

Asian & Pacific Islander National Cancer Survivors Network



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Greetings from National Advisory Council Chair

As we enter spring 2010, I would like to extend a warm welcome to everyone on behalf of the Asian & Pacific Islander National Cancer Survivors Network (APINCSN). For over a decade, the Network has advocated for improved care, access to services, and inclusive health data for Asian Americans, Native Hawaiians, and Pacific Islanders (AAs and NHPs) affected by cancer.

As APINCSN's new National Advisory Council (NAC) Chair, I first wish to recognize the tireless leadership of our outgoing Chair, Susan M. Shinagawa. Susan's energy and expertise are matched only by her joyful character and generous nature. She continues to inspire everyone who has the good fortune of meeting her, and I am grateful to step into this role knowing that Susan has laid such a strong foundation before me. Susan will continue to serve on our NAC as Immediate Past Chair, and we are all grateful for her ongoing support and guidance.

My family moved from Vietnam to the United States in 1975. My cancer story began in high school, when my aunt Oanh was struck by colon cancer. Aunt Oanh lived with my family in New Jersey, and she was a second mother to me. She ultimately passed on with the cancer before my high school graduation. At the time, I knew nothing of colon cancer screening and early detection, nor did she. In fact, with her limited English proficiency, I later learned that she went through cancer treatments without ever being told in Vietnamese that she had cancer. My

Giang T. Nguyen,
MD, MPH, MSCE,
APINCSN National
Advisory (NAC)
Council Chair

Susan M.
Shinagawa,
APINCSN NAC
Immediate Past
Chair



cancer journey continued with my grandmother, who struggled bravely against oral cancer, the legacy of years chewing betel leaves in Vietnam (a common practice in Vietnamese culture for her generation). Finally, my own father developed lymphoma and leukemia when I was a medical student. I will never forget those final moments as I sat with him in the hospital room during his final hours in this life.

Now, as a family physician, educator, and public health researcher, I deal with cancer on many levels, from prevention to screening to coordination of treatment and care. As an immigrant, I see the particular challenges that cancer presents to patients and families who do not share the cultural and linguistic background of the mainstream institutions where they seek care. I became a member of the Network in order to fight the disparities facing AAs and NHPs, to dispel the myths surrounding cancer and our communities, and to advocate for improvements in treatment and care for all cancer survivors. Please join me in this important journey!

-Giang T. Nguyen, MD, MPH, MSCE

Vietnamese Colorectal Cancer DVD



Marie Tran
Watch her video at:
<http://www.youtube.com/watch?v=pUdlrxXeuhk>

Marie Tran, the Project Coordinator of the Breast and Cervical Cancer Education Project at the Vietnamese Social Services of Minnesota, seeks to dispel myths and educate her own Vietnamese community with a DVD entitled “Colon Cancer and How to Prevent It.” The DVD is divided into three parts—Colon Cancer, The Colonoscopy, and a Survivor Story. While the DVD is completely in Vietnamese, it comes with an English transcription.

In the Vietnamese community, colorectal cancer, cancer of the colon or rectum, is one of the top five commonly diagnosed cancers. Risk factors for colorectal cancer include a high fat and low fiber diet, obesity, tobacco use, and a family history of colorectal diseases. Unfortunately, colorectal cancer screening rates are much lower for Vietnamese Americans (45%) than non-Hispanic Whites (62%). It is recommended that people begin screening at age 50 to detect polyps (growths in the colon and rectum) at an early stage. Studies show there are many disparities within this community that prevent them from fully understanding this cancer and getting screened and treated: difficulty speaking or reading English, little education, and low employment rates/income. This free DVD will provide them with the culturally and linguistically appropriate education on colorectal cancer.

For a free copy of Ms. Tran’s DVD, please contact: *Vietnamese Social Services of Minnesota* (www.vssmn.org) at (651) 917-2945 or by email at mariemhtran@vssmn.org.

Fourth Annual Houston Chinese Cancer Patient and Caregiver Summit by Shane Chen

APINCSN Co-Founder, Susan M. Shinagawa was a keynote speaker at the Fourth Annual Houston Chinese Cancer Patient and Caregiver Summit on Saturday, January 9, 2010 at the Community Room of the American First National Bank. Summit organizers included Light and Salt Association, Herald Christian Crusade-Chinese Cancer Support, Tzu Chi, and Asian Cancer Council. The event drew more than 120 participants and was conducted in Mandarin. The annual Cancer Patient and Caregiver Summit is geared towards providing insights to healthy lifestyle, caregiver tips and resources, and advocacy opportunities to improve cancer survivorship.

Susan and Dr. Furjen Deng, a member of the Board of Directors of Light and Salt Association, were interviewed by Asian Insights broadcasts on TV 55.5, Houston's ethnic cable television station. Dr. Deng talked about the importance of cancer support in the Chinese community, and Susan talked about APINCSN and the Community

Page 2 Advocacy & Training on Cancer & Health (CATCH) Leadership Training opportunities.



Cancer Patients, Caregivers and Survivors Attending the Summit



Hostess Elsie Huang, Susan M. Shinagawa, Dr. Furjen Deng and Host Edmond Gor

Making Strides to Improve Health in the USAPI

By Lee Buenconsejo-Lum, MD

Effective programs and advocacy to control the entire spectrum of cancer require accurate baseline information and surveillance. The technology, resources and complexity required for a meaningful cancer registries have been difficult to maintain in the U.S. Affiliated Pacific Island (USAPI) jurisdictions*, especially when superimposed on a base of inadequately trained and inadequate numbers of health workers. Additionally, limitations in cancer diagnosis hamper accurate recording of information. Many cancer patients are still diagnosed too late, rendering the patient ineligible for off-island curative care. Most have no option except to remain at home to die, with inadequate access to palliative care.

Recognizing the critical need for improved data quality across the USAPI, the Cancer Council of the Pacific Islands (CCPI) has a long-term goal to develop functional cancer registries in each of the jurisdictions. The University of Hawai`i (UH) Department of Family Medicine and Community Health received funding from the Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR) to conduct a cancer registry assessment in 2005-2006. This informed the policy decision to regionalize cancer registry functions, while allowing for jurisdiction-specific data and reporting needs. UH works with the jurisdictions to develop the Pacific Regional Central Cancer Registry (PRCCR). The PRCCR, housed at the University of Guam, continues to leverage resources and build partnerships upon existing National Cancer Institute-(NCI)-funded efforts to improve the Guam Cancer Registry.

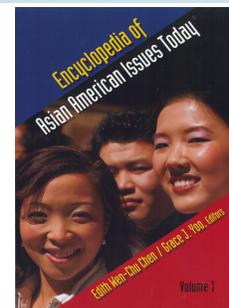
The first two years of the PRCCR cooperative agreement focused on training, policy development and addressing infrastructure challenges. Technical assistance and training, conducted in partnership with the Hawai`i Tumor Registry and CDC NPCR has developed a cadre of “home-grown” cancer registration professionals. Despite ongoing challenges, four of the six USAPI successfully reported 243 cancer cases for diagnosis year 2007 and an additional 351 cases for 2008 to the CDC NPCR in January 2010. These cancer registries are helping to lead process improvement and serve as model efforts to leverage scarce resources in close coordination with local and regional policy makers and community members. We thank the CDC, NCI, Intercultural Cancer Council, and all of the National Partnership for Comprehensive Cancer Control for their continued commitment to reduce health disparities in peoples of the USAPI.

* *The USAPI is comprised of three Flag Territories, and the three Freely Associated States (FAS). The Flag Territories are American Samoa, Guam and the Commonwealth of the Northern Mariana Islands (CNMI). The Freely Associated States include the Republic of the Marshall Islands (RMI), and the Republic of Palau (also known as Palau) and the Federated States of Micronesia (FSM) which consists of the states of Yap, Pohnpei, Kosrae, and Chuuk .*

Contributors to Asian American Textbook

APINCSN NAC member Dr. Mai-Nhung Le and APIAHF staff members Roxanna Bautista and Mavis Nitta had a great opportunity to contribute to the “Encyclopedia of Asian American Issues Today.” They contributed to the health section focusing on cancer among Asian Americans. This entry on cancer illustrates that when you disaggregate the data by ethnicity there are high rates of specific cancers among our communities. This section was divided and emphasized the cancer rates, challenges and issues, support for patients and family members, and the future outlook for the Asian American community.

For more information about the book, check out www.greenwood.com.



Remembering Chris Pablo



Chris Pablo's "BEAT LEUKEMIA" golf ball.

Christopher Gerard Pablo was a member of the APINCSN Steering Committee for 11 years. Even before his diagnosis with chronic myelogenous leukemia 15 years ago, Chris was a devoted health and social justice advocate. He was an attorney at Goodsill Anderson Quinn and Stifel law firm, was the former Director of Public Affairs at Kaiser Permanente, and was a Special Assistance to the U.S. Senator Daniel K. Inouye (HI). During his 30 years of his work, he helped pass legislation on patient's rights, indoor smoking ban, organ donation, and funding for breast and cervical cancer treatment for the uninsured women. He volunteered for the

Leukemia & Lymphoma Society, American Cancer Society and Steering Committee of the Hawai'i Department of Health Comprehensive Cancer Control Coalition. Chris was an amazing community leader who took pride in his work and was dedicated to helping the people of Hawai'i.

Last June, Chris was the recipient of the APINCSN's Frank Atherton Hua Peng Chong Cancer Survivorship Champion Award at the *Voices 2009: Amplifying the Call for Healthy Communities* Conference. Sadly, Chris lost his life to cancer on December 9, 2009, but the body of his work will be hailed by those whose lives he touched.



Susan Shinagawa, Chris Pablo, Sandy Pablo, and Giang Nguyen at June 2009 APIAHF Voices Awards Reception

Chris' Book of Hope Quote: "I believe in the good of patients sharing their stories and getting help for all dimensions: body, mind, spirit, and soul. Merely knowing about the disease, prognosis, and cures is just one dimension. Healing encompasses the whole self, not just the curing of the body from the disease."

CARE and Sisterhood in Atlanta By Carissa Chang

The Center for Pan Asian Community Services, Inc. (CPACS) has been reaching the greater Atlanta community with this voice in mind since its founding 30 years ago under the concept of "people need people." CPACS continues to provide linguistically and culturally competent social and health services to counteract issues faced by immigrants, refugees and other racial-ethnic minorities.

In 2007, CPACS started Korean Cancer Alliances and Resources for Empowerment (CARE), the first Asian in-language breast cancer support group in the South. CARE aims to reduce the burden of breast cancer among Asian American women diagnosed with breast cancer. It is the first culturally- and language-appropriate support group for Asian American women in the area. A trained facilitator and peer leader lead two-hour sessions twice a month. CARE provides: immediate support for women during the crisis period; the opportunity to share personal experiences of coping; knowledge of current treatments, prevention and rehabilitation; an explanation of the Western support system available; and friendship during survivorship. Now in its fourth year, CARE has expanded its services to begin a Chinese language CARE group in 2009.



"I know that I am not alone anymore."

The voice of sisterhood resonates loudly as the CARE groups prepare to participate for a third year in the annual Komen Atlanta Race for the Cure. Each year, the CPACS team grows to include not only the survivors but their families and CPACS staff. These community experiences have allowed women to celebrate their accomplishments and to see that they do not need to be alone in their journey anymore.

To see a video of Korean CARE, visit <http://www.youtube.com/watch?v=yOzOPTLxGno>.

Yu-Ai Kai's Japanese American Cancer Forum

Yu-Ai Kai Japanese American Community Senior Service Center in San Jose, CA held their "Cancer in the Nikkei Community: Awareness, Coping, and Resources" Forum on February 6, 2010. Over a hundred people attended this first Yu-Ai Kai - Kenko (healthy) Living Series. The keynote speaker was Dr. Marjorie Kagawa-Singer, from University of California, Los Angeles School of Public Health and Department of Asian American Studies, who spoke on cancer among the Japanese American community. She mentioned that Japanese American women have the highest breast cancer rates compared to other Asian American groups, while the men have the fastest-growing rate of colorectal cancer among all ethnic groups. She also stated that there must be greater efforts to educate and outreach regarding the risk of cancer among the Japanese American community.



Yu-Ai Kai Cancer Forum Audience

Because the audience was bilingual, the physicians, cancer survivors and caregiver speakers who spoke English and Japanese in different sessions. Dr. Katsuto Shinohara and Dr. Robert Nishime addressed cancer prevention and risk factors. They shared that current findings suggest the increased life expectancy and the Westernized diets and behaviors contribute to the greater risk for some types of cancer, particularly for those Japanese families who have lived in the U.S. longer. Susan M. Shinagawa, past APINCSN Steering Committee member Joanie Kajiwara Neveu, and a breast cancer survivor of 26 years, Eiko Yamaichi, were the breast cancer survivor panelists who talked about their survivorship, getting screened as early as possible, and having support from family and friends to help through their survivorship. This cancer forum was a great opportunity to educate and outreach to the Japanese American community in the San Francisco Bay Area to help them understand cancer risks, prevention and survivorship. Due to the interest from this Forum, Yu-Ai Kai will be starting a cancer survivor support group and a caregiver support group.



Breast Cancer Survivor Panel: Joanie Kajiwara-Neveu, Eiko Yamaichi, and Susan M. Shinagawa

For more information contact (408) 294-2505 or staff@yuaikai.org and visit Yu Ai Kai's website at www.yuaikai.org.

Community Members Receive Cancer Advocacy and Leadership Training in PA By Dr. Giang T. Nguyen

From November 5-7, 2009, members of the Asian American and Pacific Islander communities convened in Philadelphia for a 2½-day training sponsored by the Asian & Pacific Islander National Cancer Survivors Network (APINCSN). Representing cultural organizations, healthcare facilities, social service agencies, academic programs, and others, this diverse group of 17 community members met at the local office of the American Cancer Society. Most participants were local, but two people came from as far as Houston, TX. The workshop was scheduled to take place before the American Public Health Association (APHA) national annual meeting, so that workshop participants could stay in the City of Brotherly Love for the APHA convention as well.

In total, there were five sessions: 1) Cancer 101 in Asian American, Native Hawaiian and Pacific Islander (AA and NHPI) Communities; 2) Communication on Cancer and AA and NHPI Communities; 3) Data Advocacy; 4) Policy & Legislative Advocacy; and 5) Establishing Ethnic-Specific and Language-Specific AA and NHPI Cancer Support Groups. A special highlight included a session on Communications with a guest from the local ethnic media, New Mainstream Press Inc. Community members also learned the difference between media alerts and press releases, and they had the opportunity to practice their legislative advocacy skills. Workshop presenters came from the Philadelphia region as well as Washington, D.C., Houston and California.



Philadelphia CATCH Leadership Training Participants

This program in Philadelphia was the 3rd installment of an ongoing nationwide leadership training known as CATCH, which stands for “Community Advocacy & Training on Cancer & Health.” It is funded by the Centers for Disease Control and Prevention (CDC) and administered for the Network by the Asian & Pacific Islander American Health Forum (APIAHF).

For more information about the CATCH Leadership Trainings or to see if you can schedule a program in your community, please contact Mavis at cdprogram@apiahf.org.

Program Assistant Spotlight



Brianna Loughridge,
Chronic Diseases
Program Assistant

We have a new addition to our Chronic Diseases Program! Brianna Loughridge joined us as our Program Assistant this past December. She is a graduate from Emory University with a Bachelor’s Degree in International Studies and Chinese Language and Literature. For one semester, she was on a study abroad program at the Beijing Institute of Education in China where she had an opportunity to surround herself in the Chinese culture and language.

Before she came to the APIAHF, Brianna was an intern at the San Francisco Department of Public Health assisting the public health staff with Hepatitis and AIDS meetings, along with writing the script for the health disaster preparedness online training videos.

Please welcome Brianna to the Chronic Diseases Program!

JOIN APINCSN!

APINCSN 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 AA and NHPI communities. Please join us in growing this national network of Asian American, Native Hawaiian and Pacific Islander (AA and NHPI) cancer survivors, family members, caregivers, health care providers, researchers, advocates, and community members and organizations to move forward in the comprehensive cancer control movement. We are 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 and NHPI survivorship resources, and promoting cancer survivors into national policymaking and research committees.

Network Membership Benefits:

- Connection to a network of experts
- Collaboration on various cancer-related projects
- Opportunities to network through meetings and teleconferences
- Access to AA and NHPI specific cancer information, resources and materials
- Use of APIAHF's advocacy resources
- Obtain capacity building assistance and training, such as data and language materials and policy advocacy training
- Opportunities to provide feedback and determine cancer priorities
- Communication of national health policy and advocacy action alerts
- Receive APINCSN Newsletters
- Subscription to AA and NHPI cancer listserv: apicancer
- Involvement in APINCSN workgroups, CATCH Leadership Trainings, and Speakers Bureau

To become a member of APINCSN, please contact Roxanna Bautista at rbautista@apiahf.org or at (415) 568-3304.

CATCH Us in Phoenix, AZ

Join us at our **Community Advocacy & Training on Cancer & Health (CATCH) Leadership Training**. Our next stop is at St. Joseph's Hospital and Medical Center in Phoenix, Arizona (500 W. Thomas Road, Phoenix, AZ 85013). Our training is for 2.5 days from April 8 thru April 10, 2010.

Thursday, April 8: 8:00am — 4:30pm

Friday, April 9: 8:30am — 4:30pm

Saturday, April 10: 8:30am — 12:00 noon

This training will provide information on:

1. Introduction to Cancer 101 in AA and NHPI Communities
2. Communications on Cancer and AA and NHPI Communities
3. Data Advocacy
4. Policy & Legislative Advocacy
5. Establishing Ethnic-Specific and Language-Specific AA and NHPI Cancer Support Groups



Space is limited, so please RSVP by contacting Mavis at (415) 568-3311 or cdprogram@apiahf.org. The deadline to RSVP is March 31, 2010.

Calendar: January - June 2010

January:

National Cervical Cancer Screening Month

February:

National Cancer Prevention Month

March:

National Colorectal Cancer Awareness Month

April:

National Cancer Control Month

Testicular Cancer Awareness Week, April 1-7

National Young Adult Cancer Awareness Week,
April 4-10

National Minority Cancer Awareness Week,
April 18-24

National Oral, Head and Neck Cancer Awareness
Week, April 18-24

May:

Melanoma/Skin Cancer Detection and Prevention
Month

National Cancer Research Month

Brain Tumor Action Week, May 2-8

Women's Health/Cancer Awareness Day, May 9
(Mother's Day)

National Women's Health Week, May 9-15

World No Tobacco Day, May 31

June:

National Cancer Survivors Day, June 6

National Men's Health Week, June 14-20

Men's Health/Cancer Awareness, June 20 (Father's
Day)



Asian & Pacific Islander National Cancer Survivors Network

The Asian & Pacific Islander American Health Forum (APIAHF) is a national policy organization that influences policy, mobilizes communities, and strengthens programs and organizations to improve the health of Asian American, Native Hawaiian and Pacific Islander (AA and NHPI) communities. Founded in 1986, APIAHF provides guidance to individuals, groups, organizations by providing technical assistance, trainings, and help with organizational development. APIAHF works with community advocates, public health leaders, and policymakers to generate policy and systems change that benefit our communities at national, state, and local levels. APINCSN has been a program of APIAHF for eleven years.

The mission of the Asian & Pacific Islander National Cancer Survivors Network (APINCSN) is to minimize the burden of cancer and improve the quality of life of Asian Americans, Native Hawaiians and Pacific Islanders by dispelling myths, reducing disparities and providing hope, with the ultimate vision of having empowered, cancer-free Asian American, Native Hawaiian and Pacific Islander (AA and NHPI) communities.

For more information about how to become a member of the Network, go to www.apincsn.org.

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