

Asian & Pacific Islander National Cancer Survivors Network Fall Newsletter



Asian & Pacific Islander National Cancer Survivors Network

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AA & NHPI Cancer Survivorship Conference



The Asian & Pacific Islander American Health Forum (APIAHF) and the Asian & Pacific Islander National Cancer Survivors Network (APINCSN) hosted the first ever Asian American, Native Hawaiian & Pacific Islander (AA & NHPI) Cancer Survivorship Conference: *Dispelling Myths, Reducing Disparities & Providing Hope*, which was held July 22-24, 2008 at the Sheraton Gateway Hotel in Burlingame, CA. 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. There were approximately 213 participants, including at least 62 cancer survivors. These participants came from

California, Hawai`i, Georgia, Illinois, Iowa, Maryland, Michigan, Minnesota, New York, Ohio, Pennsylvania, Tennessee, Texas, Washington, and Washington, D.C., along with the U.S. Pacific Island Jurisdictions: American Samoa, Chuuk, Commonwealth of the Northern Mariana Islands, Guam, Kosrae, Marshall Islands, Palau, Pohnpei, and Yap. It was a supportive and caring conference environment that was respectful of each individual, their cultures and languages.

On the first day, there were interactive pre-conference workshops, such as Grant Writing and Cancer Clinical Trials.

The Opening Ceremony started with APINCSN honoring the late Reverend Frank Chong, a

cont. Cancer Survivorship Conference

co-founder of the APINCSN. Our keynote speaker Dr. Jackie Young, Chief Staff Officer for Mission at American Cancer Society, Hawai`i Pacific Inc. and breast cancer survivor, spoke about her survivorship and that “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.

On the second and third days of the conference, participants heard directly from cancer survivors and health care providers about challenges faced by cancer patients and survivors and recommendations for improving access to and quality of health care in terms of cancer care; complementary, alternative and integrative medicine; patient navigation; community-based participatory research; and unique health issues and challenges faced by Asian American, Native Hawaiian & Pacific Islander communities. Some of the speakers’ presentations are available at www.apiahf.org/programs/cdp/conf.htm.

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 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.



*APIAHF & APINCSN:
Susan M. Shinagawa,
Mavis Nitta,
Roxanna Bautista, & Krysel Filo*



Mona Bormet & Wendy Ho at the Policy Center

THANK YOU!

APIAHF and APINCSN would like to thank our sponsors, speakers, moderators, network, staff, volunteers and participants for making the 2008 Asian American, Native Hawaiian and Pacific Islander Cancer Survivorship Conference possible. A huge thank you to our sponsors, Centers for Disease Control and Prevention; Susan G. Komen For The Cure, National Office; Stanford Hospital & Clinics; Lance Armstrong Foundation; Susan G. Komen For The Cure, San Francisco; American Cancer Society, California Division; Susan G. Komen For The Cure, Los Angeles; California Pacific Medical Center; and Wal-Mart for graciously providing support for the conference.

Frank A. Chong Cancer Survivorship Award



The late Rev. Frank A. Chong

To commemorate the late Reverend Frank A. Chong's life and activism, and ensure that his memory will endure in the hearts and minds of Asian American, Native Hawaiian and Pacific Islander cancer survivorship and cancer care communities, we are delighted and honored to announce the establishment of the "Frank A. Chong Cancer Survivorship Award." The inaugural award was presented posthumously to Frank on July 22, 2008 and Dr. Reginald C.S. Ho received the award at the first Asian American, Native Hawaiian & Pacific Islander Cancer Survivorship Conference and delivered the award to Sherry Chong, Frank's wife.

This award will be presented biennially at a national meeting to honor an Asian American, Native Hawaiian or Pacific Islander cancer survivor or community cancer advocate who exemplifies Frank's spirit of compassion and hopefulness, and dedication of service to the community. The current and past APINCSN Steering Committee and APINCSN National Advisory Council members and Network members will be asked to submit nominations for this award. The next Frank A. Chong Cancer Survivorship Award will be presented to the selected awardee at the APIAHF's Voices Conference in June 2009 in Washington, D.C.



*Frank A Chong Cancer Survivorship Award
Dr. Ho Tran, Dr. Reggie C.S. Ho, & Susan M. Shinagawa*

2008 LIVESTRONG Summit - Ohio

From July 24-27, 2008 the Lance Armstrong Foundation (LAF) brought together 1,000 cancer survivors and advocates to the 2008 LIVESTRONG Summit at Ohio State University. Invited delegates from across the nation were selected due to their passion to improve cancer prevention and survivorship issues. Jay Aromin from Guam Communication Network in Long Beach, CA and Lora Falealili from the American Samoa Cancer Support Group in Pago Pago, American Samoa attended the event. In fact, Ms. Falealili was recognized for being the delegate that traveled the farthest to attend the Summit.

The first day of the Summit included the LIVESTRONG Presidential Town Hall on Cancer, which was moderated by Lance Armstrong and Paula Zahn. It provided an opportunity for the presidential candidates to share their cancer plan and answer questions from the audience. Senator John McCain (R-AZ), who is a three-time cancer survivor, attended the Town Hall. Senator Barack Obama (D-IL) was unable to attend due to a scheduling conflict.

During the Summit, the participants were given the necessary tools to support LAF's efforts to make cancer a national priority. They learned tools and techniques on how to raise money for their organizations to help in the fight against cancer. Their grassroots advocacy training mobilized the delegates to influence policy that concern them. Speakers, such as Lance Armstrong; Dr. Richard Carmona, the 17th Surgeon General of the U.S.; Dr. Harold Freeman, the President and Founder of the Ralph Lauren Cancer Center in Harlem; and Stefanie Spielman, founder of Stefanie Spielman Breast Cancer Fund and three-time cancer survivor, talked about the inequalities in the U.S. regarding the access to the healthcare system and provided knowledge and skills to inspire and empower the participants to address cancer care in their communities. For Summit highlights check out: www.livestrong.org/summit.

Tools & Strategies for Developing & Sustaining AAPI Cancer Support Groups Capacity Building Workshop at the AA & NHPI Cancer Survivorship Conference

The goals of this capacity building workshop were to increase awareness about the importance of culturally and linguistically tailored cancer support groups, its role in addressing cancer disparities and impacting cancer prevention, screening, treatment, and survivorship, and sharing examples of successful cancer support programs and their successes and challenges in development and sustaining their support groups; to learn about how to start and maintain a support group to best meet the needs of the cancer support group participants; and to encourage participants to dialogue about developing, sustaining, challenges, and successes of support groups our diverse communities. The workshop speakers were Lei-Chun Fung from the San Francisco Chinese Women's Cancer Support Group, Lourdes Quitugua from Guam Communications Network, Lora Taylor Falealili from the American Samoa Cancer Survivors Cancer Support Group, and Chaiwon Kim from the Center for Pan Asian Community Services.



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.”

From left to right: Lei-Chun Fung, Lora Falealili, Lourdes Quitugua, and Chaiwon Kim

Lei-Chun Fung has facilitated this Chinese women's cancer support group in San Francisco for 14 years now. Support group facilitators have helped women examine the emotional and psychological issues they face as they cope with the illness. A variety of Eastern and Western techniques were utilized to assist women in their healing and recovery. In 1999, the Ms. Fung 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. Ms. Fung has been able to sustain the support groups because of affiliation with a public health clinic in the Chinese community and because of her success in securing grants to fund the groups.

Lourdes “Lou” 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. 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. Ms. Quitugua shared how GCN leveraged local resources in Guam to start the support groups and conduct educational forums around breast cancer.

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. Falealili 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 (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 secured 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.

Interns Spotlight

This past Summer of 2008, APIAHF’s Chronic Diseases Program had 3 wonderful interns help with the development of cancer educational materials and fact sheets, prepare for the Asian American, Native Hawaiian & Pacific Islander Cancer Survivorship Conference, and correspond with APINCSN resources.

- Lillian Chen is currently a student at the University of California at Berkeley who is majoring in molecular and cell biology and/or public health.
- April Joy Damian was a Young People For Fellow and worked on a Blueprint for Social Justice pilot program that addresses heart disease and diabetes among Filipinos in San Francisco. She is currently applying to medical school.
- Soubarna Mishra volunteered on the production of the event program and signage for APIAHF’s Food For Thought event in 2007 and 2008. She has a background in international relations and marketing.

This internship gave them the opportunity to understand the health issues among AA & NHPI communities and learn about how health policy, research, and advocacy aspects can change the field of public health.

Health Through Action Grantees

Health Through Action (HTA) is a \$16.5 million, 5-year community investment initiative and a partnership between the W.K. Kellogg Foundation (WKKF) and the Asian & Pacific Islander American Health Forum (APIAHF). This is the first cooperative effort between a private foundation and a national Asian American, Native Hawaiian and Pacific Islander (AA & NHPI) organization united to support vulnerable AA & NHPI communities in reducing and eliminating health and health care disparities and inequities.

HTA strives to improve the health and health care for AA & NHPI children, adults, and families by supporting various community investments and promoting systems changes through its five components: 1) Strengthen community capacity to address local health needs; 2) Increase data collection and research on AA & NHPI health; 3) Strengthen national policy and advocacy efforts; 4) Build a national network for AA & NHPI health; and 5) Support the development and implementation of a national NHPI health agenda.

Twelve communities from ten states received grants to energize their efforts including Arizona, Georgia, and Texas. The grantees are provided technical assistance to develop their capacities in six areas: organizational development (e.g. staff and board development, strategic planning, sustainability), collaboration development, policy advocacy, data, local evaluation, and communications.

Three HTA grantees address cancer related issues ranging from conducting focus groups, education and screening, to developing patient navigator systems. The three lead agencies for these grantees are:

- Asian Pacific Community in Action, Phoenix, AZ: APCA is in Maricopa County, which is home to the largest AA & NHPI population in Arizona. APCA will address liver cancer that includes developing and implementing a screening and prevention plan for the community.
- Center for Pan Asian Community Services, Doraville, GA: Georgia is among the top ten states with the fastest growing AA & NHPI populations, with more than 175,000 AA & NHPI residents in Metropolitan Atlanta alone. Through this grant, the CPACS is assessing their community's needs, and develop targeted health education and promotion programs that address breast cancer.
- Asian American Health Coalition of Greater Houston, Inc., Houston, TX: Houston is one of the ten U.S. cities with the largest AA & NHPI population. The Coalition uses the funding to raise awareness and mobilize the community, advocate for policy and systems changes, and implement culturally and linguistically appropriate breast cancer awareness, screening and intervention programs.

Donate to APINCSN

APINCSN is made possible by the generous support of people like you! Please make a donation today to help APINCSN continue the cancer survivorship work in the AA & NHPI communities. Your donation is tax-deductible.

You can send a check to:

Asian & Pacific Islander American Health Forum
450 Sutter Street, Suite 600
San Francisco, CA 94108

*Please write your check to the "Asian & Pacific Islander American Health Forum." In the memo line, write "APINCSN".



Capacity Building Assistance & Trainings Available

APIAHF offers capacity building assistance (CBA) for AA & NHPI communities offering cancer prevention, education, and survivor support resources to AAs & NHPIs.

APIAHF provides CBA in the following areas:

- Health information and data on AAs & NHPIs and cancer and other chronic diseases
- APIAHF developed materials and publications
- AA & NHPI language materials and resources
- Program development assistance (program planning, implementation, evaluation, grant writing, how to work with AA & NHPI communities)
- Presentation requests
- Linkages and referrals to community members and community based organizations
- Letters of support
- Collaboration on specific activities
- Training requests

Local or regional trainings in the following areas:

- Grant Writing
- Program Development
- Organizational Development
- Policy Advocacy
- Media Spokesperson/Media Advocacy
- Cultural Competency

APIAHF provides CBA around cancer to health departments, community based organizations (CBOs), cancer support groups, voluntary health organizations, community members, AA & NHPI serving cancer programs, health centers, and medical centers. To request CBA, please contact Roxanna Bautista at rbautista@apiahf.org or at (415) 568-3304.

APINCSN Online Cancer Resources Directory

The APINCSN Online Cancer Resource Directory is a compilation of organizations that offer cancer services for AA & NHPI communities. It provides detailed information about some of our network members, the AA & NHPI communities they serve, and the types of cancer services they provide. Cancer patients, survivors, advocates, organizations and health care professionals have requested the development of this directory to assist in patient referrals to culturally and linguistically appropriate cancer services.

The online directory is searchable by type of service, location, and languages spoken, and includes their contact information; cancer services; cancer/site served; language services; ethnicities served; regions covered; and fees for services. If you find any errors or would like to update your entry for the APINCSN Online Cancer Resource Directory, please contact us.

Visit our website to access the APINCSN Online Cancer Resources Directory at <http://www.apiahf.com/devsearch/data.asp>. If you would like to be included in the online directory in addition to becoming an APINCSN member, please contact Roxanna Bautista at 415-568-3304 or rbautista@apiahf.org.

Calendar: Oct – Nov 2008

OCTOBER:

Breast Cancer Awareness Month

October 17: National Mammography Day

October 23-25: Society for Public Health Education's
Catching the Wave: Changing the Tides for
Health Education and Health Promotion
Conference in San Diego, CA

October 25-29: American Public Health Association
Annual Meeting: Public Health Without Borders
in San Diego, CA

*International Brain Tumor Awareness Week (Oct
26–Nov 1)*

NOVEMBER:

Lung Cancer Awareness Month

Pancreatic Cancer Awareness Month

National Family Caregivers Month

Nov 6-7: Annual American Institute for Cancer
Research Conference on Food, Nutrition,
Physical Activity and Cancer in Washington, D.C.

DECEMBER:

Dec 16-18: National Institutes of Health Summit –
The Science of Eliminating Health Disparities in
National Harbor, MD

The 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 & Pacific Islander (AA & NHPI) communities. Founded in 1986, the Health Forum approaches activities with the philosophy of coalition-building and developing capacity within local AA & NHPI communities. We advocate on health issues of significance to AA & NHPI communities, conduct community-based capacity building assistance and training, provide health and U.S. Census data analysis and information dissemination, and convene regional and national conferences on AA & NHPI health. APINCSN has been a program of APIAHF for ten years.

APIAHF

ASIAN & PACIFIC ISLANDER
AMERICAN HEALTH FORUM

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