast and cervical screening services
- Education to health professionals to improve the breast and cervical screening process
- Mechanisms to monitor the quality of the breast and cervical screening process
- Linkages with key partnerships

The Hawai'i Department of Health's BCCCP partners with 16 community clinics, hospitals, and organizations to provide breast and cervical screening services to women 50 to 64 years of age who are low income (at or below 250% of the federal poverty level) and have no or insufficient health insurance, particularly Native Hawaiian and Filipino women.

In accordance with state policy, only those who receive screening services through Hawaii's NBCCEDP-funded breast and cervical cancer early detection program are eligible for treatment through Medicaid.

State and Federal Government

Hawai'i has two U.S. Representatives and two U.S. Senators. Representative Hirono, who once served as Honorary Chair for the Hawai'i Race for the Cure, has served in the House since 2007. Hirono serves on the Education and Workforce Committee and the Transportation and Infrastructure Committee.

On the local level, Hawaii's government comprises 25 senators and 51 representatives, headed by Democratic Governor Neil Abercrombie. The Hawai'i Affiliate is currently developing a working relationship with elected officials on both federal and state levels through the Affiliate Komen Advocacy Alliance team.

To engage in greater advocacy and policy development at the state level, the Affiliate may wish to focus on and develop relationships with local-level politicians such as Senator Rosalyn Baker, Consumer Protection Chair; Senator Suzanne Chun-Oakland, Human Services Chair, Majority Whip, and Senator David Ige, Ways and Means Chair; Josh Green, Health Chair. In the House of Representatives, the Affiliate should seek to establish a relationship with Representative John Mizuno, Human Services Chair; Representative Robert Herkes, Consumer Protection Chair; Representative Marcus Oshiro, Finance Chair; and Representative Ryan Yamane, Health Chair.

Health Systems Analysis Findings

Consistent with the breast cancer incidence and screening data, the more rural of the Hawaiian Islands have a disadvantage to optimal breast health. As highlighted in this Health Systems Analysis, Honolulu County has the most comprehensive cancer screening, imaging, and treatment in the state, and is often the place to which many neighbor island residents must travel in order to receive treatment. Many of the other islands lack the proper resources to care for women at all levels of the Continuum of Care, from education to treatment to survivorship.

As we have also seen in the breast cancer incidence and screening data, women with lower income and education face many barriers to breast health services. For example, Maui has a significant proportion of non-U.S. citizens, mostly Hispanics and Filipinos, who do not qualify for MedQuest or BCCCP. In accordance with federal and state policy, only participants receiving screening services through Hawaii's NCCEDP-funded breast and cervical cancer early detection program (BCCCP) are eligible for treatment through Medicaid's BCCCT program. This impacts those who are able to afford screening but unable to afford the cost of treatment. Additionally, BCCCP does not address the needs of those unable to qualify for Medicaid.

Given this analysis, our Affiliate needs to continue to target underserved women on the rural islands of Hawai'i. For these women, cost of services, availability of services and transportation to services will be of the utmost importance. Filling in these gaps will help more Hawaiian women to access beneficial care at all levels of the Continuum of Care.

Community Survey Findings



Data Sources and Methodology Overview

To gain a better understanding of breast health and breast cancer perspectives of women in the community, qualitative telephone interviews were conducted with 12 identified community leaders. The interviews provided a greater understanding of the needs, limitations, beliefs, and overall consensus of what women might expect from their providers.

Community leaders were generally very eager to share information about breast health and breast education in their communities, noting their hope for improved services and support in this regard. Data was analyzed to reveal common themes in our communities.

Qualitative Data

Informants identified a wide range of attitudes and beliefs within their communities. Fear of a poor outcome appeared to be a common barrier that prevented women from getting proper screening. According to informants, fear seems to stem from cultural background and experiences.

Large populations of Filipino and Native Hawaiian women reside in Kaua'i and Maui Counties. In addition, a growing Hispanic community is also present. The cultural beliefs of these groups sometimes prevent them from getting treatment. For example, members of the Filipina community were willing to be screened; however,

older Filipino women were not comfortable receiving screenings from male providers. Little interaction has been reported with the Hispanic population.

A breast cancer diagnosis has various implications to women and their families. On some islands, significant hardships result due to the lack of treatment services. High treatment costs are compounded by the cost of travel to other islands to seek treatment and ongoing care. As a result, a diagnosis of breast cancer could have a significant impact on a family's time and resources.

The lack of on-island breast cancer care facilities also appears to be a barrier to screening and follow-up care or treatment. Many women must leave the island in order to seek care. This often entails taking a full day off from work and taking a costly ferry or airplane ride. Once at their destination, taxi services are needed to transport women to and from appointments, and if appointments span over the course of a day, hotel accommodations may also be required. Additionally, the current economy has caused many women and/or their family members to lose their jobs and health insurance/medical coverage, preventing them from obtaining treatment.

Some businesses host penny jars that invite island residents to leave loose change to provide stipends for cancer treatment, transportation, airfare, and lodging. Some transportation providers also assist with travel expenses by providing discounted fares. In some communities, women are provided with transportation to Maui to receive mammograms. Through this program, women are educated on the importance of receiving a mammogram and given reminders about their next appointment. There have been efforts made to bring providers to these communities to conduct screenings; however follow up care must often be sought off-island.

Knowledge related to breast health and breast cancer is influenced by multiple factors including English proficiency, cultural values and beliefs, and level of breast health education. Interviews have revealed that there is a large population of Filipina field workers, half of whom do not speak English. These non-English speaking workers are unable to obtain regular screenings and care. According to informants, English speaking Filipina workers have a higher likelihood of gaining access to these services. Educational materials in the various Filipino languages may help this population to gain knowledge about breast health. Similarly, immigrants from the Federated States of Micronesia could benefit from educational and support materials in their native language.

Respondents indicated that many Native Hawaiian and mixed ethnic women may feel panicked and inconsolable and perceive a breast cancer diagnosis as a death sentence. Some women respond in this manner because they have not experienced cancer or chronic illness within their families. These individuals often respond well when counseling and support is provided, and if the patient participates in treatment, treatment regimens are explained in detail. Respondents indicated that

individuals who have greater knowledge are better equipped to handle a breast cancer diagnosis.

In order to educate the public about breast cancer, one respondent indicated that he is currently investigating the benefits of airing cancer prevention tips on the radio, and including resources for more information and education. Others suggested that education and outreach begin at the elementary school level in order to change the social perception of cancer. Normalizing views early in development may decrease the fear that often prevents breast cancer patients from seeking treatment. Targeted discussions related to gender could be provided as appropriate.

In certain Asian and Pacific Islander communities, beliefs surrounding cancer could result in individuals and families experiencing shame. Although Asian and Pacific Islander families are often large and part of multi-generational households, shame may still be present and can lead to a lack of support and decreased likelihood of seeking follow-up care and treatment.

The Young Men's Christian Association (YMCA) offers movement classes to help breast cancer survivors cope with side effects of treatment. Outrigger canoe paddling programs, open to all survivors has also been effective at ameliorating lymphedema and provides an informal support group to all participants. Support groups are not currently available on all islands, but may help to provide psychological support to breast cancer patients.

Resources for family members of cancer patients are more limited. Family counseling services from psychologists with backgrounds in oncology and support groups are needed. Presently, counseling is limited to clinical psychologists and online support organizations.

Annual cancer screening events and free mammography services have been effective in targeting women in Kaua'i and Maui Counties. However, the majority of participants at these screening events generally have health coverage. Efforts are being made to attract uninsured and underinsured women.

Incentive programs have also been suggested as another way for providers to encourage women to seek breast health services. These programs may increase awareness and the number of women who seek breast health services by emphasizing its importance. Support from state and federal levels would be helpful in providing free or low-cost education, services and support in target communities.

Respondents indicated that regular, recurrent information would be beneficial in establishing and maintaining breast health awareness. Providers need to ensure that women diagnosed with breast cancer encourage their children to receive regular and early screenings due to their heightened familial risk.

Qualitative Data Findings

Our interviews revealed several community themes:

- Out-of-pockets costs and lack of transportation are two of the biggest barriers to optimal breast health. It is clear from the interviews that many women in Hawai'i are aware of the need for breast health and proper screening but are unable to access resources because they are too expensive and/or they are not able to find services nearby and must therefore often travel to another island for care.
- For certain populations, literacy and language are also barriers to optimal breast health. The population of Hawai'i is unique in its racial and ethnic make-up. Given the variety of literacy levels and spoken languages, many women are not able to receive breast health education or services in a way that is easy for them to understand. Therefore, our Affiliate needs to offer educational materials and help in a variety of languages.
- Other barriers to screening include fear and differing cultural perspectives related to cancer and chronic illness. Community leaders and breast health educators should be culturally aware and culturally sensitive when providing information and services.
- Survivorship services are needed in several communities. Currently there are programs available on some islands to provide formal or informal support for breast cancer survivors. Various community members indicated the need for psychologists with a specialty in oncology to provide individual and family care and support.

These qualitative findings reveal several important gaps along many levels of the Continuum of Care. In fact, cost, transportation, language, literacy, and cultural barriers transcend all levels of the Continuum from education to post-diagnosis. The findings also highlighted the need for additional emphasis on survivorship services in our communities.

Conclusions

Putting the Data Together

From the data provided, it is clear that Hawai'i faces several disparities in breast health services. In particular, women with lower income, lower levels of education, and who are unemployed face the greatest barriers to care. In our state, these women tend to be Native Hawaiian and Filipino. We also have a fair number of women ages 65 and older who have not been having the recommended schedule of breast cancer screenings.

Many of the screening and diagnosis barriers faced by Hawaiian women are due to cost and lack of local services (or transportation to services). The state's population is distributed over several islands separated by miles of ocean. Rural areas are home to the poorest and most ethnically diverse populations. The qualitative data also highlighted the language, literacy, and cultural barriers that many of these women face. It is, therefore, essential that programs and services address disparities across the state.

Selecting Affiliate Priorities

Given the findings of our 2011 Community Profile, we have the following priorities:

- **To collaborate and partner with other cancer organizations to increase available breast screening, diagnosis, treatment and follow-up care services throughout the Hawaiian Islands to the low income, uninsured and underinsured and increase access to these services.** This approach will provide an opportunity to leverage the resources and knowledge gained from these individual organizations' efforts to create a more comprehensive and interconnected approach to the breast cancer problem in Hawai'i. Address the transportation issue which is a major barrier to screening, diagnosis, treatment, aftercare, and support within isolated populations, especially areas such as Lana'i, Moloka'i, and Ni'ihau.
- **Provide education on the importance of breast self-awareness and screening tests to all individuals throughout the Hawaiian Islands though focusing primarily on racial/ethnic minorities.** Remove cultural and linguistic barriers to regular mammography. Provide language and literacy sensitive education and resources to underserved women.
- **Expand Hawai'i Affiliate's presence throughout the Hawaiian Islands focusing primarily on Neighbor Islands.** Expand our volunteer base and improve volunteer training through conferences, events and educational opportunities. Create liaison positions on the Neighbor Islands to increase networking on behalf of Komen. Increase Partners and Advocates throughout the Islands.

Marketing/Fund Raising Priorities

The Hawai'i Affiliate has one fundraiser, Race for the Cure®, a special event. They are also in the process of starting a golf tournament as an additional fundraising source.

We continue to aspire to:

- Raise funds with integrity, honesty and truthfulness;
- Act according to the highest standards and visions of the Komen organization;
- Put philanthropic mission above personal gain;
- Value the privacy and interests of all those affected by our actions;
- Inspire others through a sense of dedication and high purpose;
- Demonstrate concern for the interests and well-being of those affected by our actions;
- Affirm, through personal giving, a commitment to philanthropy and its role in society;
- Foster cultural diversity and treat all people with dignity and respect; and
- Adhere to the spirit as well as the letter of all applicable laws and regulations.
- Transparency and accountability and communicating to the community, which consists of potential donors, about how funds are being used

Public Policy Efforts

The Hawai'i Affiliate needs to become more involved at the local level with legislation and advocating for disparate populations. By developing relationships with key legislators at the local level the affiliate will be able to:

- Protect state funding for BCCCP screening at the present level.
- Ensure that access to health care continues to be available for indigent and other disparate population identified as high risk for cancer.
- Support legislation that may be introduced by other organizations containing an association to breast cancer prevention and treatment that can be aligned with Komen's overall goals.

Developing these relationships can be accomplished through several methods:

- Organizing patients, survivors, and volunteers from Komen to write, email or phone their local and Congressional representatives.
- Organizing Affiliate members contact the key legislators via phone, email, or fax to introduce themselves.
- Create Champions for the Cure Community Day at the State Capital.
- Continue to participate with the Susan G. Komen for the Cure Advocacy Alliance.

Future Steps

With the continued support of Komen National and our wonderful community volunteers and service workers, we can make 2011 a great year for Komen Hawai'i, as we continue our pledge to save lives and end breast cancer forever.

Appendix A: Data Asset Map of Maui County



Appendix B: Data Asset Map of Kaua'i County

