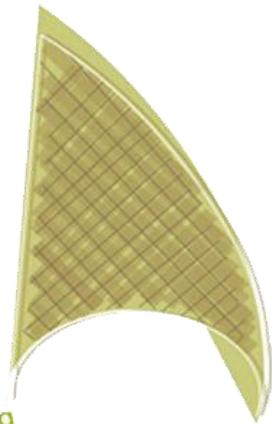


# WINCART

Weaving an Islander Network for Cancer Awareness Research and Training



## **WINCART Summary of Accomplishments 2005-2010**

**Issued March 18, 2011**



## **About Us**

Weaving an Islander Network for Cancer Awareness, Research, and Training (WINCART) is a unique, collaborative, community participatory effort to reduce cancer health disparities among Pacific Islanders in Southern California. From 2005-2010, the WINCART network involved eight community-based agencies (Ainahau O Kaleponi Hawaiian Civic Association, Guam Communications Network, Orange County Asian Pacific Islander Community Alliance, Pacific Islander Health Partnership, Samoan National Nurses Association, Sons and Daughters of Guam Club, Tongan Community Service Center/Special Service for Groups, Inc., and the Union of Pan Asian Communities) along with researchers from five universities (California State University, Fullerton, University of Southern California, University of California, Irvine, University of California, Los Angeles, and University of California, Riverside). The network worked together to promote community education, research and training for five of Southern California's Pacific Islander populations: Chamorros, Marshallese, Native Hawaiians, Samoans, and Tongans.

## **WINCART History**

WINCART was founded in May 2005 with funds from the National Cancer Institute's (NCI) Center to Reduce Cancer Health Disparities. Our network primarily serves the estimated 100,000 Pacific Islanders who reside in Southern California within the counties of Los Angeles, Riverside, Orange, San Bernardino, and San Diego. Through our collaborative community efforts, we aim to reduce the disproportionate burden of cancer affecting five of the largest Pacific Islander populations in Southern California: Chamorros, Marshallese, Native Hawaiians, Samoans and Tongans.

## **WINCART Mission Statement**

WINCART's mission is to reduce cancer health disparities among Southern California's Pacific Islander populations through increasing cancer awareness, collaborative research programs, and providing valuable leadership and training opportunities. From 2005-2010, the specific aims for the network were to:

1. Develop and implement programs to increase cancer awareness among Pacific Islanders from primarily five populations in Southern California: Chamorros, Marshallese, Native Hawaiians, Samoans, and Tongans.
2. Improve access to and utilization of effective cancer prevention and control interventions among Pacific Islanders.
3. Create opportunities to increase the number of well-trained Pacific Islander researchers through trainings, mentorship, and participatory research projects.
4. Facilitate the development of research grants that address the cancer needs of Pacific Islanders, with a focus on primary (obesity and tobacco) prevention, access and navigation, and survivorship.
5. Sustain community-based education, training and research activities by increasing partnerships with governmental and community agencies, funders, and policymakers.



## **WINCART Community Education**

The WINCART network strives to serve all Pacific Islanders who live in Southern California. Within the last five years, activities have focused on the five largest Pacific Islander populations: Chamorros, Marshallese, Native Hawaiians, Samoans and Tongans. Topics addressed within the five-year period include: cancer protection (diet, physical activity, and smoking), cancer screening (breast, cervical, and colorectal), cancer diagnosis, treatment and survival. In addition, WINCART developed two toolkits to assist and educate the community. These toolkits are titled *Samoan Cancer 101 Education Tool Kit* and *A Community-Centered Approach to Developing and Pilot-Testing a Colorectal Cancer Education Campaign for Pacific Islanders in California*. Together, the network hosted over 800 outreach events and impacted more than 65,000 individuals.



## **WINCART Education and Outreach**

21 outreach events	4,215 individuals	(Year 1)
223 outreach events	27,886 individuals	(Year 2)
200 outreach events	22,983 individuals	(Year 3)
182 outreach events	5,310 individuals	(Year 4)
200 outreach events	6,841 individuals	(Year 5)

**Total Outreach Events: 826    Total Individuals Impacted: 67,235**



**Title:** A Community-Centered Approach to Developing and Pilot-Testing a Colorectal Cancer Education Campaign for Pacific Islanders in California

**Project Purpose:** Five Pacific Islander communities in Southern California: Chamorro, Marshallese, Native Hawaiian, Samoan, and Tongan, and members of the WINCART scientific advisory board collaborated in designing a colorectal cancer (CRC) awareness and prevention campaign. Weaving an Islander Network in Cancer Knowledge Attitudes, Beliefs and Behaviors (WINCKABB), was formed under the support and direction of WINCART (Weaving an Islander Network in Cancer Awareness, Research and Training, grant number CA114591-01), one of 25 Community Network Programs funded by the National Cancer Institute's Center to Reduce Cancer Health Disparities. Through a community participatory approach as well as various educational activities, WINCKABB aims to increase CRC knowledge and awareness in order to promote dialog among Pacific Islander community members, dispel myths and address taboos about cancer, increase patient-initiated conversations with health providers regarding CRC screenings, and ultimately encourage early participation in CRC screenings.



**Rationale:** Limited cancer epidemiology data for the Pacific Islander populations suggest that CRC is a prominent cancer for both sexes. A study of Samoans and Hawaiians living in California and Hawai'i, using data from the Los Angeles County/University of Southern California Cancer Surveillance Program (1972-1989) and the Hawai'i Tumor Registry (1981-1990), found that cancer of the rectum was among the top prevalent cancer sites for Hawaiian and Samoan men and women. Another study of residents of Guam, using cancer mortality data collected by the Guam Cancer Registry, found that age-adjusted cancer mortality rates, including colorectal cancer, for Chamorros, the indigenous peoples of Guam, was more than 25% higher than the U.S. rate. Although good informational materials on CRC exist, it is not as effective with many Pacific Islander communities. The images, messages and underlying values that provide incentives for cancer screening participation do not resonate with Pacific Islander populations. WINCKABB CRC campaign fills this gap in education and outreach by taking the appropriate steps to culturally tailor cancer information.

**Implementation:** The formation of WINCKABB could only be achieved through the promotion of community ownership and community capacity by integrating community input throughout the development of the educational campaign. A WINCKABB work group - consisting of five community partners representing the Native Hawaiian, Samoan, Chamorro and Tongan communities, and WINCART staff - was assembled and charged to: 1) recommend appropriate mechanisms to outreach and educate community members on CRC, 2) advise in the development of cancer education materials, 3) advise in the development of the survey

questionnaire and method of administration, and 4) update WINCART Community Advisory Board members on progress and request feedback.



**Results:** The educational materials developed (flipchart and bookmark) have been pre-tested in the five respective Pacific Islander communities and were printed prior to campaign launch in the summer 2008. Perhaps most notable and meaningful to the community members thus far was the development and creation of a public service announcement video. In addition to developing educational materials, WINCKABB also spearheaded the development of a video, in which indigenous Pacific Islander community advocates, health educators, health professionals, and cancer survivors gathered together to share stories and thoughts on cancer and health as it relates to the Pacific Islander culture, values, and beliefs. These individuals and a video production crew gathered at a park in Orange County on February 13, 2008 to shoot video interviews of

indigenous community members. This event was groundbreaking in our WINCKABB campaign as it was the first community-based endeavor of its kind in the Pacific Islander community. Furthermore, this event was the quintessential representation of key values and beliefs in the Pacific Islander community (intergenerational values, community cohesiveness, and selflessness). Thanks to the help of Ed Royce, Trisha Pereira, Joanne Lightford, and the staff of Royce Entertainment Group, a video was created and disseminated via several avenues, including workshops, conferences, individuals, and community events.



**Lessons Learned:** The development of CRC educational materials highlighted the importance of using peripheral tailoring strategies, such as images of cultural icons incorporating faces from targeted communities, and the use of vibrant colors and island landscapes in the educational materials. The video shoot highlighted the importance of using different multimedia to communicate a key health message in a culturally appropriate way. “Talk story” is a unique attribute and deeply rooted in the oral tradition of Pacific Islander generations. Talk story is still used as a method to relay important messages and stories within the Pacific Islander communities. Thus, this video is a vital supplement to the educational print materials as it includes indigenous Pacific Islanders sharing personal testimonies and important messages about cancer, health, and well-being.

**Partners:** ‘Imi Hale, one of the 25 Community Network Programs funded by the Center to Reduce Cancer Health Disparities, was generous in sharing its insightful experiences, CRC campaign materials, and intervention assessment tools.

**Funding:** Complementing the support provided by the NCI’s Center to Reduce Cancer Health Disparities (CA114591-01), the California Department of Public Health provided funding to assist in offsetting the costs of developing culturally and linguistically tailored CRC educational materials.

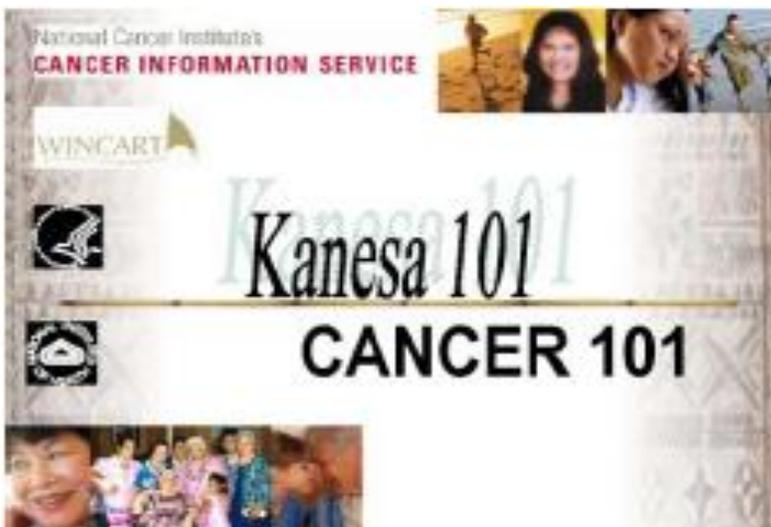


**Title:** Samoan Cancer 101 Educational Toolkit

**Project Purpose:** A collaborative partnership was formed between WINCART, the Cancer Information Service (CIS) Southern California Partnership Program, based at the University of Southern California (USC), Norris Comprehensive Cancer Center, Orange County Asian and Pacific Islander Community Alliance (OCAPICA) and the Samoan National Nurses Association (SNNA) to adapt the CIS “Cancer 101” educational tool to be culturally appropriate for all Pacific Islander groups, specifically for the Samoan community, and to develop the Samoan Cancer 101 Education Toolkit.



**Rationale:** Nationally recognized in-language, culturally appropriate and culturally responsive cancer education curricula is lacking in the Pacific Islander communities. In response to this need, the WINCART partners (Pacific Islander communities of Southern California) have adapted and developed formal and informal cancer-site education materials and education sessions. In order to address the need for culturally appropriate cancer education curricula, WINCART community partners collaborated with CIS to adapt and developed a curriculum targeting the Samoan community in Southern California.



**Implementation:** The “Samoan Cancer 101” education tool focuses on general information about cancer and specific information about breast, cervical, colorectal, and prostate cancer with adults ages 40 and older as the target audience. The education curriculum was adapted from the CIS Cancer 101 education tool, which was originally developed by NCI’s Spirit of Eagles and NCI CIS Northwest Region, a team of community and academic partners who reflected Samoan cultural nuances, language, word use and reading comprehension, cultural images, and intergenerational communication.

**Focus group evaluation:** A focus group of six Samoan adults, ages 18 and older, assessed the usability, cultural appropriateness, cultural responsiveness and the overall effectiveness of the curriculum within the Samoan

cultural context. Focus group members served the role of both participant and reviewer by participating in (1) the pre- and post-education survey, (2) the education session, and (3) the focus group discussion on the effectiveness of the education tool.

**Results:** The focus group consisted of six Samoan women, the majority of whom were over the age of 29 (83%), married or widowed (67%), and associated with a faith-based group (100%). Feedback from the focus group includes: the need to shorten the PowerPoint presentation and education session to less than one hour, to allow time for pre- and post-surveys, discussion, and question and answer sessions. The group expressed the need for more cultural images and slides on cultural beliefs, such as “Aitu” (Spirit) and “Vailaau” Samoan (Samoan medicine). The groups stated that the myths about disease, especially cancer, play a strong role in how people address the need for prevention, screening, and treatment of cancer. The group suggested that the education on myths strongly delineate between myth and fact so that there is no confusion for participants. One of the strongest points expressed by the focus group was that the educational curriculum must be rolled out to younger adults in order to plant seeds for positive health behavior, screening and treatment. Finally, the groups stressed the importance of reaching the Samoan community through the appropriate gatekeepers, recommending community organization leaders and the church as the primary point of contact for the community.



**Lesson Learned:** The language used must be adapted to accommodate a wider audience with varying language skills especially in reaching older adults. Translation into Samoan is an essential part of adapting the curriculum. Appropriate images to explain concepts and stimulate interest represent an additional change suggested by the focus group. One focus group participant said, “We did a presentation on cervical cancer and they had no idea what we were talking about. But once we showed a chart and said, ‘this is what it is and this is where it is located,’ they understood. We had to say it in Samoan before they understood. Lastly, in order

to add credence to the curriculum, the group reinforced the use of partner organizations and to allow community access to follow-up information if needed.

**Partners:** This collaboration included the Cancer Information Service (CIS) Southern California Partnership Program, based at the University of Southern California, Norris Comprehensive Cancer Center, WINCART and WINCART community partners; the Orange County Asian Pacific Islander Community Alliance (OCAPICA) and the Samoan National Nurses Association (SNNA) on the adaption and development of the Samoan Cancer Education Toolkit. In addition, the following individuals played key roles in developing the “Samoan Cancer 101” education tool: Seumaninoa Pauina (OSA/ CSUF), Jacqueline Tran (OCAPICA), Tiffany Ng (CIS/CSUF), Sora Park Tanjasiri (WINCART), Sala Mata’ali’i, Dorothy Schmidt-Vaivao, Genesis Lutu (SNNA), Jonathan (Tana) Lepule (UPCA), Kimo Suafilo (Westminster), June Pouesi (OSA), and Ruth Peters (WINCART).

**Funding:** WINCART is funded by the NCI’s Center to Reduce Health Disparities (UO1 CA114591).



## **WINCART Research & Training**

Pacific Islanders represent a wide diversity of ethnic populations. Despite their differences in nationalities, Pacific Islanders generally face low socioeconomic and other barriers to health care, leading to high rates of cancers. In order to address these critical disparities in cancer mortality and morbidity among the Pacific Islander communities in California, WINCART used community-based participatory research (CBPR) approaches to forge collaborations between community and university researchers. These CBPR approaches led to the success of numerous studies that assessed the needs and developed health programs for Pacific Islanders in Los Angeles, Orange, and San Diego counties



### **WINCART Studies & Funding: Partial List**

<b>Project Title</b>	<b>Funding</b>
Informal and Formal Support and Needs Among Samoan Survivors	\$ 69,686
Cancer Incidence in PI Populations in the U.S.	\$ 50,000
Pacific Islander Health Pipeline Program	\$100,840
Physical Activity and Nutrition among Pacific Islander Youth	\$353,327
Correlates of Cancer Screening for Pacific Islanders in California	\$ 69,750
Projected Incidence of Cancer among Pacific Islanders Living in California	\$ 81,500
Behavior and Beliefs Related to Diet among Native Hawaiians in Southern California	\$ 71,872
Creating the Pacific Islander Physical Activity Questionnaire (PIPAQ)	\$ 55,499
Lymphedema and Pacific Islander Breast Cancer Survivorship	\$ 52,564
Summer Research Experience for Students	\$ 44,135
HIV and HPV Risk among Pacific Islander Youth	\$175,000
Patient Navigation for Tongan Americans	\$210,000
<b>Total:</b>	<b>\$1,334,173</b>



## **WINCART Funding: Complete List 2005-2010**

### **Received Year 1-3:**

1. Informal and Formal Support and Needs Among Samoan Survivors Principal Investigator: Sora Park Tanjasiri, DrPH, MPH, Awarded: \$69,686 Funder: California Breast Cancer Research Program (CA BCRP) Time Frame: July 2006-December 2007
2. Cancer Incidence in Pacific Island Populations in the U.S. Principal Investigator: Myles Cockburn, PhD. Awarded: \$50,000, Funder: National Cancer Institute, Time Frame: October 2006-September 2007
3. Pacific Islander Health Pipeline Program, Lead: Orange County Asian and Pacific Islander Community Alliance, Awarded: \$100,840, Funder: The California Endowment, Time Frame: April 2007-March 2008
4. Physical Activity & Nutrition among Pacific Islander Youth: An Exploratory Study, Principal Investigator: Sora Park Tanjasiri, DrPH, MPH, Awarded: \$353,327, Funder: National Cancer Institute, Time Frame: April 2007-March 2009
5. Correlates of Cancer Screening for Pacific Islanders in California, Principal Investigator: Sora Park Tanjasiri, DrPH, MPH, Project Leader: Alek Sripipatana, MPH, PhD(c), Awarded: \$69,750, Funder: National Cancer Institute-CRCHD, Time Frame: August 2007
6. Projected Incidence of Cancer Among Pacific Islanders Living in California, Principal Investigator: Sora Park Tanjasiri, DrPH, MPH, Project Leader: Sela Panapasa, PhD, Awarded: \$81,500, Funder: National Cancer Institute – CRCHD, Time Frame: August 2007
7. Behavior and Beliefs Related to Diet in Native Hawaiians in Southern California, Principal Investigator: Sora Park Tanjasiri, DrPH, MPH, Project Leader: Archana McEligot, PhD, Awarded: \$71,872, Funder: National Cancer Institute-CRCHD, Time Frame: August 2007
8. Creating the Pacific Islander Physical Activity Questionnaire (PIPAQ), Principal Investigator: Sora Park Tanjasiri, DrPH, MPH, Project Leader: Karen L. Moy, PhD, Awarded: \$55,499, Funder: National Cancer Institute-CRCHD, Time Frame: August 2007

### **Received Year 4:**

9. Lymphedema and Pacific Islander Breast Cancer Survivorship pilot project. Project Leader: Nellie Sgambelluri. Awarded \$52,564 Funder: National Cancer Institute-CRCHD Time Frame: 2008

### **Received: Year 5**

10. Summer Research Experience for Pacific Islander Students (ARRA funding) Project Leader: Mary Anne Foo. Awarded (for student stipend and research expenses): \$44,135. Time Frame: May 2009-September 2010
11. Research on HIV/AIDS Related Cancer among Racial/Ethnic Minority and Underserved Person in the U.S.: Exploring the Intersection between HIV and HPV among Pacific Islanders (Admin Supplement). Project Leader: Anthony DiStefano. Awarded: \$175,000 Time Frame: October 2009-September 2010
12. Increasing Cancer Screening, Treatment and Support in the Tongan Community through Patient Navigation. (ARRA funding). ) Project Leader: TCSC. Awarded: \$210,000 Time Frame: October 2009-September 2011

**Report Summary:** Informal and Formal Support and Needs among Samoan Survivor **Co-Principal**  
Investigators: Sala Mata'ali'i, MSN, MBA & Sora P. Tanjasiri, DrPH **Participating Institutions:**  
Samoan National Nurses Association; California State University, Fullerton **Award Number:** 12AB-4100  
& 12AB4101 **Funded by:** Recovery Act Funds for Administrative Supplements; National Cancer  
Institute, Center to Reduce Cancer Health Disparities **Funding Amount:** \$69,686 **Date of Study:** 7/1/06-  
12/31/07

**Purpose:** This pilot study explores the formal and informal support needs of Samoan women diagnosed with breast cancer and to what degree these informal and formal social support mechanisms, or lack thereof, fulfill the needs of current Samoan survivors.

**Specific Aim #1: Develop an appropriate interview methodology for exploring social support needs and experiences** - In August 2006, we conducted a preliminary search of available literature and information regarding the nature of existing breast cancer interventions as well as the various mainstream psychosocial needs of women with breast cancer. On October 4, 2006, we held our first CAB meeting at which CAB members were acquainted with each other and the projected project activities. Subsequently, on November 21, 2006, we conducted a focus group at which CAB members reviewed each question in the survivor interview guide and made appropriate suggestions and changes based on their knowledge of Samoan culture, community, values and beliefs.

**Specific Aim #2: Develop a family/friend component to this methodology to explore their involvement as informal supporters for the survivor** - A similar approach that was used to develop the survivor interview instruments was used to develop a draft interview guide and written survey for the informal supporters as well. In addition, interview staff provided their expertise regarding questions that would be difficult but important to ask supporters. Review of the draft interview instrument was provided by our CAB at the June 2007 CAB meeting, and translated by CAB members into Samoan.

**Specific Aim #3: Conduct purposive sampling and interviewing of Samoan breast cancer survivors** - In April 2007, Co-PI Sala Mata'ali'i generated an initial list of approximately 20 breast cancer survivors in the Samoan community who were identified as potential interviewees for our project. On April 23, 2007, we conducted a three-hour interviewer training session to orient interviewers with the various forms, interview guides, and interview protocol for our project. Monthly meetings with study interviewers were held on May 7<sup>th</sup>, June 14<sup>th</sup>, and July 23<sup>rd</sup> to discuss participant recruitment and interview experiences, as well as initial impressions from the data collected. Followup meetings were also held with the CAB on July 10<sup>th</sup> and with the study consultant on July 9<sup>th</sup> and July 23<sup>rd</sup> to update all partners on the progress of the interviews and generate more ideas for addressing emergent issues.

**Specific Aim #4: Recruit and interview at least two informal supporters regarding their provision of support and care** - In order to recruit the supporters of breast cancer survivors, we asked each survivor at the

end of their interview to provide the names of 1-2 supporters whom they feel are key individuals who have been involved, or should have been involved, in their breast cancer experiences. These names were obtained via the written survey, and then transferred to a supporter recruitment list maintained by Ms. Mata'ali'i. These strategies resulted in a total of 40 supporters interviewed, for a total sample size of 60 interview participants (20 survivors and 40 supporters).

**Specific Aim #5: Identify the emergent categories and themes related to women's social support needs and experiences** - Transcriptions of all interviews was initiated in June, and continued throughout the interview process. We designated one interviewer to assist with all transcriptions requiring

**Pilot Project:** Summer Research Experience for Pacific Islanders Students **Project Investigator:** Mary Anne Foo **Participating Institutions:** Orange County Asian and Pacific Islander Community Alliance **Funded By:** Recovery Act Funds for Administrative Supplements **Funding Amount:** \$44,135 **Time Frame:** May 2009 to September 2010

**Brief description:**

California has 218,304 Pacific Islanders (PIs), yet only 4.6% of PIs in California age 25 years and older have a bachelor's degree or higher and less than 1% of those working are in the health care industry with a majority as home health aides. This project seeks to increase the number of PI high school and college students who pursue research careers in health-related sciences and to support 20 young PIs to enter into health professions education and/or training programs in order to promote and contribute to cancer health disparities, cancer-related research, and health-related science. This project will address WINCART's aims by (1) increasing training opportunities for PI students in order to promote, support, and mentor their interest in pursuing higher education leading to careers in health-related research and (2) involving the PI students in WINCART's ongoing studies, thus providing support to current community and university researchers to further ongoing and future research activities.



### Study Aims of the ARRA Award:

1. Recruit two PI high school students and 18 PI college students to work on summer research projects each year for a total of 20 students;
2. Place PI students with academic institutions and/or community organizations to work on research projects focused on PI cancer health disparities and cancer-related research;
3. Provide mentorship and academic support to PI students to increase the number of students who pursue health careers in cancer health disparities and cancer-related research and health-related science.



### Aims Achieved:

Over a two-year span, **20 Pacific Islander students** (18 undergraduate and two high school students) participated in the summer research internship project. Students were placed with academic/research mentors and community-based organization participating in health disparities research activities. Students were placed with faculty throughout Southern California: California State University Fullerton, Claremont Graduate University, University of California, Los Angeles, University of California, San Diego/San Diego State University, California State University, Dominguez Hills and a local NCCCP site, and Saint Joseph Hospital of Orange Center for Cancer Prevention and Treatment. Preceptors were engaged in cancer health disparities work and provided research studies linked to PI communities.

Student summer research activities included: (1) conducted literature reviews, (2) developed story board on a cancer curriculum, (3) assisted in qualitative research - focus group, interviewed key informants (under preceptor supervision), (4) transcribed data from a patient navigation project among Tongans, (5) transcribed data evaluating a patient navigation project among Chamorros, (6) participation in a qualitative study on HIV/AIDS- related cancer study among Chamorros and Tongans, and (7) assisted on data analysis with a Native Hawaiian tobacco prevention study. Training workshops included understanding health disparities, especially cancer among PIs; learning and understanding the need for a diverse health care workforce and opportunities available to students; empowering the students with skills and resources for higher education (e.g. how to read a manuscript) and providing a network of peer and professionals for mentorship and support.

The project, as part of OCAPICA's workforce diversity program, successfully submitted an abstract to APHA as part of an oral presentation on "A health workforce diversity program: Planning, development and implementation of a community-lead health workforce development program tailored to Native Hawaiian and PI students in Southern California" and was presented November 6-10, 2010 at the 138<sup>th</sup> Annual American Public Health Association Conference in Denver, Colorado.





## Cancer-Related Risk Factors among Pacific Islanders in California

### Summary of Scientific Progress

**Pilot Project:** Cancer-Related Risk Factors among Pacific Islanders in California **Co-Principal Investigators:** Sora P. Tanjasiri, MPH, DrPH & Alek Sripipatana, MPH, PhD **Participating Institutions:** California State University, Fullerton **Grant Supplement Number:** 3 U01 CA114591-03S2 **Funded By:** National Cancer Institute-CRCHD **Funding Amount:** \$81,500 **Time Frame:** August 2007

#### **Introduction:**

Compared to nearly all other ethnic groups, Native Hawaiians and other Pacific Islanders (NHPs) demonstrate some of the poorest cancer-related health risks and outcomes. Therefore, it is imperative that race/ethnic-specific data be made available for policymakers, health providers and public health professionals. Promoting preventive health behaviors like colorectal exams, mammograms and Pap smear tests will be more effective if the underlying factors that promote these health services are identified.

#### **Theoretical Framework:**

The Andersen Model of Health Service Utilization was the theoretical framework guiding the statistical analysis in identifying predisposing, enabling, and need factors associated with participation in cancer screening (Andersen, 1995).

#### **Purpose**

(1) To establish baseline rates for cancer-related risk factors (including tobacco use, obesity, and early detection behaviors) among Pacific Islanders across California; (2) To examine the predictors of these risk factors in order to identify opportunities for community-based and policy-level intervention actions.

#### **Materials and Methods:**

Secondary data analysis of the California Health Interview Survey (CHIS), concatenating 2001 and 2003 waves of the CHIS, was employed to develop statistical models that identify facilitators and barriers to colorectal cancer screening, mammogram, and Pap smear tests. The pilot project has undertaken several activities in order to document the needs of Pacific Islanders in California. Step 1: Convened an advisory board of community-based leaders who have expressed interests in increasing NHP specific data related to cancer. Step 2: Survey data analysis. Using multiple waves (2001 and 2003) of the CHIS datasets, multivariate statistical models were developed to identify facilitators and barriers to cancer prevention behaviors using the Anderson model of health service utilization as a theoretical guide (Andersen, 1995). Step 3: Dissemination of the results of these analyses to community audiences. Community report-back sessions were conducted with leaders of the NHP communities to share the findings using lay terminology, and facilitated brainstorming of the implications for intervention development and future research.

#### **Results:**

***Colorectal Cancer Screening:*** Of the Native Hawaiian and Pacific Islanders ages 50 and over in CHIS 2001 and CHIS 2003, 60.7% (n=116) responded ever having a colonoscopy, sigmoidoscopy, or FOBT. When colorectal cancer screening was regressed on the predisposing, enabling, and need variables identified in table 2, respondents were more likely to have had a CRC screening with increasing age (OR = 1.056), having 3 alcoholic drinks per week (OR = 6.513), U.S. citizenship (OR = 6.468), and having 3 doctor visits in the past year (OR = 5.536).

**Pap Tests and Mammograms:** When Pap test in the past 3 years among Native Hawaiian and Pacific Islander women 21 years and older was cross-tabulated with predisposing, enabling and need factors, being overweight or obese ( $X^2 = 6.320$ ,  $p < .05$ ), alcohol consumption ( $X^2 = 9.313$ ,  $p < .05$ ), U.S. citizenship ( $X^2 = 7.240$ ,  $p < .01$ ), insurance status ( $X^2 = 5.530$ ,  $p < .05$ ), usual source of care ( $X^2 = 9.00$ ,  $p < .01$ ), doctor visits ( $X^2 = 23.355$ ,  $p < .001$ ), and having a health condition that requires special equipment ( $X^2 = 4.842$ ,  $p < .05$ ) were all related. Among NHPI women 40 years and older, age ( $X^2 = 8.910$ ,  $p < .05$ ), smoking status ( $X^2 = 8.192$ ,  $p < .05$ ), U.S. citizenship ( $X^2 = 6.662$ ,  $p < .01$ ), insurance status ( $X^2 = 4.094$ ,  $p < .05$ ), usual source of care ( $X^2 = 10.445$ ,  $p < .001$ ), and doctor visits ( $X^2 = 14.359$ ,  $p < .01$ ) were related with obtaining a mammogram in the past 2 years.

**Pap Smear Test:** Of the Native Hawaiian and Pacific Islander (NHPI) women 21 years and older, 94% ( $n=298$ ) responded ever having a Pap smear. However, 84% ( $n=268$ ) indicated that they had a Pap smear within the past 3 years. When screening status within the past 3 years was regressed on the variables identified in table 2, overweight/obesity (OR = 0.325), citizenship (OR = 33.756), the interaction of citizenship and insurance status (OR = 0.033), having 1, 3, or 5 doctor visits in the past year (ORs = 5.017, 3.945, 12.079, respectively), and having a health condition that requires special equipment (OR = 0.168) were predictive of Pap screening status.

**Mammogram:** Among the NHPI women 40 years and older in the CHIS 2001 and 2003, 85.3% ( $n=162$ ) reported ever having a mammogram. There was one respondent who “did not know” if she ever had a mammogram. Due to the invasive nature of a mammogram, this datum was aggregated into the “never had a mammogram” category. Although a large proportion (85.3%) of women reported ever having a mammogram, only 71.6% ( $n=136$ ) have had their mammograms in the past 3 years. When mammogram status within the past 2 years was regressed on the variables identified in table 3, age (OR = 1.044), smoking status (OR = 0.271), citizenship (OR = 111.022), insured status (OR = 32.784), the interaction of citizenship and insurance status (OR = .007), and having 3 (OR = 7.080) or 5 (OR = 4.713) doctor visits in the past year were predictive of having a current mammogram.

### **Implications:**

Citizenship played an important factor in obtaining colorectal cancer screening, Pap tests and mammograms. This finding highlights the fact that Pacific Islanders are a heterogeneous population and represent an array of backgrounds and circumstances that impact their access to health care in the U.S. These findings also highlight the importance of individual health behaviors. *Obesity* was found to be a barrier to obtaining Pap tests and *current smoker* status a barrier for obtaining mammogram. These findings underlie the fact that cancer prevention and early detection has to incorporate multi-level and multi-faceted approaches. That access to care is not the factor to account for in order to address cancer health disparities in Pacific Islander populations. Additionally, cultural concepts around cancer and cancer screening need to be better understood among Native Hawaiian and Pacific Islanders.

### **Project Limitations:**

The most prominent limitation to this research project is the constraints due to small sample size. Even when combining multiple waves of the California Health Interview Survey (CHIS) the analytic sample size limited the amount of covariates that could be entered in the regression models, especially when stratifying the analysis by gender and age. As a result of small sample size, many of the findings did not reach statistical significance, although they may have been suggestive and followed theoretical patterns found in previous studies. Another constraint of small sample size was the inability to break out the NHPI sample by ethnic sub-group. The NHPI category is comprised of heterogeneous groups, each with its own culture, language and socio-political history and relationship with the U.S., all of which have implications for successful cancer interventions.



## Projected Incidence of Cancer among Pacific Islanders Living in California

### Summary of Scientific Progress

**Pilot Project:** Projected Incidence of Cancer among Pacific Islanders Living in California **Co- Principal Investigators:** Sora P. Tanjasiri, DrPH & Sela V. Panapasa, PhD **Participating Institutions:** University of Michigan; Harvard University; California State University, Fullerton **Grant Supplement Number:** UO1CA114591-03S3 **Funded By:** National Cancer Institute-CRCHD **Funding Amount:** \$50,000 **Time Frame:** August 2007

#### **Introduction:**

Until recently, Pacific Islanders were aggregated with Asians to form the broad Asian Pacific Islander (API) category, which created ongoing measurement problems due to the high level of heterogeneity within this category (Yu & Liu, 1994; Williams, 1999; House & Williams, 2000; Srinivasan & Guillermor, 2000; Panapasa & Williams, 2006; Moy 2007). Analyses of API data continue to demonstrate that the relatively better health status of Asians masked the serious health disparities among Native Hawaiian Pacific Islander groups (Chen & Hawks, 1995; Hoyert & King, 1997; Williams & Collins, 1995; Hayward & Heron, 1999; Frisbie et al, 2001; Williams, 2005). The significance of the pilot project is derived in large part by the lack of useful baseline information on cancer incidence and cancer-related health patterns among Native Hawaiian and Other Pacific Islanders—one of the medically underserved target populations outlined in the vision for the CRCHD. Further, better understanding of the social disparities and inequities among Pacific Islanders and their communities is essential to inform interventions and policies to reduce cancer disparities (Krieger, 2005). At present, demographic analysis of disaggregated API data and existence of detailed information for cancer among Pacific Islanders and its subgroups is limited (Goggins & Wong, 2007; Miller, Chu, Hankey & Reis, 2008). This lack of information has hampered the need to develop meaningful prevention programs and interventions with the diverse Pacific Islander communities.

#### **Theoretical Framework:**

The project draws on the socioeconomic status (SES) model (Chu, Miller & Springfield, 2007; Freeman, 1989; 2004; Ward, Jemal Cokkinides, et al, 2004; Williams & Collins, 2001) to help understand cancer disparities among Native Hawaiian and other Pacific Islanders and provides scientific evidence for the elevated risk of cancer among NHPs and lends tremendous support to further examine the social inequalities in cancer incidence, prevalence, detection and treatment, as well as survival in this underserved population.

#### **Purpose:**

(1) To describe the state of cancer among Native Hawaiians and other Pacific Islanders living in California. Specifically to calculate projections for the populations selected for the study, estimate cancer incidence level, examine the distribution of cancer risk, and compare cancer incidence levels across the different Pacific Islander subgroups. (2) To actively collaborate with Pacific Islanders in the WINCART communities in order to increase cancer awareness and education through dissemination of project findings.

#### **Materials and Methods:**

California Surveillance, Epidemiology, and End Results (SEER) Program was used to derive descriptive and numerator information on cancer incidence. The 1990 and 2000 U.S. Census and National Center for Health Statistics Mortality and Natality Detail Files for 1990-2004 were used to calculate population estimates for

Native Hawaiians, Samoans and Guamanians/Chamorros. Age-specific and age-adjusted incidence rates were calculated for all forms of cancer.

### **Calculating intercensal estimates of NHOPi populations in California:**

Population level denominators for this study were derived from a special tabulation of the NHPI population in 1990 by the U.S. Census Bureau, Racial Statistics Branch and the total population enumerated from the 2000 U.S. Census of Population Standard Files 1 (SF1). The numerator information on mortality was obtained from the National Center for Health Statistics (NCHS) Multiple Cause of Death (MCD) data. Birth data for intercensal estimates was obtained from the NCHS Natality Detail Files for 1990 to 2000.

***The Cohort-Component Approach:*** The basic estimation technique used to generate intercensal denominators takes advantage of the demographic accounting approach to population growth often referred to as the balancing equation, a fundamental measure of population change across time (Shyrock & Siegal 1971). The balancing equation is typically written as:

$$\text{Pop}(t) = \text{Pop}(t-1) + \text{Births}(t) - \text{Deaths}(t) + (\text{In-migration}(t) - \text{Out-Migration}(t)) \quad (1)$$

***Age-Specific Cancer Incidence:*** The cancer incidence rate is the proportion of new cancers of a specific site/type occurring in a population at risk:

$$\text{Age-Specific Incidence Rate} = (\text{New cancers}_{a,x} / \text{Population}_{a,x}) \times 100,000.$$

### **Results:**

Younger Pacific Islanders (under 15 years) reflect atypically low rates of cancer diagnosis compared to the U.S. population. Age-specific cancer incidence rates for NH/PIs were measurably lower than the total population of Whites, Blacks and Other Races. When age structure is accounted for using the age-adjusted cancer incidence rates, NH/PIs are observed to be reaching elevated levels of cancer incidence similar to Whites and Blacks

### **Conclusions:**

There are three main findings from this analysis. First, younger Native Hawaiian and Pacific Islanders reflect atypically low rates of cancer diagnosis compared to the U.S. population; second, younger NH/PIs may require increased attention to ensure adequate screening for cancers; and third, Pacific Islanders are experiencing elevated levels for cancer similar to their White and Black counterparts. Under-screening could explain the low overall observed prevalence for cancer in general and particularly for youths. Under-reporting and undiagnosed cases are consistent with health care utilization patterns seen for NHPIs due to increased poverty, lower SES and high uninsured among Pacific Islanders (Panapasa, Phua & McNally, 2008; U.S. Census 2005; KFF & APIAHF, 2008) and this represents an opportunity to increase community involvement through appropriate education, navigation and outreach on the importance of screening.

### **Implications:**

Evidence-based research on the Native Hawaiian and Pacific Islander population and its subgroups is essential to develop meaningful prevention programs and effective interventions and policy change to reduce cancer disparities. Disaggregated baseline information is important to better understand the NHPI population cancer risks and key determinants associated with the elevated risk of cancer among subgroups.

### **Project Limitations:**

The core methodological limitation for this pilot represents a central thread in all work associated with NHPI health research—limited data availability. Changes in reporting practices for vital statistics by NCHS in the early 1990s now allows for the tabulation of select NHPI populations (Native Hawaiian, Chamorro and Samoan) but no information exists for smaller NHPI populations. Further, NCHS continues to collapse residual NHPI populations with Asian residuals making the disaggregation of these disparate groups impossible. Census data, essential for denominator information faces similar challenges.



## Behavior and Beliefs Related to Diet in Native Hawaiians in Southern California

### Summary of Scientific Progress

**Pilot Project:** Behaviors and Beliefs Related to Diet in Native Hawaiians in Southern California **Co-Principal Investigators:** Sora P. Tanjasiri, DrPH & Archana J. McEligot, PhD **Grant Supplement Number:** UO1CA114591-03S4 **Funded By:** National Cancer Institute-CRCHD **Funding Amount:** \$71,872 **Time Frame:** August 2007

#### **Introduction:**

Health disparities, specifically cancer rates, exist between populations and contribute to reduced quality of life, illness and mortality. Currently, native Hawaiians have the third highest mortality rate of all invasive cancers in the United States and the highest mortality rate due to cancer in the country compared with any other ethnic group (Tsark 1998). Several lifestyle factors, specifically diet, have been linked to cancer risk. Even if the data are conflicting, a diet high in vegetable, fruit and fiber has been protective, while a diet high in saturated fats may increase the risk of some types of cancers. However, only recently has the National Cancer Institute and the American Cancer Society distributed information related to dietary intake and cancer to the Native Hawaiian community (Hughes 1998). Therefore, the need to reduce this disparity is critical and urgent. Several lifestyle factors, specifically diet, have been linked to cancer risk.

#### **Theoretical Framework:**

For the present study, the conceptual framework used to develop the survey is derived primarily from two theories, social cognitive theory and the transtheoretical model. Based on the conceptual framework of social cognitive theory, *predisposing factors* related to behavior and beliefs regarding one's health in conjunction with external conditions can directly affect the *self-regulation* activities of the individual that allows the person to learn which behavioral management strategies are most effective to achieve a desired goal. In addition to social cognitive theory, we will measure stage of change related to healthful eating based on the Transtheoretical Model (TTM) or also commonly referred to as Stages of Change Model. TTM underscores the dynamic processes of behavioral change in five stages that include: precontemplation, contemplation, preparation, action and maintenance. Applying both the TTM and social cognitive theory models for developing the questionnaire will allow to measure different factors that influence eating habits/behaviors at different developmental/change phases. Also, readiness to change behavior and/or what stage of change the present population is in is unknown. Therefore, measuring strategies used for healthy eating in conjunction with stages of change and assessing dietary intakes allows for a more in depth characterization of dietary behaviors in the Native Hawaiian population that will lead to the future development of more effective dietary intervention.

#### **Purpose:**

(1) To measure dietary intakes, including vegetable, fruit and macro and micronutrients via 24-hour telephone dietary recalls in 60 Native Hawaiian adults ( $\geq 21$  yrs) residing in Orange and Los Angeles counties. (2) To develop and pilot a questionnaire that measures psychosocial (behavior and beliefs) and cultural factors related to eating habits in 60 Native Hawaiian adults residing in Orange and Los Angeles counties. (3) To assess the relationship between the newly piloted behavior and belief scales (related to eating habits) with dietary intakes (vegetable, fruit, fiber, etc.) measured via 24-hour dietary recalls.

## **Materials and Methods:**

The present study was a cross-sectional study that recruited 62 Native Hawaiians residing in Orange and Los Angeles counties. Participant recruitment and data collection took place at community-based settings in Orange and Los Angeles counties. The present study protocol was based on extensive input from the Community Advisory Board (CAB). A Community-Based Participatory Research (CBPR) approach was used and several strategies were used to ensure community-based collaboration throughout each of the study phases.

Part 1 of the study focused on development of a questionnaire to assess behavior and beliefs related to diet and eating habits in Native Hawaiians in Orange and Los Angeles counties. The questionnaire was adapted from existing questionnaires (Northwehr 2006, Northwehr 2006b, Satia 2000). For Part 2, trained community liaisons/leaders reviewed the study and consent procedures with potential participants at an initial community gathering and obtained height and weight measures. After obtaining consent, participants were scheduled to complete three 24-hour dietary recalls which provided quantitative measures of vegetable, fruit, fiber and many other nutrients. Once the 24-hour recalls were completed via telephone, the newly developed questionnaires on beliefs and behaviors related to eating habits were distributed by trained community members at a second local community gathering to the same participants that completed the dietary recalls.

## **Results:**

Mean dietary intakes of Native Hawaiians residing in Southern California were as follows: vegetable servings ( $2.52 \pm 1.54$ ), fruit servings ( $1.66 \pm 1.64$ ), fiber ( $16.83 \pm 7.20$  g), % energy from fat ( $34.39 \pm 7.48$ ), whole grain servings ( $1.63 \pm 1.60$ ) and refined grains ( $3.73 \pm 1.93$ ). BMI distributions were: 13% normal weight, 32% overweight and 55% obese. The psychosocial data showed that the population expressed a lack of social support for exercising and diet, while outcome expectancies for the benefits of a healthful diet and exercise program were high. All the discussion groups expressed concern over diet and weight management, both as an individual and community issue. The dietary data indicate that Native Hawaiians residing in Southern California should aim to increase their vegetable, fruit, fiber, whole grains and reduce % energy from fat and refined grains. In addition, 87% of the population was either overweight or obese.

## **Implications:**

Dietary intakes suggest that Native Hawaiians residing in Southern California have similar intakes to the general U.S. population and need to improve on vegetable, fruit, fiber and % energy from intakes. In relation to the psychosocial data, the present community would benefit from an intervention that involves stronger social support for both exercise and diet and therefore designing a community/family-based intervention may be effective for Hawaiians residing in Southern California. Also, we found a high prevalence of overweight and/or obese participants in the present population, suggesting that implementation of an effective dietary intervention that is socially, culturally and ethnically specific for Native Hawaiians in Southern California is critical.

## **Project Limitations:**

Although participants showed high interest in the study, conducting three recalls via the telephone was burdensome for some participants and therefore we used either two telephone dietary recalls to assess their dietary intakes and/or collected dietary data via e-mail or mail. However, the same procedures/quires used via the telephone were also applied for assessing diet via e-mails and mail. In addition, over 30% of the participants were not present at the second assessment and/or were recruited at various community gatherings and therefore, self-reported height and weight data were used rather than measured in-person via a height and weight scale.



## Creating the Pacific Islander Physical Activity Questionnaire

### Summary of Scientific Progress

**Pilot Project:** Creating the Pacific Islander Physical Activity Questionnaire (PIPAQ) **Co-Principal Investigators:** Sora P. Tanjasiri, DrPH & Karen L. Moy, PhD **Participating Institutions:** San Diego State University **Grant Supplement Number:** 3U01 CA114591-03S5 **Funded By:** National Cancer Institute-CRCHD **Funding Amount:** \$55,499 **Time Frame:** August 2007

### Introduction

**B.1 Reducing Health Disparities among Native Hawaiian and Other Pacific Islanders** - Native Hawaiian and Other Pacific Islanders in the U.S (NHOIP) represent a wide diversity of population groups, with over 19 census defined groups, each with their own culture, language, traditions, and political and migration history. Several international studies have reported that, compared to non-Hispanic Whites, NHOPIs demonstrate high prevalence of obesity and low levels of physical activity in NHOPI, as well as increased incidence of breast (150%), ovarian (200%) and cervical (500%) cancers, and dramatically higher case fatality rates for coronary heart disease.

**B.2 Establishing a Valid Instrument to Assess Population Physical Activity Levels** - Prior to implementing effective PA interventions to target high-risk populations, an accurate assessment of the proportion of the population meeting current PA recommendations is required. Physical Activity Questionnaire (PAQ) remains the most feasible instrument for population-level assessments. Before the PAQ is used, it must be validated by an objective measure in the specific population it is intended for, as any conclusions related to its validity are limited to the population in which it was administered.

**B.3 Gaps Addressed by this Pilot Research** - This study will produce the first culturally-specific PA measurement instrument for NHOPIs, and conduct preliminary usability and feasibility testing for a future PIPAQ validity and reliability study. Once validated, baseline PA data for NHOPIs can be used to monitor trends in PA participation and measure the effectiveness of PA interventions aimed at tackling cultural issues associated with obesity and chronic diseases and conditions in this high-risk population. Future studies could add to PIPAQ by addressing determinants of PA (e.g. environmental or psychosocial) that promote or hinder PA participation. Understanding these cultural influences on PA, a behavioral determinant of obesity, is required to successfully promote personal awareness, attitudes, beliefs and skills that motivate NHOPIs to lose weight or avoid further weight gain.

### Theoretical Framework:

Objective physical activity monitors are ideal for collecting accurate data on physical activities performed during a given sampling period. The Actiheart and ActiTrainer monitors are two technologically advanced devices which could potentially be used in this population to validate the newly created physical activity questionnaires.

**Purpose:**

(1) To develop the PIPAQ, a culturally specific measurement instrument for NHOPIs through a collaborative effort among PA researchers and NHOPI community leaders and members. (2) To set the stage for a subsequent full-scale PIPAQ validity and reliability study by assessing cultural appropriateness of the PIPAQ and objective PA measurement instrument, the Actiheart.

**Materials and Methods:**

This study enrolled n=40 (16M, 16F) NHOPI, aged 21-65 years, to participate in gender-stratified focus group discussions and usability and feasibility testing of the PIPAQ and the Actiheart, an objective PA measurement device. The sample equally represented NHOPI adults of both genders who engage in various levels of physical activity and speak English 'very well'. UPAC and SNNA were responsible for participant recruitment, which targeted individuals representing the major NHOPI subgroups (Native Hawaiian, Samoan, Guamanian/Chamorro, Tongan) residing in Southern California. Focus group discussions, facilitated by Sala Mata'ali'i from SNNA, addressed cultural perceptions and influences related to physical activity. At the end of each discussion, participants were compensated \$50 for their time, travel and cooperation. Qualitative data obtained from the discussions were used to determine how to culturally modify existing physical activity questionnaires from New Zealand (NZPAQ-SF and NZPAQ-LF). Two versions of PIPAQ were created (PIPAQ-SF and PIPAQ-LF), which were presented to community leaders for final approval on overall comprehension and cultural-appropriateness and acceptability.

**Results:**

Short and long versions of the Pacific Islander Physical Activity Questionnaire (PIPAQ-short and PIPAQ-long, respectively) were developed through collaboration among physical activity researchers and NHOPI community leaders in San Diego and Los Angeles. The Actiheart was the preferred monitor due to higher comfort and lower participant burden. Self-reported duration of physical activities was most difficult to recall, compared to activity type, frequency and intensity.

**Implications:**

Given the magnitude of the public health burden associated with overweight and obesity in this population, it is important to evaluate culturally-appropriate instruments to assess key lifestyle behaviors such as physical activity. This pilot study has produced two culturally-specific questionnaires to assess physical activity levels and has set the stage for a full-scale PIPAQ validity and reliability study. If the PIPAQ-short and/or PIPAQ-long shows acceptable validity and reliability, future studies in both clinical and community-based settings can utilize these instruments with confidence to facilitate monitoring of trends, cross-cultural comparisons, evaluation of physical activity interventions and identification of individuals or groups at greatest risk for health conditions related to inactive lifestyles.

**Project Limitations:**

This study included relatively small sample sizes for focus group discussions and pilot testing, and while community partners strived to recruit a diverse sample of participants, we do not know how representative these samples were. However, the main NHPI subgroups were represented and participants provided an abundance of specific feedback on both subjective and objective physical activity measurement devices, with a clear majority on the favored instruments from the NHPI perspective.



## Lymphedema and Pacific Islander Breast Cancer Survivorship

### Summary of Scientific Progress

**Pilot Project:** Lymphedema and Pacific Islander Breast Cancer Survivorship **Co-Principal Investigator:** Sora P. Tanjasiri, DrPH & Nellie R. Sgambelluri MD, MPH **Participating Institutions:** Guam Communications Network; California Chamorro Breast Cancer Survivors Alliance; Kanana Fou Samoan Congregational Christian Church; First Samoan Congregation Church of Westminster; California State University, Fullerton **Grant Supplement Number:** 3U01CA114591-0353 **Funded By:** National Cancer Institute-CRCHD **Funding Amount:** \$52,564 **Time Frame:** August 2008

#### **Introduction:**

Breast cancer is the leading cause of cancer for Pacific Islanders, with rates increasing compared to all other racial groups. One complication of breast cancer and its treatment is Lymphedema (LE) of the affected upper extremity, which is a consequence of surgery and radiation therapy treatments that result in destruction to the lymphatic drainage system. Unfortunately, nothing is currently known about the experience and needs of Pacific Islander breast cancer survivors regarding their knowledge of LE, their communication about risks with providers and community resources, and their own possible preventative and/or self-management behaviors.

#### **Theoretical Framework:**

The conceptual model for this study is the Health Belief Model (HBM), which posits that perceived susceptibility and severity to a disease, along with the barriers and benefits regarding the health behavior, predict a health behavior.

#### **Purpose:**

(1) To develop a qualitative focus group discussion guide that explores cultural and psychosocial factors specific to knowledge and attitudes of LE risk, early detection and management; (2) To recruit a total of 40 Chamorro and Samoan breast cancer survivors to participate in focus group discussions about their LE knowledge and attitudes, as well as how LE influenced their treatment decisions; (3) To apply the focus group results to develop a model peer-education program to increase LE knowledge and positive attitudes towards early detection and management that can be tested in a future study.

#### **Materials and Methods:**

This study enrolled n=23 Pacific Islander women breast cancer survivors age 36-79 to participate in focus group discussions separated by Chamorro or Samoan ethnicity. All participants spoke English. Although all participants were breast cancer survivors, not all participants had experienced LE. The present study used a qualitative exploration of the knowledge and awareness of LE risk, early detection and management among Pacific Islander breast cancer survivors who self identify as Chamorro or Samoan. Four focus groups and two key informant interviews were conducted in Los Angeles, Orange County and San Diego with Pacific Islander breast cancer survivors who had completed treatment for their primary cancer. Using the community-based participatory research (CBPR) approach, community leaders were trained to conduct all data collection activities and partners were involved in coding qualitative transcripts, identifying key results from these data, and developing an LE educational program that addresses the informational needs of survivors, providers and community facilitators.

## **Results: Focus Groups**

**Knowledge:** Of the 13 Chamorro participants, six had personal experience with LE with two others who knew those with LE although not having had personal experience with LE. The remaining five participants had no knowledge of LE despite having had therapy for their breast cancers including surgery and radiation. Prior to having had personal experience with LE, a minority had received information from health professionals or educational brochures. The rest received information from friends or acquaintances that had LE, breast cancer conferences/support groups or, most disturbingly, after having a painful swollen arm later diagnosed as LE.

**Attitudes:** Participants universally felt susceptible to LE, especially when faced with the information shared in the groups that LE may occur at any time after treatment for breast cancer. Other reasons cited for perceived susceptibility included attitudes that the affected arm was fragile and that susceptibility might increase as age increased and immunity and mobility declined. Participants noted that younger women may feel less susceptible to LE.

**Curriculum:** Participants stated that content of a LE education curriculum should include an explanation of what LE is and how it might manifest, information on the cause of LE and a wide range of ways to present the curriculum were deemed acceptable as long as these resources were accessible to those with limited reading ability and could be made available in Chamorro and English. All agreed that seeing Pacific Islander faces of all ages on curricula and getting information from survivors was very important.

**Guidelines:** Participants expressed trust of the NLN guidelines and stated that most of the information was helpful/practical, easy to follow, self-explanatory and culturally appropriate. However, there seemed to be confusion over who the guidelines were meant for and further clarification of specific recommendations was sought.

**Group dynamics:** Certain topics caused much participation and excitement within groups including discussion about GCN and the resources they provide to the community. Also, a discussion about the focus group experience leading to increased camaraderie in participants was noted. As mentioned earlier, the groups became quit agitated and anxious when discussing perceived high susceptibility to LE. Groups also discussed aging and increased susceptibility to disease with age due to decreasing immunity. No discussion on how to improve immunity or decrease susceptibility to disease (outside of LE) was discussed.

## **Results: Project**

Deliverables included completion of focus groups and interviews, mentorship activities, and advisory committee meetings. In addition, the project leader completed a biostatistics course and web module training on Atlas.ti, which was used to aid analysis. A video curriculum was developed. Finalized version being completed at this time will consist of interviews with two LANA-certified physical therapists and a loosely scripted conversation between survivors woven together into a more culturally acceptable than a standard lecture format video.

## **Implications:**

As a result of this pilot project, we have furthered our understanding of knowledge, attitudes, beliefs, and behaviors related to risk reduction for LE among Chamorro breast cancer survivors. In addition, we have developed a culturally appropriate education intervention to reduce LE incidence and complications in Pacific Islander breast cancer survivors. This curriculum will help address the LE information gap identified by the community and help decrease feelings of anxiety and helplessness these women feel when faced with LE susceptibility. This curriculum may be translated into other languages and changed/pilot tested for cultural acceptance in other communities.



## Research on HIV/AIDS Related Cancer Among Racial/Ethnic Minority and Underserved Person in the U.S.

### Summary of Scientific Progress

**Pilot Project:** Research on HIV/AIDS related cancer among racial/ethnic minority and underserved person in the U.S.: Exploring the intersection between HIV and HPV among Pacific Islanders (Admin Supplement)  
**Project Leader:** Anthony DiStefano **Participating Institutions:** California State University, Fullerton; Tongan Community Service Center/Special Service for Groups; Guam Communications Network **Grant Supplement Number:** UO1CA114591-05S2 **Funded By:** Recovery Act Funds for Administrative Supplements; National Cancer Institute, Center to Reduce Cancer Health Disparities **Funding Amount:** \$175,000 **Date of Study:** October 2009 to September 2010

#### **Brief description:**

A one-year qualitative needs assessment that explored community awareness, attitudes, beliefs and types of communication related to risk of HIV and HPV infection among Chamorro and Tongan young adults in Southern California. The study was a Community-Based Participatory Research (CBPR) collaboration of two community partner organizations (Tongan Community Service Center [TCSC] and Guam Communications Network [GCN]) and one academic partner (Department of Health Science, California State University, Fullerton [CSUF]).

#### **Specific Aims**

1. To identify the socio-cultural, environmental, and individual-level barriers and facilitators of prevention and early detection of HIV and HPV for Tongan and Chamorro young adults.

This aim was met by adhering closely to one of the two guiding theoretical frameworks: the social-ecological model. This model provided the framework to understand risks and behaviors from a multi-level social context while taking into account institutional and cultural aspects of behavior, perceptions and risks. At the *individual* level, the study assessed the risk and protective factors for HIV and HPV among Pacific Islander (PI) youth. Focus groups with parents assessed communication at the *interpersonal* level and attitudes and beliefs at the *cultural* level. At the *community* level, community leaders and providers were interviewed and helped to determine PI young adults' access to resources, services and social capital. Community leaders also provided insights into the organizational level influences on PI young adults, thus contributing to our understanding of risk and protective factors at the *organizational* level.

2. To describe the needs of Tongan and Chamorro young adults regarding HIV and HPV prevention and early detection from the perspectives of medical, mental health and social services providers who work with these communities; and from community leaders representing social groups, youth groups, and faith-based organizations. This aim was met by following the second guiding theoretical framework during our needs assessment: the PRECEDE portion of the PRECEDE-PROCEED Model. The study was very successful in completing the first four of PRECEDE's five phases: determining problems; isolating health determinants; and assessing predisposing, enabling and reinforcing factors, and moderately successful in completing PRECEDE's fifth phase: discovering interventions.

3. To apply Community Based Participatory Research (CBPR) approaches to inform the planning, implementation and evaluation of this qualitative needs assessment, including (1) the establishment of a community advisory board (CAB) to provide oversight; (2) involving community partners in all phases of study development, implementation, and data analyses; (3) co-facilitated data dissemination and report-back to the community and (4) co-facilitated development of future research proposals.

The CAB was very active and we acquired their feedback and guidance in all phases of the study. The academic and community partners shared the burden of all phases of the study equally, including data analysis, which is unusual among CBPR studies as actually implemented. Dissemination activities was led by the community: (1) a community forum that mixed our report-back of study findings with education on HIV and HPV; and (2) community and academic oral presentations at the 138<sup>th</sup> APHA Annual Meeting and Exposition, Denver Colorado. Next step is the submission of manuscripts for publication in peer-reviewed academic journals.

**Methods:** Purposive and chain referral sampling benefited from participants' familiarity with, and trust in, the partner organizations. We were able to capitalize on the resulting social capital in our recruitment efforts. Our final sample size (n=95), inclusive of both focus groups and key informant interviews, was very close to our targeted sample size of n=96. Figures 1 and 2 illustrate the study design as executed with the final sample in each study subgroup in the focus groups and key informant interviews, respectively.

After providing informed consent, all participants completed a pre-interview demographic questionnaire prior to an interview or focus group participation. Interviewers/facilitators used interview guides while conducting the interviews, which were audio-recorded. Focus groups were done in groups of 5-12 participants and were stratified by gender and study group (young adults, parents, community leaders and service providers). Focus groups had an average duration of 50 to 122 minutes, and key informant interviews were between 25 to 88 minutes.

Verbatim transcripts were produced for each of the recorded interviews/focus groups and analyzed independently by teams of two coders (one community partner and one academic partner). Once all data was coded, team-coded data files were merged into one data file per community (Tongan and Chamorro). Differences in coding were discussed; and only agreed-upon codes were used for final analysis of major themes. This analysis was done using ATLAS.ti version six. We ran descriptive statistics using SPSS 18 for data collected from the demographic questionnaires.

### **Implications:**

- Health education alone is not enough to prevent HIV and HPV risk behaviors in the Chamorro and Tongan communities
- Need a more comprehensive change to make the environment that Chamorro and Tongan young adults grow up and live in conducive to good sexual health
- Tongan community: Church leaders' willingness to have sexual health referral lists on hand if young adults come in to talk about these issues
- Mentoring parents on how to have sexual health-related talks with their children
- Overcoming cultural barriers that prevent access to health services and screenings
- Need for community support (buy-in) in order to launch an intervention project



## **WINCART Dissemination**

From 2005 to 2010 the professionals at WINCART have dedicated their time and effort to the multidisciplinary research focused on the cancer disparities experienced among Pacific Islanders residing in Southern California. To address these critical disparities, WINCART trained community leaders and promoted awareness of cancer prevention. Today, these efforts have been recognized nationwide



### **WINCART Publications, Presentations, & Policy/ Convening**

WINCART Publications	= 22
WINCART Presentations	= 56
WINCART Policy Meetings/Convening	= 7



## WINCART Publications & Presentations

### Publications

#### Year 1-3

1. Kagawa-Singer, M., Tanjasiri, S. P., Lee, S. W., Foo, M. A., Nguyen, T. N., Tran, J., & Valdez, A. (2006). Breast and cervical cancer control among Pacific Islander and Southeast Asian women: Participatory action research strategies for baseline data collection in California. *Journal of Cancer Education, 21*(1), S53-S60.
2. Tanjasiri, S. P., Tran, J. H., Palmer, P. H., & Valente, T. W. (2007). Network analysis of an organizational collaboration for Pacific Islander cancer control. *Journal of Health Care for the Poor and Underserved, 18*, 184-196.
3. Tanjasiri, S.P., Tran, J.H., Palmer, P.H., Foo, M.A., Hannemann, M., Lee, C., Sablan-Santos, L., & Sripipatana, A. (2007). Developing a Community-Based Collaboration to Reduce Cancer Health Disparities among Pacific Islanders in California. *Pacific Health Dialogue 14*(1), 119-172.

#### Year 4

4. Tanjasiri, S.P., Sablan-Santos, L., Merrill, V., Flores Quitugua, L., & Goo Kuratani, D. (2008). Promoting breast cancer screening among Chamorro women in Southern California. *Journal of Cancer Education, 23*(1), 10–17. doi: 10.1080/08858190701821386
5. Tanjasiri, S.P., & Tran, J.H. (2008). Community capacity for cancer control collaboration: Weaving an islander network for cancer awareness, research and training for Pacific Islanders in Southern California. *Cancer Detection and Prevention, 32*(1), S37-40.
6. Chu, K. C., Chen, M.S., Dignan, M.B., Taylor, E., Partridge, E., & Community Network Program Principal Investigator (2008). Parallels between the development of therapeutic drugs and cancer health disparity programs: Implications for disparities reduction. *Cancer, 113*(10), 2790-2796.

#### Year 5

7. Beale, K. K. (2010). Identifying the cause of cancer health disparities: Biologic and non biologic determinants. *Californian Journal of Health Promotion, 8*(special edition), 101-111.
8. Briand, G., & Peters, R. (2010). Community commentary: Cultural considerations for breast and cervical cancer education among Marshallese Women in Orange County. *Californian Journal of Health Promotion, 8*(special edition), 84-89.
9. Liu, L., Tanjasiri, S.P., & Cockburn, M. (2010) Challenges in identifying Native Hawaiians and Pacific Islanders in population-based cancer registries in the U.S. *Journal of Immigrant and Minority Health.*
10. Manglona, R.D., Robert, S., Isaacson, L.S.N, Garrido, M., Untalan, F.B., Sablan-Santos, L., Lee, D., & Peters, R. (2010). Strengthening a social support network for breast cancer screening the Chamorro community through the use of performance and video media. *Californian Journal of Health Promotion, 8*(special edition), 90-95.

11. McEligot, A.J., McMullin, J., Pang, K., Bone, M., Winston, S., Ngewa, R., & Tanjasiri, S.P. (2010). Diet, psychosocial factors related to diet and exercise, and cardiometabolic conditions in Southern Californian Native Hawaiians. *Hawai'i Journal of Public Health, He Huliau special issue*, 69(7), 16-20.
12. Moy, K.L., Sallis, J.F., & David, K.J. (2010). Health indicators of Native Hawaiian and Pacific Islanders in the United States. *Journal of Community Health*, 35(1), 81-92. doi: 10.1007/s10900-009-9194-0
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14. Moy, K.L., Sallis, J.F., & Tanjasiri, S.P. (2010). Culturally-specific physical activity measures for Native Hawaiian and Pacific Islanders. *Hawai'i Journal of Public Health, He Huliau special issue*, 69(7), 21-24.
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17. Tanjasiri, S.P., Lew, R., Kuratani, D.G., Wong, M., & Fu, L. (2010). Using photovoice to assess and promote environmental approaches to tobacco control in AAPI Communities. *Health Promotion Practice*. doi: 10.1080/08858190701821386
18. Tisnado, D.M., Sablan-Santos, L., Guevara, L., Quitugua, L., Castro, K., Aromin, J., Quenga, J., & Tran, J. (2010). A case study in community and academic engagement for a community-partnered research approach. *Californian Journal of Health Promotion*, 8(special edition), 39-51.
19. Tran, J.H., Mouttapa, M., Ichinose, T., Pang, J.K., Ueda, D., & Tanjasiri, S.P. (2010). Sources of information that promote breast and cervical cancer knowledge and screening among Native Hawaiians in Southern California. *Journal of Cancer Education*, 21(1), 588-594. doi: 10.1007/s13187-010-0078-x
20. Tran, J., Wong, M., Wright, E.K., Fa'avae, J., Cheri, A., Wat, E., Camacho, K.L., & Foo, M.A. (2010). Understanding a Pacific Islanders young adults perspective on access to higher education. *Californian Journal of Health Promotion*.\*
21. Tui'one, V., Hui, B., Tulua-Tata, A., & Tisnado, D.M. (2010). The Tongan American health professionals association promoting health through sharing, mentoring and networking. *Californian Journal of Health Promotion*, 8(special edition), 73-83.
22. Valente, T.W., Fujimoto, K., Palmer, P., & Tanjasiri, S.P. (2010). A network assessment of community-based and universities to reduce cancer disparities. *American Journal of Public Health*, 100(7), 1319-1325.

## Presentations

### **Presented in 2005**

1. Kuratani, D. *Weaving an Islander Network for Cancer Awareness, Research and Training (WINCART)*, Poster presented at the Community Networks Cancer Health Disparities Summit, National Cancer Institute, Rockville, Maryland, July 2005.
2. Pang, K.J. *Weaving an Islander Network for Cancer Awareness, Research and Training (WINCART)*, Presented at the American Public Health Association, Philadelphia, PA, December 2005.

### **Presented in 2006**

3. Kagawa-Singer, M. *Community Based Participatory Research: The Weaving an Islander Network for Cancer Awareness, Research and Training (WINCART) Network, Challenges and Successes*, Poster presented at the Office of Minority Health Symposium, Washington, D.C., January 2006.

4. Tanjasiri, S.P. and Lepule, T. *Weaving an Islander Network for Cancer Awareness, Research and Training: Community-Based Participatory Research and Network Analysis*, Poster presented at the Intercultural Cancer Council 10th Biennial Symposium, Washington D.C. April 21, 2006.
5. Tanjasiri, SP. *Cancer and Pacific Islanders: Weaving an Islander Network for Cancer Awareness, Research and Training* Poster presented at the CA REACH 2010 Conference, Los Angeles, CA, May 2006.
6. Lee, C. *Weaving an Islander Network for Cancer Awareness, Research and Training (WINCART): A Community-Based Participatory Research Approach with Pacific Islanders in Southern California*, Poster presented at the Community-Campus Partnerships for Health 9<sup>th</sup> Conference, Minneapolis, Minnesota, May 2006.
7. Sripipatana, A. and Tran, J. *Improving Access to and Utilization of the Cancer Care Continuum through Community-Based Participatory Research*. Poster presented at the Asian Pacific Islander Health Forum Health Summit, San Francisco, CA September 2006.
8. Valente, T. *Creating Community University Partnerships to Reduce Cancer Disparities Among Pacific Islanders*, Poster presented at the American Public Health Association 134th Annual Conference, Boston, MA, November 2006.
9. Sripipatana, A. *NHOPI Risk Behavior in California*. Poster presented at the American Public Health Association 134th Annual Conference, Boston, MA, November 2006.

#### **Presented in 2007**

10. Pang, J.K., Sablan-Santos, L., Lepule, T. and Foo, M.A. *Community-Based Participatory Research: The Weaving an Islander Network for Cancer Awareness, Research and Training (WINCART) Network*, Poster presented at the Asian Pacific American Community Research Roundtable conference, Los Angeles, CA, March 2007.
11. Bryant, K., Surani, Z., Mummert, A., and Rarick, J. *Evolution and Evaluation of the Cancer 101: A Cancer Education and Training Program*. Oral presentation session presented at Global Pacific health Conference, Honolulu, Hawaii. June 2007.

#### **Presented in 2008**

12. Sripipatana, A., Wong, M., Tran, J., Aromin, J., Fakasi`ieki, P., Lepule, J., Pang, J., Pang, V., Peters, R., and Tanjasiri, S.P. *Partnering in a Colorectal Cancer Awareness, Education and Screening Campaign for the Pacific Islander Community*. Poster presented at Cancer, Culture and Literacy: Methodologies and Best Practices for Addressing Cancer Health Disparities, Tampa, FL., May 2008.
13. Panapasa, S. *Pattern of Cancer Incidence among U.S. Pacific Islanders: Evidence from the Surveillance, Epidemiology, and End Results Database, 1990-2004*. NCI Cancer Health Disparities Summit: Eliminating Cancer Health Disparities through Science, Training and Community. Poster Presented at Bethesda MD, July 2008.
14. Panapasa, S. *Cancer Incidence among US Pacific Islander Patients: Evidence from 1990 to 2004*. Poster presented at the Asian American, Native Hawaiian & Pacific Islander Cancer Survivorship Conference: Dispelling Myths, Reducing Disparities & Providing Hope, San Francisco July 2008.
15. Sabado, M., Mata`ali`i, S., Hanneman, M., Howe, S., Lutu, O., Tupua M., Vaivao, D., & Tanjasiri, S.P. *Investigating Spiritual Aspects of Breast Cancer among Samoan Survivors and Supporters*. PHEHP Student Award Winning Poster presented at American Public Health Association, 136th Annual Meeting & Expo, San Diego, CA, October, 2008.
16. Sripipatana, S., & Tanjasiri, S.P. *Factors Promoting Breast and Cervical Cancer Screening Among California's Pacific Islander Women*, Poster presented at American Public Health Association 136th Annual Meeting & Expo, San Diego, CA., October, 2008.

17. Sora Park Tanjasiri, S. P., and Aitaoto, N. *Elements of Community Partnerships (Pacific Islanders)*. Small group discussions conducted at American Public Health Association 136th Annual Meeting & Expo, San Diego, CA., October, 2008
18. Sablan-Santos, L., Quitugua, L. F., Lepule, J., Maguadog, T., Perez, R., Young, S., Young, L. & Takahashi, L. M. *Protecting our Community by Talking our Stories: Culturally Appropriate HIV Capacity Building Among Pacific Islander Organizations in Southern California*. Poster presented session presented at American Public Health Association 136th Annual Meeting & Expo, San Diego, CA, October, 2008.
19. Tanjasiri, S. P. *Stimulating evidence-based community participatory research: Lessons learned from the WINCART experience in California*. Roundtable presentation at American Public Health Association 136th Annual Meeting & Expo, San Diego, CA., October, 2008.
20. Sripipatana, A., & Tanjasiri, S. P. *Correlates of Cancer Screening for Pacific Islanders in California*. Presented poster at American Public Health Association 136th Annual Meeting & Expo, San Diego, CA., October, 2008.
21. Sripipatana, S., Wong, M., Tran, J., Pang, J., Pang, K., & Tanjasiri, S.P. *Partnering in a colorectal cancer awareness, education and screening campaign for the Pacific Islander community*. Poster presented at American Public Health Association 136th Annual Meeting & Expo, San Diego, CA., October, 2008.
22. Panapasa, S., Williams, D. R., & Tanjasiri, S. P. *Projected Incidence of Cancer among Pacific Islanders Living in California*. Roundtable presentation presented at American Public Health Association 136th Annual Meeting & Expo, San Diego, CA., October, 2008
23. Tanjasiri, S. P., Mata'ali'i, S., & Sabado, M. *Exploring the Cancer Experience among Samoan Survivors and Supporters*. Roundtable presentation at American Public Health Association 136th Annual Meeting & Expo, San Diego, CA., October, 2008.
24. Sablan-Santos, L., Quitugua, L. F., Aromin, J., Guevara, J., Flores, J., Alcantara, A., Manglona R., & Henrich, F. *Chamorro Cancer Survivors Network: Linking Guam and California in Cancer Survivorship, Patient Navigation and Advocacy*. Poster presented at American Public Health Association 136th Annual Meeting & Expo, San Diego, CA., October, 2008.
25. Tanjasiri, S. P. *Challenges and Strategies to Oversampling Pacific Islanders for Health Surveillance*. Oral presentation at American Public Health Association 136th Annual Meeting & Expo, San Diego, CA. October, 2008.
26. Sripipatana, A., & Tanjasiri, S. P. *Factors Promoting Breast and Cervical Cancer Screening among California's Pacific Islander Women*, Poster presented at WINCART Network Meeting, San Diego, CA. October, 2008.
27. Panapasa, S., Williams, D. R., & Tanjasiri, S. P. *Projected Incidence of Cancer among Pacific Islanders Living in California*. Poster presented at WINCART Network Meeting, San Diego, CA. October, 2008.
28. Sripipatana, A., & Tanjasiri, S. P. *Factors Promoting Breast and Cervical Cancer Screening among California's Pacific Islander Women*, Poster presented at WINCART Network Meeting, San Diego, CA. October, 2008.
29. Moy, K. L., Tanjasiri, S. P., & Sallis, J. Poster presented *Creating the Pacific Islander Physical Activity Questionnaire (PIPAQ)*, at WINCART Network Meeting, San Diego, CA. October, 2008.
30. Panapasa, S. *Projected Incidence of Cancer Among Pacific Islanders Living in California*. Poster presented at the NIH Health Disparities Summit, December 2008.
31. Pang, J. K. *Navigating Toward Health and Well Being*. Poster presented at The California Endowment, Center for Healthy Communities, Los Angeles, CA. Dec, 2008.

**Presented in 2009**

32. Sripipatana, A., & Tanjasiri, S. P. *Factors Promoting Colorectal Cancer Screening among Pacific Islanders*. Poster presented at the American Association for Cancer Research (AACR) The Science of Cancer Health Disparities. Carefree, AZ., February 2009.

33. McEligot, A. J., McMullin, J., Pang, J. K., Bone, L., Tanjasiri, S. P., Winston, S., & Ngewa, N. R. *Assessing diet, body mass index and other characteristics in Native Hawaiians in Southern California*. Poster presented at American Association for Cancer Research (AACR) The Science of Cancer Health Disparities. Carefree, AZ., February 2009.
34. Sablan-Santos, L., Quitugua, L. F., Guevara, L., & Aromin, J. *Identifying Chamorro Cancer Survivorship Needs through the Development of a Community-Based Database*. Poster presented at American Association for Cancer Research (AACR) The Science of Cancer Health Disparities. Carefree, AZ., February 2009.
35. Moy, K. L., Tanjasiri, S. P., & Sallis, J. *Creating the Pacific Islander Physical Activity Questionnaire (PIPAQ)*. Poster presentation at He Huliau - A turning Point. Eliminating Health Disparities in Native and Pacific Peoples: Cardiometabolic Disease, Costa Mesa, CA., February 2009.
36. McEligot, A. J. *Diet, Attitudes and Beliefs/Beliefs Study*. Poster presented at He Huliau - A turning Point. Eliminating Health Disparities in Native and Pacific Peoples: Cardiometabolic Disease, Costa Mesa, CA., February 2009.
37. Sripipatana, A., & Peters, R. *Weaving an Islander Network for Cancer Knowledge Attitudes Behaviors and Beliefs*. Oral presentation at The Office of Minority Health's Third National Leadership Summit on Eliminating Racial and Ethnic Disparities in Health 2009, Washington DC. February 2009.
38. Foo, M. A. *Utilizing a Community Networks Program model to develop the capacity of community based organizations to address cancer disparities*. Poster presented at the NCI/CRCHD CNP Meeting, Rockville, MD, July 2009.
39. Sripipatana, A. *Correlates of Cancer Screening for Pacific Islanders in California*. Poster presented at the NCI/CRCHD CNP Meeting, Rockville, MD, July 2009.
40. Tanjasiri, S. *Culturally Tailored Colorectal Cancer Campaign*. Poster presented at the NCI/CRCHD CNP Meeting, Rockville, MD, July 2009.
41. Lutu, G., & Vaivao, D. *From Patient to Advocate: How the Chamorro Breast Cancer Survivors Alliance educates women*. Oral presentation at the 2009 California REACH US Conference, Long Beach CA, September 2009.
42. Tui One, V. *Tongan American Health Professional Association*. Oral presentation session at the 2009 California REACH US Conference, Long Beach CA, September 2009.
43. Pang, V and Briand, G. *Voices-Breaking the Silence*. Oral presentation at the 2009 California REACH US Conference, Long Beach CA, September 2009.
44. Aromin, J. *Understanding the Knowledge, Attitudes, Behaviors of PI Regarding Hep B*. Presented by Oral presentation at the 2009 California REACH US Conference, Long Beach CA, September 2009.
45. Sgambelluri, N, & Sablan-Santos, L. *Breast Cancer Associated with Lymphedem-Early Detection and Prevention in PI Women*. Oral presentation at the 2009 California REACH US Conference, Long Beach CA, September 2009.
46. Vaivao, D., & Lutu, G. Santos, L. *Samoan Breast Cancer Outreach, Education, and Screening*. Oral presentation session at the 2009 California REACH US Conference, Long Beach CA, September 2009.
47. Tisnado, D. & Sablan-Santos, L. *Evaluating CB Patient Navigation: Engagement between community and academic partners*. Oral presentation at the 2009 California REACH US Conference, Long Beach CA, September 2009.
48. Quitugua, L. F., Sablan Santos, L., & Gumataotao, A. P. *California Chamorro Breast Cancer Survivors Alliance: An Example of Empowerment, Capacity Building and Outcome*. Presented by Oral presentation at American Public Health Association 137th Annual Meeting & Expo, Philadelphia, PA. November 2009.
49. Valente, T. W., Palmer, P. H., & Tanjasiri, S. P. *A Network Assessment of Community-based Participatory Action: Linking Communities and Academies to Reduce Cancer Disparities*. Oral presentation session presented at American Public Health Association 137th Annual Meeting & Expo, Philadelphia, PA. November 2009.

## Presented in 2010

50. Tanjasiri, S. P., Gonzalez, M., Peters, R., Nacpil, L., Harris, N., Harness, J. *A Health Disparities and Clinical Trials Disparity Partnership to Reduce Colorectal Cancer among Pacific Islanders in Southern California*. Poster presented at the 3<sup>rd</sup> annual Disparities Summit of the American Association of Cancer Researchers, Miami, October 2, 2010.
51. Kelley, T., Moy, K., Sablan-Santos, L., Lepule, T., *Exploring Strategies for a Culturally-Specific Physical Activity Intervention for Native Hawaiian and Pacific Islanders*, Poster presented at He Huliau, Waikiki, Hawaii, May 7-8, 2010.
52. Moy, K., Sallis, J., Trinidad, D., McEligot, A., *Health Behaviors of Native Hawaiians and Pacific Islanders: Finding from the 2005 California Health Interview Survey*, Poster presented at He Huliau, Waikiki, Hawaii, May 7-8, 2010.
53. Moy, K., Sallis, J., Ice, C., Kelley, T., Lepule, T., *Physical Activities Correlates for Native Hawaiians and Pacific Islanders in Mainland United States*, Poster presented at He Huliau, Waikiki, Hawaii, May 7-8, 2010.
54. DiStefano, A. S., Hui, B., Vunileva, I., Tui'one, V., Takahashi, L., Santos, L., Flores Quitugua, L., Quenga, J., Peters, Ruth, Dimaculangan, J., Barrera-Ng, A., Aromin, J. , Tanjasiri, S. P., *Factors influencing HIV and HPV Risk and Prevention among Tongan and Chamorro Young Adults in Southern California*, Poster Presented at APHA, November 8, 2010.
55. Khushbindar L., Peters, R., Aromin, J., Fakasi'ieki, P., Lepule, J., Pang, K., Pang, K., Sripipatana, A. and Tanjasiri, S. P., *Tools for Addressing Cancer Disparities: A Culturally Appropriate Colorectal Cancer Awareness, Prevention and Screening Educational Toolkit for Pacific Islander Communities*, Poster Presented at APHA, November 8, 2010.
56. DiStefano, A. S., Quitugua, L. F., Aromin J., Barrera-Ng, A., Dimaculangan, J. Hui, B., Peters, R., Quenga, J., Santos, L., Takahashi, L., Tui'one, V., Vunileva, I., and Tanjasiri, S.P., *Enhancing Social Justice in Research: Building an Effective CBPR Collaboration between Two Pacific Islander Community Partners and a University Research Team*, Poster Presented at APHA, November 8, 2010



## **Policy Meetings/Convening**

### **Year 1-3**

- 1 August 23, 2006: Meeting with AANCART in Oakland, California. to discuss the potential directions of their policy agenda. One of the outcomes to this meeting is the development of a Policy 101 Brief (currently being developed in collaboration with Koy Parada of AANCART to be provided to AANCART members).
- 2 September 15, 2006: Asian and Pacific Islander Health Forum policy convening in San Jose, California. A presentation on WINCART and its policy agenda over-sampling. Also met with other Pacific Islander attendees who were interested in strategizing a statewide campaign for collecting and presenting data on California's Pacific Islander populations. The result of the momentum started at this event is a two-day conference to be held in Carson, Calif on April 23 and 24, co-sponsored by the Asian and Pacific Islander Health Forum and the Office of Minority Health.
- 3 April 24 and 25, 2007: Carson Community Town Hall, Carson, California. A meeting among Pacific Islander community organizations and representatives from federal agencies, including Dr. Garth Graham, to discuss a Pacific Islander Health agenda. One of the outcomes to this meeting is to include Pacific Islanders in funding opportunities and agenda-building on health disparities issues.
- 4 October 10 and 11, 2007: Native Hawaiian and Pacific Islander Alliance. A continuation of the meeting initiated in Carson to dialogue with federal agency representatives about a Pacific Islander health agenda

### **Year 4-5**

- 5 May 2008: APISCAN, Sacramento, California.
- 6 May 2009: APISCAN, Sacramento, California.
- 7 May 2010: APISCAN, Sacramento, California.



## WINCART Center: Next Steps 2010-2015

Efforts to reduce cancer health disparities among Pacific Islanders (PIs) in the U.S. are significantly hampered by the lack of disaggregated epidemiological, behavioral, genetic and clinical data, as well as a dearth of community-based best practice education and intervention programs. In order to address these challenges, we build upon the successes of the first Community Network Program (CNP) *WINCART: Weaving an Islander Network for Cancer Awareness, Research and Training* (U01CA114591/WINCART1). This new WINCART Center (U54 CA153458) is based upon WINCART1 needs assessments, community outreach education and junior investigator training activities, with the long-term goal of reducing PI cancer health disparities in Southern California. Through community-based participatory research (CBPR) principles and processes, the WINCART Center builds collaborations between communities and academic institutions to promote research, training, implementation and evaluation of education related to beneficial biomedical and behavioral procedures and translation of all activities into lasting community benefits.

The overarching CBPR principles and processes of the WINCART Center derive from those established in WINCART1, and include: (1) shared participation by both community and academic researchers in the planning, development, implementation and evaluation of community education, research and training activities; (2) co-learning between all academic and community partners via joint activities in the Center's core, programs, and projects; (3) collaboration mechanisms through the Center Steering Committee and Community Advisory Groups that ensure fidelity to CBPR tenets among center partners and trainees; and (4) promotion of lasting community benefits across multiple levels of factors associated with PI cancer health disparities. The WINCART Center also incorporates the multilevel population health approach to address health disparities, and employs new technologies (including distance learning, electronic surveys and intervention systems) to capitalize upon existing center network ties and catalyze new CBPR collaborative among community and academic partners. The overarching **specific aims** of the WINCART Center are to:

1. Design and conduct CBPR cancer health disparities pilot (regarding bio-specimen knowledge, attitudes and beliefs) and intervention research (smoking cessation) for Pacific Islanders in Southern California;
2. Develop, evaluate and disseminate best practices for addressing multilevel PI cancer health disparities and co-morbid conditions through community-based health promotion and education activities;
3. Develop, support and train PI and other postdoctoral and early stage investigators in CBPR; and
4. Integrate center cores, programs and projects to stimulate and synergize new opportunities for collaborative multilevel cancer health disparities and co-morbid conditions research with communities and academic institutions within the WNCART Center's three geographic regional areas of Los Angeles, Orange and San Diego counties in Southern California.



**Special Acknowledgments**

**Kia Manuia – Si Yu'us ma'ase – Komol tata – Mahalo – Fa'afetai – Malo 'aupito**

**“It takes a village” WINCART owes its success to the individuals and groups that contributed to the endeavors of this program.**

**Community Advisory Board:**

- Ainahau O’ Kaleponi
- CA Chamorro Breast Cancer Survivor’s Alliance
- Guam Communications Network
- Los Angeles Partnered for Progress
- NCI Cancer Information Service
- Orange County Asian and Pacific Islander Community Alliance
- Orange County Health Care Agency – Cancer Detection Partnership
- Pacific Islander Health Partnership
- Samoan National Nurses Association
- Sons and Daughters of Guam Club
- Tongan Community Service Center/ SSG
- Union of Pan Asian Communities

**Scientific Advisory Board:**

- Dr. Leslie Bernstein
- Dr. E. Richard Brown
- Dr. Myles Cockburn
- Dr. Wendy Cozen
- Dr. Dennis Deapen
- Dr. Michael Goran
- C. Anderson Johnson
- Dr. Marjorie Kagawa-Singer
- Dr. Archana McEligot
- Dr. Juliet McMullin
- Dr. Malcolm Pike
- Dr. Kim Reynolds
- Dr. Jean Richardson
- Ms. Susan Shinagawa
- Dr. Thomas Valente (Evaluator)

**Steering Committee:**

- Dr. Sora Park Tanjasiri, Principal Investigator
- Ruth Peters, Program Manager
- Dr. Paula Healani Palmer, Co-Principal Investigator
- Mary Anne Foo, Community Co-Principal Investigator
- Tana Lepule, Community Representative
- Vanessa Tuione, Community Representative
- Dr. Keola Beale, Clinical Representative
- Dr. Alek Sripipatana, Policy Coordinator
- Dr. Mayte Canto, NCI Center to Reduce Cancer Health Disparities