



Asian & Pacific Islander National Cancer Survivors Network

Summary Report of  
The Asian American, Native Hawaiian &  
Pacific Islander Cancer Survivorship Conference:  
*Dispelling Myths, Reducing Disparities & Providing Hope*  
July 22 – 24, 2008 • Sheraton Gateway Hotel – San Francisco International Airport



*The famous Susan M. Shinagawa photo of the audience during the conference opening reception*

# Asian & Pacific Islander National Cancer Survivors Network

**A**sian & Pacific Islander National Cancer Survivors Network (APINCSN) was co-founded in 1998 by Susan M. Shinagawa and the late Reverend Frank A. Chong and is a network of cancer survivors, their family members, health care providers, researchers, and community members and organizations who are concerned about the issue of cancer and survivorship in the Asian American, Native Hawaiian and Pacific Islander (AA & NHPI) communities. APINCSN is striving to break the isolation that many cancer survivors feel when they are first diagnosed and going through treatment. We are a national advocacy coalition, working with others to educate and advocate on the issue of cancer through speaking events, online networking, coordinating AA & NHPI survivorship resources and promoting cancer survivors into national policymaking and research committees.



Asian & Pacific Islander National Cancer Survivors Network

The mission of the Asian & Pacific Islander National Cancer Survivors Network is to minimize the burden of cancer and improve the quality of life of Asians and Pacific Islanders by dispelling myths, reducing disparities and providing hope. The Network's vision is to have empowered, cancer-free Asian and Pacific Islander communities. ↪

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## Asian & Pacific Islander American Health Forum

**T**he Asian & Pacific Islander American Health Forum (APIAHF) is a national advocacy organization dedicated to promoting policy, program, and research efforts to improve the health and well-being of Asian American, Native Hawaiian, and Pacific Islander (AA & NHPI) communities. Founded in 1986, APIAHF approaches activities with the philosophy of coalition-building and developing capacity within local AA & NHPI communities. APIAHF advocates on health issues of significance to AA & NHPI communities, conduct community-based technical assistance and training, provide health and U.S. Census data analysis and information dissemination, and convene regional and national conferences on AA & NHPI health.



The mission of Asian & Pacific Islander American Health Forum (APIAHF) is to enable Asian Americans, Native Hawaiians and Pacific Islanders to attain the highest possible level of health and well-being. It envisions a multicultural society where Asian American, Native Hawaiian and Pacific Islander communities are included and represented in health, political, social and economic areas, and where there is social justice for all. ↪

## DAY 1 — TUESDAY, JULY 22, 2008

7:30 am – 5:00 pm CONFERENCE REGISTRATION

8:30 am – 11:30 am PRE-CONFERENCE CONCURRENT  
CAPACITY BUILDING TRAINING WORKSHOPS

**Grant Writing for Asian American, Native Hawaiian and Pacific Islander Community-Based Organizations**

Jonathan “Tana” Lepule, Pacific Islander Festival Association (PIFA); Union of Pan Asian Communities (UPAC)

Amy Wong, MPH, CHES, Kaiser Permanente

Karen Heckert, PhD, MPH, MSW, Pacific Center of Excellence to Eliminate Disparities (CEED), University of Hawai‘i

**From Cancer Survivor to Cancer Advocate: Policy & Legislative Advocacy**

Mona Bormet, MPH, CHES, Asian & Pacific Islander American Health Forum (APIAHF)

Wendy Ho, MPA, Asian & Pacific Islander American Health Forum (APIAHF)

**Media Spokesperson**

Bill Imada, IW Group, Inc.

Tina Vanichsan, IW Group, Inc.

Craig Tomiyoshi, IW Group, Inc.

**Tools & Strategies for Developing & Sustaining Asian American and Pacific Islander Cancer Support Groups**

Lei-Chun Fung, MPH, MSW, San Francisco Chinatown Public Health Center (CPHC)

Lourdes Quitugua, Guam Communications Network (GCN)

Chaiwon Kim, RN, Center for Pan Asian Community Services (CPACS)

Lora Taylor Falealili, American Samoan Cancer Survivors Group, Samoan breast cancer survivor

**Cancer Clinical Trials for Asian American, Native Hawaiian and Pacific Islander Communities**

Rachel Mesia, MPH, California Region, National Cancer Institute's Cancer Information Service

Kimlin Tam Ashing-Giwa, PhD, City of Hope's Center for Community Alliance for Research & Education

Natasha Blakeney, MPH, and Soon Han, MD, Education Network to Advance Cancer Clinical Trials (ENACCT)

Margaret Stauffer, MFT, The Wellness Community

11:30 am –12:00 noon LUNCH

12:00 noon – 3:00 pm SET UP EXHIBITS

2:00 noon – 3:00 pm PRE-CONFERENCE CONCURRENT  
CAPACITY BUILDING TRAINING WORKSHOPS  
REPEATED EXCEPT FOR CANCER CLINICAL TRIALS

3:00 pm – 4:00 pm BREAK

4:00 pm – 4:30 pm OPENING CEREMONY

4:30 pm – 5:00 pm WELCOME AND OPENING SPEAKERS

Invocation: Rev. Ken Yamada, Berkeley Higashi Honganji Buddhist Temple

Welcome on Behalf of Asian & Pacific Islander American Health Forum (APIAHF):

Ho L. Tran, MD, MPH, President & CEO, APIAHF

Welcome on Behalf of Asian & Pacific Islander National Cancer Survivors Network (APINCSN):

*“Who we are, where we were, where we are and where we're headed”*

Susan M. Shinagawa, Co-Founder and Co-Chair, APINCSN; Past Chair, Intercultural Cancer Council;

Japanese American breast cancer survivor

5:00 pm – 5:30 pm HONORING REVEREND FRANK CHONG, APINCSN CO-FOUNDER / CO-CHAIR

Presenters: Susan M. Shinagawa, Ho L. Tran, MD, MPH, and Janice Louie

Announcement of establishment of the Frank Chong Cancer Survivorship Award and presentation of award, posthumously, to be accepted by Frank's friend and colleague, Reginald C.S. Ho, MD.

5:30 pm – 6:00 pm KEYNOTE SPEAKER: Jackie Young, PhD, "Help is on the way..."

Introduction: Susan M. Shinagawa

Keynote Speaker: Jackie Young, PhD

Chief Staff Officer for Mission, American Cancer Society Hawai'i Pacific, Inc.; APINCSN Inaugural Steering Committee Member; Korean breast cancer survivor

6:00 pm – 8:00 pm OPENING RECEPTION with multicultural entertainment and food stations

8:00 pm ADJOURNMENT OF DAY 1

## DAY 2 — WEDNESDAY, JULY 23, 2008

8:00 am – 8:50 am CONTINENTAL BREAKFAST — Sponsored by Susan G. Komen for the Cure, San Francisco Bay Area Affiliate

9:00 am – 11:30 am OPENING PLENARY SESSION

Cancer Survivorship through the Eyes of Survivors & Providers

*Moderator:*

Fidelia Butt, MD, Kaiser Permanente, Chinese breast cancer survivor

*Cancer Survivors:*

Jose Batto, American Cancer Society volunteer, Filipino liver cancer survivor

Lucianne Latu, Taulama For Tongans, Tongan pediatric bone cancer survivor

Jina Peiris, Saath, South Asian Cancer Foundation; APINCSN Inaugural Steering Committee Member, Sri Lankan breast cancer survivor

Suzanne Robert, Guam Communications Network, Chamorro breast cancer survivor

Bermin F. Weilbacher, Pohnpeian prostate cancer survivor from the Federated States of Micronesia

*Healthcare Providers:*

Giang T. Nguyen, MD, MPH, MSCE, University of Pennsylvania School of Medicine

Nitin K. Shah, MD, University of California, Irvine Medical Center

Victor T. Tofaeono, MD, FACS, Lyndon B. Johnson Tropical Medical Center, American Samoa

Evaon Wong-Kim, PhD, MPH, MSW, California State University, East Bay

12:00 noon – 12:30 pm LUNCH — Sponsored by the American Cancer Society, California Division

12:30 pm – 2:00 pm LUNCHEON PLENARY SESSION

Patient Navigation

*Moderator:*

Rachel Mesia, MPH, California Region, National Cancer Institute's Cancer Information Service

Tu-Uyen N. Nguyen, PhD, MPH, California State University, Fullerton

Zul Surani, Southern California, National Cancer Institute's Cancer Information Service; Saath, South Asian Cancer Foundation

JoAnn Umilani Tsark, MPH, 'Imi Hale Native Hawaiian Cancer Network, Papa Ola Lokahi

Karen Kanehailua Teshima, 'Imi Hale Native Hawaiian Cancer Network, Papa Ola Lokahi, Hawaiian primitive neuroectodermal (Ewing's) cancer survivor

2:00 pm – 2:15 pm BREAK

2:15 pm – 4:00 pm                    PLENARY SESSION

**Unique Health Challenges & Issues in Selected Asian American Communities**

*Moderator:*

Susan M. Shinagawa, Co-Founder & Co-Chair, APINCSN

Zul Surani, California Region, National Cancer Institute's Cancer Information Service;  
Saath, South Asian Cancer Foundation

Lady Fabian, Seton Medical Center, Sinag Tala, Filipino breast cancer survivor

Debra Oto-Kent, MPH, Health Education Council, Japanese breast cancer survivor

Dao M. Fang, MSW, Hmong Women's Heritage Foundation

4:00 pm – 4:15 pm                    BREAK

4:15 pm – 6:00 pm                    CONCURRENT BREAKOUT SESSIONS

**Navigating through Cancer Information**

*Moderator:*

Rachel Mesia, MPH, California Region, National Cancer Institute's Cancer Information Service

Reginald C.S. Ho, MD, Asian and Pacific Islander Cancer Education Materials (APICEM),  
American Cancer Society (ACS)

Karen Kanehailua Teshima, 'Imi Hale Native Hawaiian Cancer Network, Papa Ola Lokahi, Hawaiian primitive  
neuroectodermal (Ewing's) cancer survivor

Joyce Chen, MS, Chinese Community Health Resource Center, Chinese Hospital

**Impact of Cancer on Asian American, Native Hawaiian & Pacific Islander Families and Caregivers**

*Moderator:*

MaiNhung Le, DrPH, MPH, San Francisco State University

Sala Mataalii, RN, MA, MBA/HCM, parent of cancer patient/survivor

MaiNhung Le, DrPH, MPH, sibling of cancer patient/survivor

Richard Robert, spouse of cancer patient/survivor

Nitin K. Shah, MD, spouse and son of cancer patients/survivors

**Palliative Cancer Care and Dignity & Quality at the End-of-Life**

*Moderator:*

Roxanna Bautista, MPH, CHES, APIAHF

Jeannette Kojjane, MPH, Pacific Region, National Cancer Institute's Cancer Information Service; Kokua Mau

Sandy Stokes, RN, MSN, Chinese American Coalition for Compassionate Care

Donna Kalauokalani, MD, MPH, University of California, Davis

6:00 pm – 6:30 pm                    DINNER

6:30 pm – 8:00 pm                    DINNER PLENARY SESSION

**Alternative/Complementary/Integrative Therapies**

*Moderator:*

Lee Buenconsejo-Lum, MD, Pacific Center of Excellence to Eliminate Disparities (CEED), University of Hawai'i

*Speakers:*

Jenny Do, JD, artist, breast cancer survivor

Beverly Burns, MS, LAc, Charlotte Maxwell Clinic and University of California, San Francisco Osher Center for  
Integrative Medicine

Kedar N. Prasad, PhD, Premier Micronutrient Corporation

Sala Mataalii, RN, MA, MBA/HMC, Samoan National Nurses Association

8:00 pm                                    ADJOURNMENT OF DAY 2

## DAY 3 — THURSDAY, JULY 24, 2008

8:00 am – 8:50 am CONTINENTAL BREAKFAST

9:00– 11:30 am BREAKFAST PLENARY SESSION

### Unique Health Challenges & Issues in Selected Native Hawaiian and Pacific Islander Communities

*Moderator:*

Jane Ka'ala Pang, RN, BSN, Pacific Islander Health Partnership (PIHP)

Camilla Ingram, Marshallese colon cancer survivor from the Republic of Marshall Islands: personal cancer story  
Victor Kaiwi Pang, Native Hawaiian Non-Hodgkins Lymphoma cancer survivor from U.S. mainland: personal cancer story

Sela Panapasa, PhD, University of Michigan, Ann Arbor: "perspective of Pacific Islanders on the U.S. mainland"

Neal A. Palafox, MD, MPH, Pacific Center of Excellence to Eliminate Disparities (CEED), and University of Hawai'i: "perspective of Pacific Islanders in the USAPI Nation"

Cynthia K. Kenui, PsyD, Native Hawaiian breast cancer survivor from Hawai'i: personal cancer story

12:00 noon –12:30 pm LUNCH

12:30 pm – 3:00 pm LUNCH PLENARY SESSION

### Increasing the Voices of Asian Americans, Native Hawaiians and Pacific Islanders through Community-Based Participatory Research (CBPR) and Community-Based Participatory Programs (CBPP)

*Moderator:*

Kimlin Tam Ashing-Giwa, PhD, City of Hope's Center for Community Alliance for Research & Education (CCARE)

MaiNhung Le, DrPH, MPH, San Francisco State University

Grace J. Yoo, PhD, MPH, San Francisco State University

Margie Kagawa-Singer, PhD, MN, RN, University of California, Los Angeles; Asian American Network for Cancer Awareness, Research and Training (AANCART)

Lucy Young, Herald Cancer Association / City of Hope CCARE

Giang T. Nguyen, MD, MPH, MSCE, University of Pennsylvania Asian Health Initiatives

Kao Kue, Southeast Asian Mutual Assistance Associations Coalition (SEAMAAC)

Sora Park Tanjasiri, DrPH, MPH, Weaving an Islander Network for Cancer Awareness, Research and Training (WINCART), California State University, Fullerton

Jonathan "Tana" Lepule, Pacific Islander Festival Association (PIFA); Union of Pan Asian Communities (UPAC)

Lee Buenconsejo-Lum, MD, Pacific CEED, University of Hawai'i

Xner Luther, Pohnpei Comprehensive Cancer Control Coalition

3:00 pm – 3:30 pm CLOSING REMARKS: Susan M. Shinagawa

Performance of "My Heroes" and Tribute Slideshow

3:30 pm CONFERENCE ADJOURNMENT

# Summary Report of The Asian American, Native Hawaiian & Pacific Islander Cancer Survivorship Conference: *Dispelling Myths, Reducing Disparities & Providing Hope*

The Asian & Pacific Islander American Health Forum's (APIAHF's) and the Asian & Pacific Islander National Cancer Survivors' Network's (APINCSN's) Asian American, Native Hawaiian & Pacific Islander Cancer Survivorship Conference: Dispelling Myths, Reducing Disparities & Providing Hope was convened July 22 to July 24, 2008 at the Sheraton Gateway Hotel- San Francisco International Airport. The constituency that was served by this conference consisted of:

- Asian American, Native Hawaiian and Pacific Islander (AA & NHPI) cancer survivors, family members, and caregivers;
- AA & NHPI cancer care professionals and service providers, and representatives of community-based organizations primarily serving AA & NHPI communities;
- AA & NHPI researchers or health service agency representatives with established community-based participatory/collaborative relationships with AA & NHPI communities;
- Representatives of community-based organizations, governmental or nongovernmental service agencies, health professionals, service providers, researchers, public health educators and students who have existing community-collaborative relationships with AA & NHPI communities.

Approximately 225 participants attended this conference. There were 62 cancer survivors and 120 who had a family member that had cancer. The conference attendees came from these states: California, Hawai'i, Georgia, Illinois, Iowa, Maryland, Michigan, Minnesota, New York, Ohio, Pennsylvania, Tennessee, Texas, Washington, and Washington D.C. There were conference attendees who traveled from all the U.S. Pacific Island Jurisdictions: American Samoa, Guam, Palau, Yap, Chuuk, Marshall Islands, Pohnpei, Kosrae, Federated States of Micronesia, and the Commonwealth of Northern Marianas Islands. This 2½ day conference was full of exciting sessions and stimulating speakers, who provided the knowledge, skills and resources necessary to empower cancer survivors, families and advocates to address cancer care and cancer survivorship issues in our communities. 🌸

## CONFERENCE GOALS & OBJECTIVES:

The goal of this conference was to provide AA & NHPI organizations and survivors with knowledge, skills and resources necessary to empower them to address cancer survivorship issues in their communities.

The conference objectives were as follows:

1. To increase AA & NHPI cancer awareness and knowledge and encourage their proactive participation in maintaining good health and, when necessary, advocating for timely and quality cancer care;
2. To increase community awareness of organizations that provide respectful, language appropriate and/or culturally tailored cancer and cancer survivorship resources and services for AAs & NHPIs in the U.S. and the Pacific;
3. To increase AAs & NHPIs knowledge, confidence, and competency in navigating through the health care systems in the U.S. and across the Pacific;
4. To demonstrate how to be an effective advocate for optimal health resources and policies for the AA & NHPI communities in the U.S. and the Pacific;
5. To increase AAs & NHPIs knowledge about alternative and complementary medicine and practices available for cancer patients and the importance of an integrative approach for optimal recovery and survivorship;
6. To provide a forum for AA & NHPI cancer survivorship and provider communities to learn about cancer challenges, issues, and concerns that are unique to a specific AA, NH or PI community or geographic region, shared among multiple communities or regions, or common across all communities and regions;
7. To provide an open forum for cancer clinicians, researchers, survivors, advocates, and general AA & NHPI communities to discuss critical areas of community-based participatory cancer services and/or research programs;
8. To obtain and learn how to access culturally and linguistically appropriate and relevant cancer educational materials developed by and for various AA & NHPI communities; and
9. To facilitate, establish and support ongoing networking opportunities within and between AA & NHPI cancer survivorship, provider, services, and research communities. 🌸

## WORKSHOPS

During the first day of the conference, July 22, 2008, there were concurrent capacity building workshops taking place. In the morning session, there were five capacity building workshops in the topic areas of cancer clinical trials, grant writing, policy advocacy, media spokesperson, and cancer support groups.

### Grant Writing for Asian American, Native Hawaiian & Pacific Islander Community-Based Organizations

This workshop offered community-based organizations, community members, and health advocates the opportunity to learn how to: understand basic grant writing skills and apply it to grants related to cancer and cancer survivorship; draft clear goals and objectives; conduct basic program planning and development; develop evaluation plans; and apply for grant opportunities. The facilitators discussed the program development process associated with proposal writing. Before writing a grant application, there are steps you need to take to prepare. The first step is to conduct a needs assessment of gathering data and information (statistics, interviews, focus groups, surveys, etc.) related to the issue and target community you would like to address through the proposed project. The second step is to develop a needs statement that describes the rationale behind the proposal. The third step is program development and thinking through of what are the main goals, objectives, and activities you want to address in the proposed project. The facilitators described several methods to help with program development, which were a Gameplan (visual tool) and a workplan (table tool). By charting out the roadmap of the project objectives and activities, you can demonstrate your organization's capability of carrying a project from beginning to end. Most grant applications require not only a narrative description of the project and how you plan to accomplish it, but also a workplan. The fourth step is to develop an evaluation plan for the project which will measure the impact of the program activities and show outcomes. The last step is to develop a budget and justification that correlates to the project objectives and activities. Workshop participants were divided into small groups to draft their own Gameplans

or workplans and ideas for projects. After the groups shared their examples, the facilitators shared grant writing and funding opportunity resources with the participants. Karen Heckert from the University of Hawai'i shared the Pacific Center of Excellence in the Elimination of Disparities (CEED) Legacy Grant opportunities with the workshop participants. These Legacy Grants provide "seed" money to communities to initiate/further develop capacity to address health disparities.

There were 50 attendees in total of the two grant writing workshops, but we received 45 completed workshop evaluations. 96% strongly agreed that the information presented by the facilitators, Amy Wong and Jonathan "Tana" Lepule, was presented in a clear and easy to understand format. 78% strongly agreed that the workshop was relevant in addressing the health needs of their community. 87% strongly agreed that the workshop increased their knowledge of program planning and workplan development. 87% strongly agreed that the workshop increased their ability to develop a health related project for their community. 80% said they were very likely to use the information from the workshop in an activity within the next six months. 87% said that their expectations were met for this workshop. As an outcome of this workshop, one of the attendees was very interested in the University of Hawai'i Legacy Grant presentation. She stayed up late that same evening to complete and submit the grant proposal for that Legacy Grant opportunity the day after the workshop. Many of the workshop participants wanted to be informed of potential funding opportunities and APIAHF will make sure to communicate those opportunities to them.

### From Cancer Survivor to Cancer Advocate: Policy & Legislative Advocacy

During this workshop, participants learned about the legislative process, how to talk to legislators and policy makers, and how to affect change at the local, state, and national levels. There was a good discussion at both workshops about the importance of policy advocacy in our communities. The workshop participants from the Pacific Island nations that did not have voting power within the U.S. government could utilize their advocacy

skills within their own local leaders and officials on their islands. The facilitators shared that legislation is something to be



interested in because there can be laws that mandate insurance coverage for preventive services (e.g. colon cancer screening) or ensure broad-based consistent application of health policy (e.g. ban smoking indoors, universal health coverage). The keys to success in advocacy involve balancing "who you know" with "what

## Advocacy Strategies! As an Advocate you:

- Speak or write in support of a cause
- Plead for or on behalf of another person or group (e.g. elders)
- Talk to your elected officials and candidates running for political office
- Attend and speak up at town hall meetings
- Visit, call or write to your legislators
- Participate in events at the state or national capitol or host your own Day at the Capitol

you know” and how to make it happen. Workshop attendees were asked if they knew who their congressional/senate and other governmental representatives were. It is important to not only know who your representatives are, but also who are other major officials you can influence. The legislative process of how a bill becomes a law, the legislative timetable, and how to find legislative resources on the internet were shared. Within the policy advocacy training binder provided, there were examples of policy advocacy tools such as letters to legislators, testimonies, newsletters, fact sheets, and op-eds. Tips and strategies of being an effective advocate were shared and participants were able to practice in small groups “mock” legislative visits. People reviewed the do’s and don’ts, decided who they were visiting (state or federal representative/senator or health official), developed their personal message and policy message; and then practiced in the small and larger group. Feedback was provided by the facilitators and small group members about how the visit turned out. The workshops

### Media Spokesperson

During this workshop, the facilitators from IW Group, Inc. provided tools on how to get your message out and how to work and build relationships with the media. Participants learned about media advocacy and how it can be an effective tool to reach our communities. The workshop started with how media relations help information reach target audiences. A decade ago, there were 200 outlets to reach the Asian population and today there are over 600 outlets. With today’s technology, 52% of Internet users get their news online. Tips and strategies were shared on how to develop good media relationships and how to work with the media. Then there was a discussion about identifying your audience and how best to communicate with them. The facilitators then shared four general rules to message development. Small groups then worked to develop three to four key messages and practiced delivering those messages within those small groups. Interview tips were shared with the workshop participants and several were able to practice the skills they learned with on-camera interviews.

ended with each participant sharing what will be his/her next action step when they return home.

Fifty-three conference participants attended the policy advocacy workshops, and all workshop attendees completed evaluations, representing a 100% response rate. Nine in ten participants (91%) strongly agreed or agreed that the workshop facilitators, Mona Bormet and Wendy Ho, helped them understand policy and legislative advocacy. Roughly two-thirds (64%) of participants reported that they had sufficient knowledge of advocacy to begin an advocacy activity within six months of the conference. Participants also noted that they found the workshop helpful and the practice interaction group exercise prepared them for communicating with legislators. Following the training, a few participants expressed interest in having the APIAHF Washington D.C. Policy Analyst facilitate policy advocacy trainings for their communities in American Samoa and in the Midwest. At the request of the American Samoa Cancer Control Coalition, APIAHF Policy Analyst, Mona Bormet, conducted three policy advocacy trainings to audiences of high school students, university students, and general community in American Samoa from October 14-15, 2008. The trainings were well received. There have been discussions among the Comprehensive Cancer Control Programs in the Pacific, University of Hawai’i, and the Centers for Disease Control and Prevention (CDC) about providing similar policy advocacy trainings conducted at this conference and in American Samoa to the other islands. In the Fall 2009, there will be a Policy and Practice Summit for Pacific Island Jurisdictions spearheaded by the CDC, American Cancer Society, National Cancer Institutes Cancer Information Service, and C-Change. It has been suggested that APIAHF be invited to this Summit and provide some assistance to the Summit planning committee due to the capacity building assistance APIAHF has provided to the Pacific Islander CCC Programs.

A total of 55 conference participants attended the media spokesperson workshops, and 29 completed workshop evaluations, which represent at 53% response rate. One-hundred percent of respondents reported that the concepts and techniques they learned were clear and simple to understand, and 100% reported that the presenters kept them interested in the workshop discussion. One-hundred percent of respondents noted that they are able to apply what they learned from the media spokesperson session to their work in cancer and cancer survivorship. Although the workshop focused on cancer and cancer survivorship, participants felt that in general, the workshop was useful for many areas. The workshop provided participants with the skills to develop an effective message and interact with reporters and media in front of a camera. One organization mentioned that the workshop gave them new ideas for how to promote their work and the resources that they have available for their community.

## Tools & Strategies for Developing and Sustaining Asian American & Pacific Islander Cancer Support Groups

During this workshop, Asian American & Pacific Islander cancer support group facilitators shared how they addressed cancer survivorship in the communities they serve and how they have sustained their support groups. Lei-Chun Fung has facilitated the Chinese women's cancer support group in San Francisco for 14 years now. A variety of Eastern and Western techniques were utilized to assist women in their healing and recovery. In 1999, the Lei-Chun organized a support group called "Dr. Play" Children's Support Group for children ages 4-14. This group was started as a response to the need for child care to the young children of the women participating in the support group. The mothers expressed difficulties in sharing their experience of cancer with their children. Both these support groups have been successful in providing the much needed psychosocial and educational needs of the women and children. Lei-Chun has been able to sustain the support groups because of affiliation with a public health clinic in the Chinese community and her success in securing grants to fund the groups.

Lourdes Quitugua of Guam Communications Network (GCN) discussed the various Chamorro cancer support groups in California that have been conducted over the past six years. More recently with funding from APIAHF's Cancer Support Groups Mentorship Program, GCN has newly developed Chamorro cancer support groups in Guam.



**Conducting Culturally Tailored & Specific Support Groups**

- Recognize importance of grassroots & community based outreach
- Be patient, open-minded, flexible, creative & persistent
- Include cultural aspects such as providing food & involving family
- Format should depend on needs of survivors
- Partner with other AA & NHPI CBOs and mainstream CBOs to aid in sustainability

Initially it was difficult to start support groups in Guam. It was important that GCN provide support group facilitation training to the potential support group facilitators on the island. GCN was able to reach 40 Chamorro cancer survivors and held 29 cancer support group meetings. In addition, GCN created and shared 100 cancer survivors' resource guides for Guam cancer survivors. GCN leveraged local resources to start the support groups and conduct educational forums around breast cancer.



Quote from one of the workshop attendees:

*"It was good to hear about the different cancer support groups from different communities. I think it would have been great to share this with the general audience, especially those who don't understand the importance of support groups."*

Lora Taylor Falealili from the American Samoa Cancer Survivors Support Group discussed the obstacles to developing and maintaining support groups. The development of the now two-year old support group was inspired by the American Samoan Community Cancer Coalition, a group that is dedicated to addressing the various needs of cancer patients and survivors on American Samoa. The mission of the support group is to help the people of American Samoa fight cancer. Ms. Falealii discussed some of the challenges faced by the group which included the need for education and screening, cultural barriers, beliefs and attitudes about cancer, cost of care, and attendance to meetings. To help to address these challenges, the cancer support group continues to partner and collaborate and works to recruit cancer survivors to participate.

Chaiwon Kim from the Center of

Pan Asian Communities Services (CPACS) in Georgia shared how her organization had started a cancer support group seven years ago, but it only lasted one year. With funding from APIAHF's Cancer Support Groups Mentorship Program, CPACS has a newly developed Korean cancer support group that is approximately 17 months old. There are approximately ten cancer survivors and patients that attend the support group regularly. To promote their program, they placed ads in Korean newspapers. CPACS also conducted a cancer prevention and treatment forum for the Korean community. Guest speakers included two oncologists and a natural healer to talk about the importance of cancer prevention and detection, and services available to those diagnosed with cancer. Ms. Kim also shared CPACS' 10-minute DVD promoting the Korean cancer support group. Her organization was able to secure additional funding to address cancer survivors and cancer disparities. Her message was to not give up and be persistent in going after resources to help create programs to address your community's needs.

Sixty-eight conference participants attended the Cancer Support Groups workshops, and 54 completed the workshop evaluation, which represents a 79% response rate. Nine in ten respondents (91%) reported that the speakers, Lei-Chun Fung, Lora Taylor Falealili, Lourdes Quitugua, and Chaiwon Kim, were informative and helped them understand how to develop and sustain cancer support groups. Ninety-one percent of participants also noted that the workshop increased their knowledge of cancer support group planning, development, implementation, and maintenance. As a result of the information shared during the workshop, a Pacific Islander Nation cancer coordinator spoke to his volunteer, who also attended the workshop, and they discussed how to start a cancer support group within six months of the conference. They noted that the workshop provided several ideas, such as developing educational lectures, coping skills, and outreach services, to help start their cancer support group.

## Cancer Clinical Trials for Asian American, Native Hawaiian & Pacific Islander Communities

The speakers in this workshop discussed the importance of clinical trials, its role in addressing cancer disparities, and methods for promoting awareness of cancer clinical trials as an option for cancer treatment in Asian American, Native Hawaiian & Pacific Islander (AA & NHPI) communities. Rachel Mesia started the workshop by providing a short video from the National Cancer Institute on understanding cancer clinical trials. She discussed the different types of cancer clinical trials, where to find cancer clinical trials and information, and reasons for low AA & NHPI participation in cancer clinical trials. Dr. Kimlin Tam Ashing-Giwa provided a perspective from a cancer research and cancer center and the importance of championing equity and community inclusion in clinical trials. The next speakers represent ENACCT – Education Network to Advance Cancer Clinical Trials and they shared their program's efforts to engage communities in cancer clinical trials, such as the Korean community in Pierce County, Washington. ENACCT also works with The Wellness Community to educate new patients and health care providers about local cancer clinical trials.

A total of 50 conference participants attended the clinical trials workshop, and 21 attendees completed the workshop evaluation, which represents a 42% response rate. A diverse number of participants, including researchers, community based organization staff, non-profit staff, health educators, and cancer survivors attended the workshop. The vast majority of respondents (95%) reported that they were familiar with cancer clinical trials, some of the risks/benefits associated with clinical trials, and the ways that patients are protected. One-hundred percent of participants recognized that cancer clinical trials education and participation are critical to addressing the health disparities of AAs & NHPIs. Additionally, 100% of respondents noted that the workshop was effective in improving their understanding about the importance of cancer clinical trials, education, ethnic minority participation and addressing barriers to effective strategies. Workshop respondents also noted that in the future they would like to see linguistically and culturally appropriate information and materials about clinical trials.

## Opening Ceremony

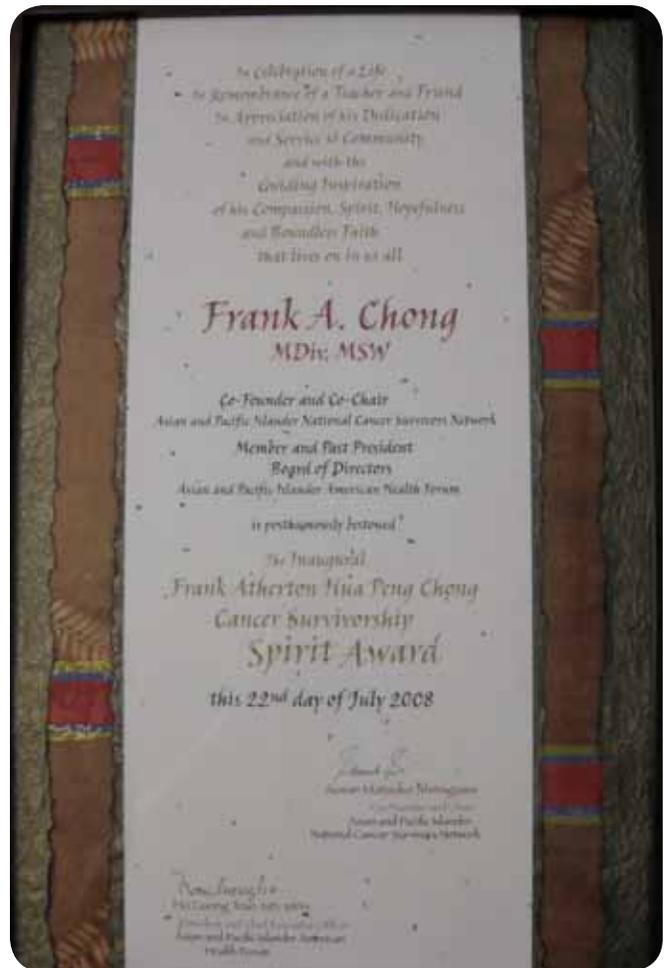
The Opening Ceremony started with an invocation from the Reverend Ken Yamada from the Berkeley Higashi Honganji Buddhist Temple. Then Dr. Ho L. Tran, President and Chief Executive Officer of the Asian & Pacific Islander American Health Forum (APIAHF) welcomed everyone to the conference. Susan M. Shinagawa, Co-Founder and Co-Chair of the Asian & Pacific Islander National Cancer Survivors Network (APINCSN) shared a powerpoint presentation highlighting the history and accomplishments of APINCSN. This insightful story telling of how the Network was founded and developed led to the honoring of the late Reverend Frank



Chong, a Co-Founder of the APINCSN, through a touching slideshow of photos and the presentation of a unique award created by Glenn C. Wong, Ms. Shinagawa, Dr. Tran, and APIAHF Board Member Janice Louie presented the **Frank Chong Cancer Survivorship Spirit Award** posthumously to Dr. Reggie C.S. Ho, a long time friend of Frank's.

Ms. Shinagawa introduced the keynote speaker, Dr. Jackie Young, Chief Staff Officer for Mission at the American Cancer Society, Hawai'i Pacific Inc. and breast cancer survivor, who spoke about her survivorship journey. She shared a story of how Frank Chong told her that "help is on the way". At the time, she did not know what he meant. But after ten years of the Network, she shared that the accomplishments that have been made in the field of cancer prevention and survivorship, "help is on the way" for cancer patients and the fight against cancer.

Due to the diversity of the AA & NHPI communities, the Opening Ceremony was followed by a reception with an assortment of Asian and Pacific Islander foods and six Asian, Native Hawaiian and Pacific Islander cultural entertainment groups, which included taichi, taiko, Chinese lion dancers, Filipino folk and Muslim dances, hula, and Tahitian dance. This reception displayed the amazing cultures and talent within our communities. All conference participants were invited to attend the conference Opening Ceremony dressed in the traditional attire from their cultural homelands.



*Dr. Ho Tran, Dr. Reggie Ho, & Susan M. Shinagawa*

"In celebration of a life. In remembrance of a teacher and friend. In appreciation of his dedication and service to community and with the guiding inspiration of his compassion, spirit, hopefulness, and boundless faith that lives on in us all."

– Award inscription

## PLENARY SESSIONS

### Cancer Survivorship through the Eyes of Survivors & Providers

The opening plenary session on July 23, 2008 was called Cancer Survivorship through the Eyes of Survivors & Providers and was sponsored by the Susan G. Komen for the Cure, San Francisco Affiliate. There were 205 attendees at this Survivor breakfast session.

The cancer survivor speakers were Jose Batto, Lucianne Latu, Jina Peiris, Suzanne Robert, and Bermin F. Weillbacher. The healthcare provider speakers were Giang T. Nguyen, Nitin K. Shah, Victor T. Tofaeono, and Evaon Wong-Kim. These Asian American & Pacific Islander cancer survivors individually shared their major issues they had with the cancer, treatment and survivorship, such as long term effects of cancer treatment and maneuvering through the health care system. Health care providers, based on their expertise and experiences, responded to survivors' major issues in a facilitated dialogue by Dr. Fidelia Butt. Suzanne Robert, a Chamorro breast cancer survivor, shared her difficulties in maneuvering through the health care system when she underwent her cancer treatment. Her husband was credited with being her advocate with the health insurance companies as she was in the hospital. Her message was to fight for what you think is best for you when undergoing care for cancer, whether that is the type of biopsy, surgery or treatment option decisions you need to make. Following Mrs. Robert, Bermin F. Weillbacher, a Pohnpeian prostate cancer survivor, shared his experiences with his cancer diagnosis and treatment. He also shared his battle with insurance companies and how he is currently taking local herbs and medicines to help with some effects from his cancer

**97% of the attendees felt the speakers were able to effectively communicate their experience and/or expertise as related to the topic of this session.**

treatment. Dr. Victor T. Tofaeono, an oncologist in American Samoa, shared the efforts that are going on there to address cancer and survivorship. He also responded to Mrs. Robert's and Mr. Weillbacher's experience and said that it is very important to communicate with your health care provider throughout your cancer care and advocate for what you feel is best for your care. The audience enjoyed and appreciated the personal stories from the cancer survivors and that this session was a great topic for the opening plenary session. This conference provided an opportunity for cancer survivors to share their experiences, and more specifically how they coped with their diagnosis and the difficulties throughout their survivorship.



*Cancer Survivorship through the Eyes of Survivors & Providers Plenary Speakers*

## Patient Navigation

The luncheon plenary session on July 23, 2008 was called Patient Navigation and was sponsored by the American Cancer Society, California Division. The purpose of this session was to provide an understanding of the values/ roles of cancer patient navigation programs, the essential components and resources for program implementation, as well as issues to consider when tailoring programs for Asian American, Native Hawaiian & Pacific Islander communities. Rachel Mesia moderated this panel and introduced the definition of patient navigation and its relationship to the cancer continuum. Zul Surani then presented the use of the National Cancer Institute Cancer Information Service (NCI/ CIS) "Cancer 101" in Navigator Trainings. Mr. Surani shared the importance of adapting training curricula to fit your audience and your setting. Dr. Tu-Uyen N. Nguyen revealed the impressive community-based health navigation from the PATH for Women Project, which is a project Promoting Access to Health for Pacific Islander and Southeast Asian Women. Dr. Nguyen discussed the similarities and differences between traditional patient navigation and community-based health navigation. Traditional patient navigation has a clinical focus while community-based health navigation focuses on the entire cancer care continuum, including accessing early detection, screening, and prevention services. She shared examples of cultural tailoring by community health navigators in the Cambodian, Chamorro, Laotian, Samoan, Thai, Tongan, and Vietnamese communities. One of the most eye opening presentation slides showed a navigation activities timeline and the total amount of time needed to navigate a woman through one health appointment can range from 3 to 25 hours and up, with an average of 15-20 hours. There needs to be sufficient training for navigators to function as knowledgeable resources and adaptable problem-solvers in their community, and there needs to be ongoing support to help identify opportunities for referrals and sources of help.

JoAnn Umilani Tsark, and Karen Kanehailua Teshima presented on the Patient Navigator Training for Cancer Care Ho'okele i ke Ola, which was developed and implemented by 'Imi Hale – the Native Hawaiian Cancer Network. The motivation for action came from the statistics that the new cancer cases are expected to increase to 10,000/year in the next decade



*From left to right: Karen Kanehailua Teshima, JoAnn Umilani Tsark, Tu-Uyen N. Nguyen, and Zul Surani*

and that Native Hawaiian and Pacific Islanders have higher cancer mortality rates than other ethnic groups in Hawai'i. People with cancer need both community-based and hospital-based assistance and there is a need for clinical-based and community-based navigators. Ms. Tsark shared the current cancer patient navigation efforts in Hawai'i. 'Imi Hale's Patient Navigator Training Curriculum was designed to "enhance cancer navigation skills" of Community Outreach Staff at Native Hawaiian Health Care Systems. The curriculum involved learning objectives in cancer knowledge, cancer services and providers, and communications. Different variations of the training were developed to accommodate needs of the staff. For several local community colleges, the Patient Navigator Training was a 16-week independent study for students. As of July 2008, there were 66 graduates of the training from all five islands. Ms. Teshima shared her experience undergoing the navigator training and the work she has been able to accomplish as a community-based navigator. Navigators help to decrease inpatient length of stay and reduce missed appointments/no shows. Navigators improve physician/hospital relations and make referring to hospital services easier than going outside of the system. Navigators field the "difficult or nervous patient" calls and direct patients to the appropriate resource. 'Imi Hale will continue to provide ongoing technical assistance to the Patient Navigators and will hold the first annual Patient Navigator Conference in Hawai'i in September 2008.

## Unique Health Challenges & Issues in Selected Asian American Communities

The afternoon plenary session on July 23, 2008 was called Unique Health Challenges & Issues in Selected Asian American Communities. Susan M. Shinagawa moderated this session and started the discussion by presenting some background on Asian American demographics, statistics, and cancer facts. In addition, Ms. Shinagawa shared references to anti-Asian racism in the U.S. and the "model minority" myth and discussed the differences and health challenges faced by Asian immigrants and Asian refugees. Both Lady Fabian and Debra Oto-Kent shared their perspectives as breast cancer

survivors. Lady Fabian discussed her cancer survivorship journey from the perspective of a nurse as well as from an immigrant community. Debra Oto-Kent communicated her cancer survivorship experience from the viewpoint of a Japanese American, which is a community that has lived in the U.S. for several generations. As Asian immigrant communities reside longer in the U.S., their rates of cancer increase. For the Hmong refugee community, there are also unequal cancer burdens, such as with liver cancer and cervical cancer. Dao M. Fang of the Hmong Women's Heritage Association discussed

their Kasha Health Program and the various services, workshops, trainings, and educational materials they provide to the community and to healthcare providers. Ms. Fang also shared the importance of case management and patient navigation with the community to ensure access to health care services, such as screenings for cervical, breast, and colorectal cancers. There are still challenges and barriers for cancer screening in the Hmong community, but organizations such as Hmong Women's Heritage Association are striving to reduce those barriers and increase screening and preventive services. Zul Surani of Saath, the South Asian Cancer Foundation discussed the importance of spirituality and religion among South Asian breast cancer survivors. South Asian women practice many religions including Hinduism, Sikhism, Buddhism, Islam, Christianity, Catholicism, and Jainism. Through a recent

*From left to right: Debra Oto-Kent, Dao M. Fang, Lady Fabian, Susan M. Shinagawa, and Zul Surani*

research study, it was found that faith and self-prayer were sources of comfort and that the spiritual community was a source of social support to the breast cancer survivors. Interventions to assist South Asian survivors should consider the role of spirituality and faith-based networks in providing social support.



## Alternative/Complementary/Integrative Therapies

The dinner plenary session on July 23, 2008 was called Alternative/Complementary/Integrative Therapies. Complementary and alternative medicine (CAM) regimens are widely used in the U.S., particularly among ethnic minority populations, as well as a growing number of majority-population cancer patients/survivors. The purpose of this session was to provide information on a variety of alternative, integrative and complementary therapies used by AA & NHPI cancer survivors to promote wellness, manage symptoms, and aid in healing during and after cancer treatment. Dr. Lee Buenconsejo-Lum moderated this session and provided a short introduction on alternative/complementary/integrative medicine, which is a group of diverse medical and health care systems, practices, products that are not presently considered to be a part of conventional medicine. Alternative means used in place of conventional medicine. Complementary means used together with conventional medicine. Integrative means combining treatments from conventional medicine and CAM

for which there is some high quality evidence of safety and effectiveness. She also shared the reasons why patients use CAM and how CAM approaches are evaluated. Dr. Kedar N. Prasad of Premier Micronutrient Corporation spoke next about multiple antioxidants in cancer care. Published studies in cancer survivors suggest that increased oxidative stress and chronic inflammation in cancer survivors may contribute to the risk of diseases. Since antioxidants reduce oxidative stress and chronic inflammation, they may produce beneficial effects in cancer survivors. Dr. Prasad has developed a formulation of micronutrients containing both dietary and endogenous antioxidants that may enhance the quality of life in cancer survivors. "We have also developed a formulation of high-dose dietary antioxidants that may prolong survival time with good quality of life in patients who have become unresponsive to all therapeutic agents. Another micronutrient formulation containing dietary multiple antioxidants may reduce the toxicity of therapeutic agents."



*Alternative/Complementary/Integrative Therapies Plenary Speakers*

Jenny Do shared her breast cancer survivorship journey and the beginning battles of making decisions in the midst of complications. She discussed how she shifted focus and tried to be "Zen" about things when she was down, and it worked. She was determined to get rid of her negative thoughts and was armed with a new outlook. Ms. Do engages in a new active life using art as an "anchor" and an outlet. She found refuge in her paintings and art and shared some slides of her paintings and art installations. The effects of art was her alternative therapy during and after cancer. She connected to other artists affected by cancer and decided to organize an exhibition showcasing their spirit of fighter and survivor. She discussed how art helps others cope with their cancer journey, along with writing. As a victim of lack of information, she started to share the experience with other women through

a series of articles published on several local papers like Viet Tribune, VTimes and NguoVietOnline. The work had some positive impact in the community. She found new strength and direction. The artworks and writings became a new source of joy and contentment. Jenny Do has realized focused messages can truly help others.

Beverly Burns from the Charlotte Maxwell Complementary Clinic presented the importance of making informed choices when it comes to Complementary and Alternative Medicine (CAM) Therapies. Ms. Burns shared that up to 85% of cancer patients use CAM during their conventional oncology treatment. There is still a communication gap between

patients and providers, especially when using CAM. She also shared several traditional Chinese medicine and herbal tools, therapies, and practices, since that is her area of expertise. She disclosed that CAM can be used for addressing cancer symptoms, nausea, fatigue, cancer pain and anxiety related to cancer.

Sala Mataalii of the Samoan National Nurses Association provided a “reality check” about the importance of communicating the use of non-traditional medicines and/or therapies to the patient’s physician while undergoing (Western) cancer treatment.

**“It does not matter how much time I will have but what matters now is that I am truly living at the moment. I have never been more productive and creative than now. Whatever I can no longer do, I immediately make a substitute for something else. It’s all about engaging in what makes you productive, alive and happy.”**  
– Jenny Do, breast cancer survivor

## Unique Health Challenges & Issues in Selected Native Hawaiian and Pacific Islander Communities

The breakfast plenary session on July 24, 2008 was called Unique Health Challenges & Issues in Selected Native Hawaiian and Pacific Islander Communities. Jane Ka’ala Pang moderated this panel of perspectives from cancer survivors, researchers, and programs in the U.S. Mainland, Hawai’i, and Pacific. Dr. Neal A. Palafox from the University of Hawai’i provided a perspective of the cancer burden and programs in the U.S. Affiliated Pacific Island Jurisdictions. He shared the population numbers and demographics of the islands in this region. He also shared the history of nuclear weapons testing and the legacy of cancer related to the radiation and impact on the cultures and communities. Dr. Palafox described the efforts to address the health and cancer issues in the Pacific. Through advocacy, initiatives, the Cancer Council of the Pacific Islands and investments by Centers for Disease Control and National Institutes of Health, there has been an increase of funding and programs to address cancer and health in the Pacific Island Jurisdictions. Such programs include Comprehensive Cancer Control Programs for each Jurisdiction, Pacific Cancer Registry, and Pacific Center of Excellence to Eliminate Disparities in breast and cervical cancer. Challenges remain in funding, personnel, expectations, and in the political environment, but there are collaborations, coalition building and resource sharing to help the communities get access to care.

Camilla Ingram is a Marshallese colon cancer survivor from the Republic of the Marshall Islands and she discussed her cancer survivorship journey of being diagnosed with cancer in the islands and the road she took to treatment and survivorship. Ms. Ingram worked closely with her local cancer coalition to share her story about the importance of screening



*From left to right: Jane Ka’ala Pang, Victor Kaiwi Pang, Dr. Sela Panapasa, Dr. Cynthia K. Kenui, Camilla Ingram, and Dr. Neal A. Palafox*

and prevention. Victor Kaiwi Pang, a Native Hawaiian non-hodgkins lymphoma cancer survivor from the U.S. Mainland, also shared his personal story of how he found out he had cancer and how his wife, Ka’ala, helped him through the cancer treatment, recovery, and survivorship. Dr. Cynthia K. Kenui shared her breast cancer survivorship journey and how it fit into her research and community work timeline. She shared how her family, spirituality, healthcare team and self advocacy helped her through her cancer experience. Dr. Sela Panapasa then presented on the pattern of cancer incidence among U.S. Pacific Islanders. The data sources used

were from the U.S. Census, SEER (Surveillance, Epidemiology, and End Results Database), and Detail Files on mortality and fertility. With the use of multiple datasets, her presentation of the data showed that Pacific Islanders had higher cancer rates than Asian groups. It's important to disaggregate data to better understand cancer disparity patterns. There is a need for disaggregated data on other Pacific Islander subgroups (e.g. Marshallese, Chuukese, and Fijians). The methodology of utilizing different data sources needs to be tested further. Approximately 75-80 Native Hawaiians and Pacific Islanders were able to meet and talk during a breakfast before this plenary. They had a separate room so they could get to know each other and network since they were from the Jurisdictions,

Seattle, Chicago and various cities of California. They are working on ways to get involved with the NHPI Alliance and future projects. It was during this breakfast that conversations led to sharing resources. Representatives from the Marshall Islands said their mammography machine was not functioning and they were unable to conduct any breast cancer screenings. Jane Ka'ala Pang said she would find out if there were resources to help alleviate this problem. After communications with the Susan G. Komen for the Cure, Inland Empire Affiliate, they had an extra mammography machine that they will be able to send to the Marshall Islands to continue the breast cancer screenings.

**“There is a great showing from the Pacific Islanders, and I had a really great time getting to know them and the issues they face in their communities.”**

**– Conference attendee comment**

## **Increasing the Voices of AAs & NHPIs through Community-Based Participatory Research (CBPR) and Community-Based Participatory Programs (CBPP)**

The last plenary session on July 24, 2008 was called Increasing the Voices of AAs & NHPIs through Community-Based Participatory Research (CBPR) and Community-Based Participatory Programs (CBPP). Dr. Kimlin Tam Ashing-Giwa moderated this panel and started off the discussion talking about the importance of community inclusion in cancer research and programs. The plenary speakers were pairs representing both the researcher institution and the community based organization. Kao Kue from the Southeast Asian Mutual Assistance Associations Coalition (SEAMAAC) talked about the research partnership developed with Dr. Giang T. Nguyen of the University of Pennsylvania. SEAMAAC and the university worked together to address health disparities in chronic illnesses and access to health care through surveys to the community. This has been a positive experience from both perspectives. Dr. Grace J. Yoo and Dr. Mai Nhung Le from San Francisco State University (SFSU) talked about their experience working with the Asian American Cancer Support Network (AACSN). Through SFSU's research and community service,

and cervical cancer educational forums for the community in 2001 and 2005. Their research findings show that supportive networks increase during diagnosis and treatment and drop afterwards. There continues to be a need for support during treatment, with a focus on emotional, informational, and spiritual aspects, and that support needs to continue after treatment. AACSN and SFSU have developed a peer counseling program for Asian American gynecological cancer survivors to be trained on assisting other cancer survivors. Lucy Young from the Herald Cancer Association (HCA) and Dr. Marjorie Kagawa-Singer from UCLA are working together to evaluate support groups for AAPI cancer survivors and expressive writing among Chinese-speaking breast cancer survivors. HCA is also working with Dr. Ashing-Giwa on research on the emotional and family well-being of Asian breast cancer survivors. These two presenters shared how the research will benefit from the partnership and how the community organizations will benefit. The research institute will gain translation and interpretation; recruitment of participants; input received on community outreach strategies; results; and more ideas for new research projects. The organizations will benefit



*Voices of AAs & NHPIs through CBPR and CBPP Plenary Speakers*

through improvements on the quality of survivor's life; assist patients and survivors to access resources and treatment care; publish study results to help improve community organizations' need to be recognized by the public/mainstream society; and attainment of funding to implement more outreach programs. Jonathan Tana Lepule and Dr. Sora Tanjasiri work together on the Weaving an Islander Network for Cancer Awareness, Research & Training (WINCART). The evolution of how WINCART came together and the accomplishments that have been made so far were shared. Within WINCART, there are eight community based organizations and five university researchers working together to increase cancer education, research, and training for Pacific Islanders in Southern California. Mr. Lepule shared that the journey to achieve that vision is not always a smooth path and there are bumps along the road to partnerships. To achieve WINCART's vision of empowered and healthy Pacific Island communities, collaboration and open communication and dialogue needs to occur throughout the project and within the working relationships. Dr. Lee Buenconsejo-Lum from the University of Hawai'i and Xner Luther from the Pohnpei Comprehensive Cancer Coalition talked prevention, education and screening in the U.S. Affiliated Pacific Islands. Challenges have come up due to time zone differences, no access to screening, balancing of priorities, and connection to the academic institution. The advantages to this collaborative relationship enriches the work with regional differences, diverse cancer perspectives, and sharing of resources and technical assistance from academia. Some take home points from this pair's presentation were

shared. There are tremendous benefits if you get the right academic partner. It often takes at least several years to get to know the community and build relationships. A strong partnership can lead to other strong partnerships and collaboratives. 🌀

#### Take Home Points:

#### *From Dr. Buenconsejo-Lum's and Mr. Luther's presentation*

- Tremendous benefits if you get the right academic partner
- Often takes at least several years to get to know the community and build relationships
- A strong partnership can lead to other strong partnerships and collaboratives

## BREAKOUT SESSIONS

During the second day of the conference, July 23, 2008, there were three concurrent breakout sessions that took place. The topic areas of these sessions included: Navigating through Cancer Information, Impact of Cancer on AA & NHPI Families and Caregivers, and Palliative Cancer Care and Dignity & Quality at the End-of-Life.

### Palliative Cancer Care and Dignity & Quality at the End-of-Life

This session began with a short video from Kokua Mau called "Breaking the Ice." The stories featured perspectives from patients, caregivers, and family members dealing with end-of-life issues in Hawai'i. Then everyone broke off into small groups and shared cultural practices of pain management and/or end-of-life. After a short time, several shared with the larger audience the similarities and differences in culture beliefs and practices. Dr. Donna Kalauokalani provided a presentation on cancer pain and symptom management. She shared information on sources of cancer pain, cancer mechanisms of pain, how cancer patients interpret pain, common side effects of cancer and treatments, and medicines, therapies, and other complementary alternative medicines used to treat cancer pain. The key message she conveyed was pain can be managed and pain control is part of cancer treatment. Then Sandy Chen Stokes discussed Chinese beliefs and practices concerning death and dying, culturally appropriate care for Chinese

at the end-of-life, and the Chinese American Coalition for Compassionate Care (CACCC). Ms. Stokes shared the results of a Chinese end-of-life educational needs assessment. Some findings from the consumers were poor communication with health care providers and they would have made a different decision if they had had more information at the time of their loved one's death. Some findings from the physicians were they would appreciate end-of-life materials and education in Chinese and would be interested in training on end-of-life issues. CACCC has developed end-of-life educational materials and trainings in Chinese. Jeannette Kojane presented about Kokua Mau, which is Hawai'i's hospice and palliative care organization. Ms. Kojane shared Kokua Mau's public and patient education; palliative care capacity building program; and training of health care providers and faith based organizations on palliative and end-of-life care.

## Impact of Cancer on AA & NHPI Families and Caregivers

Cancer affects not only the patient, but also their caregivers and families. Different viewpoints were shared from a caregiver, a parent, a son and a spouse of cancer patients in this session. Dr. Mai Nhung Le shared her perspective as a sibling of a cancer patient in her family, her sister, who unfortunately passed away from breast cancer. Sala Mataalii shared her story about taking care of her daughter who had bone cancer as a teenager and the struggles of watching your child get sick, undergo treatment, get better, become sick again, and succumb to the disease. As a parent, it was difficult to deal with the helpless feeling of not being able to make your child well again.

Dr. Nitin K. Shah revealed how he was the caregiver of both his wife and father. His wife passed away from breast cancer and his father passed away from malignant histiocytoma. Richard Robert discussed how he became his wife's voice and advocate with the health insurance companies while she underwent her breast cancer treatment. He shared a resource he created called "Managing Managed Care (HMO) Tips." Workshop participants expressed appreciation for all the speakers who shared such compelling stories of how cancer impacted them as caregivers and family members.

## Navigating through Cancer Information

This session provided an overview on navigating through cancer information, highlighting resources available, and tips for evaluating health information. Rachel Mesia shared the cancer information and resources available through National Cancer Institute and the National Library of Medicine. Dr. Reginald C.S. Ho presented about the Asian & Pacific Islander Cancer Education Materials (APICEM) Webtool. APICEM is designed to provide credible information regarding cancer treatment, screening and prevention in multiple Asian and Pacific Islander languages via the websites of the participating organizations.

Dr. Ho demonstrated how to search for cancer materials using the APICEM Webtool. Karen Teshima shared her experience as a patient navigator and how she helps to find Native Hawaiian and Pacific Islander cancer resources for the patients she serves. Joyce Chen from the Chinese Community Health Resource Center highlighted her organization's programs and services, such as the Chinese Community Cancer Information Center, cancer patient navigation services, and the bilingual health website. 🐉

## CONCLUSION

The community benefitted from this conference through the interactive format of the sessions, in addition to exhibits and meal events, it was designed to facilitate participants' learning and sharing, and enhance opportunities for information dissemination and networking.

APIAHF collected 111 evaluations, both paper and online, from our conference attendees, although there were 212 conference attendees present. Based on the conference attendees' evaluation and comments, most felt that the conference objectives were met. 93% felt that the conference increased community awareness of organizations that provide the Asian American, Native Hawaiian & Pacific Islander (AA & NHPI) specific cancer and cancer survivorship resources and services. 88% felt that the conference increased awareness about emerging areas of research, prevention, detection and treatment. 89% felt that the conference provided a forum for advocates, researchers, clinicians and the general public to discuss critical areas of community-based participatory cancer research. 92% felt that the conference demonstrated how to be an effective advocate for resources and policies for the AA & NHPI community. 91% felt that the conference increased knowledge about methods to navigate through the health care systems. 87% felt that the conference increased knowledge about alternative and complementary medicine and practices that are available for cancer patients to help with their journey through recovery and survivorship. 91% felt that the conference helped them to obtain culturally appropriate

and relevant cancer educational materials. Participants praised about how much they enjoyed the diverse conference topics, speakers and attendees of the conference. 91% of the participants strongly agreed or agreed that the conference provided knowledge, skills and resources to empower them to address cancer survivorship. Also 94% of those participants who attended thought this conference increased their awareness of organizations that provide Asian American, Native Hawaiian & Pacific Islander specific cancer and cancer survivorship resources and services. In fact, 94% thought there were enough opportunities to network with others to learn about their resources and programs. Overall, 99% of attendees thought this conference was a good investment of their time. In fact, 96% of those who responded to this question indicated they would attend a future conference on AA & NHPI Cancer Survivorship.

The conference provided a great opportunity to share, meet and establish new relationships with cancer advocates and key leaders in our communities. Attendees were appreciative of the focus on AAs & NHPIs and dissemination of information delivered by AAs & NHPIs. The conference also provided

“And the more we conven to share and empower each other, the more successful we would be in advocating for and helping all cancer survivors in our AA, NH & PI communities in the U.S. Mainland and in the Pacific. Yes, I would continue to attend future AA, NH & PI cancer survivorship conferences.”

– Conference attendee comment

an opportunity to share cancer concerns and experiences with others. In fact, some attendees expressed a desire to have this conference in their region to provide others opportunity to be a part of such convenings specifically for AA & NHPI communities. In addition, requests for similar trainings conducted during this conference were made to be conducted in the Midwest and Pacific regions.

The conference's capacity building workshops led to the development of the current Asian & Pacific Islander National Cancer Survivors Network's Community Advocacy & Training on Cancer & Health (CATCH) Leadership Training Program modules, which include AAs & NHPIs and cancer; policy advocacy; media advocacy; media spokesperson; data advocacy; and establishing and sustaining cancer support groups. AA & NHPI CBOs are requesting more information about cancer patient navigation programs for their organizations and communities. Cancer support groups are increasing and groups starting them need continued capacity building assistance in terms of the grant writing, finding resources (financial, educational, and psychosocial), setting up the cancer

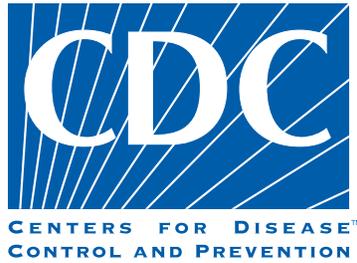
support group program logistics (location, facilitation, outreach, and retention), and activities. Policy advocacy can build the numbers of advocates to work locally, regionally, and nationally to address and begin to eliminate disparities related to cancer, increase access to cancer care and general health services, and build relationships with key decision makers. Media advocacy efforts can help to make our issues more visible and improve messaging of cancer prevention, education, screening, treatment, and survivorship in our communities.

In general, conference participants agreed that the conference was a good investment of their time. The conference increased community awareness of AA & NHPI cancer and cancer survivorship organizations, resources, and services. Additionally, it contributed to participants' knowledge of advocacy, strategies for navigating the health care system, and alternative and complementary medicine. The various sessions and speakers were all informative and useful, and nearly all of the conference participants agreed that the conference accomplished its goals. 🐾

Recommendations were made throughout the conference on how to improve access to cancer services, programs, and data collection:

- Promotion of collaborative efforts among federal, state and local agencies to address cancer among AAs & NHPIs and to improve data collection and reporting through desegregation of AA & NHPI cancer data by ethnic subgroups.
- Increase inclusion and involvement of Native Hawaiians and Pacific Islanders into Asian American national meetings and gatherings, specific to cancer.
- Continue to provide capacity building assistance to smaller and emerging AA & NHPI communities to address cancer.
- Advocate for increased participation of AAs & NHPIs in cancer clinical trials.
- Recommend over sampling of cancer data in different AA & NHPI populations.
- Investment in and advocacy for improving, funding adequately, and sustaining cancer screening, detection, diagnosis, treatment, end of life, and survivorship programs for AAs & NHPIs.
- Increase advocacy skills for patients, providers, families, and organizations.
- Collaborate with AA & NHPI ethnic media to shed light on cancer and survivorship among AAs & NHPIs.

*APIAHF thanks the following for their support in making this conference a success*



Through the generosity of Komen National, we were able to support the travel for 7 cancer survivors and advocates from the U.S. Pacific Island Jurisdictions.



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Asian & Pacific Islander National Cancer Survivors Network



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Asian & Pacific Islander National Cancer Survivors Network

Dispelling Myths

Reducing Disparities

Providing Hope

## **APIAHF**

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