

Asian & Pacific Islander National Cancer Survivors Network



Asian & Pacific Islander National Cancer Survivors Network

Inside this Issue:

- Time Traveler, Page 1 - 2
- Cancer Survivorship Research Conference, Page 3
- Minnesota Cancer Survivor Support Group, Page 4
- New York Patient Navigation Program, Page 4
- SuperMarket Tour, Page 5
- Arizona CATCH Leadership Training, Page 6
- Join APINCSN, Page 7
- Cancer Health Briefs, Page 7
- Calendar July–December 2010, Page 8



Time Traveler by Susan Matsuko Shinagawa

Travel back with me to 1991. It was a memorable and news-worthy year: South Africa outlawed Apartheid

and instituted a new constitution for a multicultural society, the U.S. led Operation Desert Storm against Saddam Hussein and the Iraqi Republican Guard, the “World Wide Web” was introduced to the public, Magic Johnson announced that he tested positive for the AIDS virus, Clarence Thomas was appointed to the U.S. Supreme Court, the Soviet Union dissolved, and the United States and Japan – each in its own way – commemorated the 50th anniversary of the bombing of Pearl Harbor.

For me, 1991 was most memorable because of 3 specific events – a *discovery*, a *response*, and an *announcement*. **First:** Five months after taking a breast self-examination workshop, I discovered a prominent and painful lump in my right breast. **Second:** Two months later, when I sought clinical evaluation of the lump by a breast surgical, his response was immediate and unequivocal: *“You’re too young to have breast cancer; you have no family history of cancer; and, besides, Asian women don’t get breast cancer.”* Accordingly, he refused to do a biopsy. **Third:** After six weeks, I sought a second opinion and underwent an excisional biopsy. The next day, I received a phone call from my surgeon, during which he announced, *“I’m sorry, Susan, but you have breast cancer.”* It was the first, but not the last time, I would hear those words. I was just 34 years old.

The following month I underwent surgery to remove my right breast, and started chemotherapy (CT) the week following Thanksgiving. I attended a cancer support group throughout the course of my CT. Everyone was very nice and extremely supportive, but I couldn’t help noticing that no one in the group looked like me. I started to become angry about the surgeon telling me, *“Asian women don’t get breast cancer”* – what a disservice, I thought – and very quickly I turned that anger into action.

By 1994, I was pretty well immersed in the cancer advocacy universe. I had already been speaking publicly about my cancer experience to various audiences across the U.S., and had been appointed to numerous California and national breast cancer advisory committees and research councils. I soaked up information like a sponge, expanding my knowledge base much further than I had ever imagined about breast cancer, research, clinical trials, data, coalitions, partnerships, government, appropriations, politics, when to compromise, and when to hold firm. During that period and the several years that followed, two things became crystal clear: (1) I had become the *token Asian and Pacific Islander (API) survivor advocate* for every mainstream entity with a (race-based) representative advisory council; the assumption being, not only did I have



September 1998—Susan Interview

expertise in every API community, but I could also act as a spokesperson for each community; (2) Despite speaking openly about my personal cancer experience across the U.S., including at health conferences focused on Asian American, Native Hawaiian and Pacific Islander (AA and NHPI) communities, in my first eight years as a breast cancer survivor, less than a handful of AA and NHPI women identified themselves to me as a fellow breast cancer survivor. Both revelations shared a common origin – AAs and NHPIs did NOT talk about cancer.



1999 - Steering Committee Meeting

Just as my frustration was reaching its pinnacle, the APIAHF convened its inaugural *Voices From the Community* conference in September 1997 to "broaden and strengthen the voices of Asian and Pacific Islander communities in impacting local and national health policy." When APIAHF's Executive Director Tessie Guillermo approached me in early 1998 with an invitation to collaborate with the APIAHF, my frustrations suddenly had a constructive outlet, and the concept for establishing a national API cancer survivors and advocacy network was born.

The inaugural Steering Committee determined that the Asian & Pacific Islander National Cancer Survivors Network's (APINCSN) mission 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.

In the 12 years since its inception, APINCSN has been instrumental in bringing about enormous change to the cancer survivorship milieu for many AAs and NHPIs. Among the most satisfying change for me, is that, now, when I speak at meetings and conferences across the nation, I have the honor and pleasure of meeting *many* AA and NHPI cancer survivors of all ages and ethnicities from across the U.S. and the Pacific, who openly and willingly share their cancer stories with me and others. This was evidenced by the APINCSN's *A Book of Hope* (2007), featuring the personal cancer stories of 14 AA and NHPI cancer survivors in their own words. It was featured on CNN's television program, "House Call with Dr. Sanjay Gupta," who interviewed Vietnamese breast cancer survivor Xiem "Mai" Tran in May 2007. In celebration of the Network's 10th Anniversary, the July 2008 *Asian American, Native Hawaiian and Pacific Islander Cancer Survivorship Conference: Dispelling Myths, Reducing Disparities & Providing Hope*, provided further evidence of the growing number of AA and NHPI cancer survivors sharing their cancer stories. Of the 225 conferees, 62 cancer survivors and 120 family members from 14 states, the District of Columbia and throughout the U.S. Associated Pacific Islands participated in the conference.



July 2008 Cancer Conference attendees

Despite these and many other improvements to the AA and NHPI cancer survivorship landscape, a commonly shared experience among breast cancer survivors is that a health care provider told them that API women don't get breast cancer. In fact, in January 2010 I spoke at Houston's 4th Annual Chinese Cancer Conference, where I met two Chinese women recently diagnosed with breast cancer. Both women, who found a breast lump, were told by their respective doctors not to worry, because, "Asian women don't get breast cancer!"

Imagine, once again, that you're a time-traveler, but now it's the year 2030. Twenty years from now, when we think back to where we are today, what will we recall? Will the most memorable moments of 2010 be that we helped AA and NHPI cancer survivors feel safe about sharing

their personal cancer stories? That we demanded and received more “seats at the table”, no longer relying upon the *token* representative to be the singular spokesperson for over 60 distinct communities?

We *have* come a long way in the past 12 years, but we still have a long way to go. We can't do it by ourselves – we need your help and support, and most importantly, we need your voices. Join us and make a difference!

*To read the full and unabridged story from Susan, please go to www.apincsn.org.

Cancer Survivorship Research: Recovery and Beyond 2010 Conference By Dr. Mai-Nhung Le

Recently, I attended the 5th Biennial Cancer Survivorship Research Conference, which took place in Washington D.C. from June 17 to June 19, 2010. I had a great opportunity to learn about current research in the area of cancer survivorship and to meet with colleagues who are doing research similar to what I am interested in doing. I left the conference feeling inspired with a sense of elation. Over 500 researchers, clinicians, and survivors came together from 44 states and 10 foreign countries with a single goal in mind: improving quality of life for cancer survivors.



The main goal of this biennial conference was to bring together investigators, clinicians, and survivors to share and learn about the most up-to-date cancer survivorship research. This 5th biennial conference was co-sponsored by the National Cancer Institute (NCI), American Cancer Society (ACS), Lance Armstrong Foundation, and Centers for Disease Control and Prevention. A major highlight of this year's conference was the role of exercise and weight control among cancer patients. At the opening session of the conference, Dr. Julia Rowland, the Director of NCI's Office of Cancer Survivorship, commented that the new focus on exercise and weight control is contributing to a growing body of research aimed at assisting cancer survivors live healthier lives. The Chief Medical Officer of ACS, Dr. Otis Brawley, stated that “cancer is more and more becoming a chronic disease.” He also commented that roughly two-thirds of cancer patients are expected to live at least five years after their cancer diagnosis. Other topics covered at the conference included: rehabilitation and recovery, follow-up care, co-morbidities and cancer, caregivers and family, young cancer survivors, survivorship in women of color, fertility and sexuality, emerging issues in outcomes measurement, e-health, social networking, and survivorship, and post-treatment communication issues. The concurrent sessions that I found to be most helpful to my research were those on caregivers and family and survivorship in women of color. Dr. Kimlin Ashing-Giwa from City of Hope in California gave a very comprehensive presentation on Health Related Quality of Life among women of color. Overall, she reported that women of color received fewer mastectomies than White women. Asian American and Hispanic women reported more concern about their social support than women from other racial groups. Although caregiving research in cancer survivors remains limited, there is a growing recognition of the importance of this area of research.

Overall, I got a great deal out of the conference. It provided a venue for those of us who are doing cancer survivorship research an opportunity to be updated with the latest research and issues concerning cancer survivorship. I was able to talk extensively with colleagues about their research agenda. I found the conference to be both educational and inspirational.

SuperMarket Tour by Jessy Lau



Tour of Hmart Great Neck

The American Cancer Society Asian Initiatives (ACS-AI) in New York organizes special activities for cancer patients and caregivers to focus on specific needs and topics that cannot be addressed in an office setting. On April 17, 2010, we were delighted to have a registered dietitian, Jennifer Kwon, give a tour at the Hmart Great Neck branch for cancer patients and caregivers. Two sessions with 20 participants each joined the tour at 10am and 1pm respectively. During the tour, Ms. Kwon explained to patients and caregivers a healthy way of shopping and how to choose the right food. Participants showed great interest when Ms. Kwon explained the nutritional facts of food that they consumed daily. They were very surprised that some of the food was not as healthy as they thought, due to additive substances. The tour helped answer many culturally related nutrition questions from patients and caregivers. Based on the positive response we received, ACS-AI will organize a similar activity every year.



James Kim receiving Appreciation Award

ACS-AI is happy to partner with Hmart to provide education about nutrition and healthy eating. To honor Hmart for their outstanding community service and strong commitment to improving the health of the Korean community, ACS-AI presented a certificate of appreciation to Mr. James Kim, Hmart Great Neck Branch Manager, on May 11, 2010.

New York Patient Navigation Program by Jessy Lau

In response to the increasing need from cancer patients in the Asian community, ACS-AI has expanded its Patient Navigation services to several hospitals and oncology clinics in New York. In August 2009, cancer survivor Mr. Berlin Lee began providing navigation to cancer patients at the St. Vincent Hospital Cancer Center. Being a prostate cancer patient, he readily gains trust from fellow male cancer patients and uses his own experience to encourage others to better cope with the disease and treatment. In the past eight months, Mr. Lee has provided guidance and support to 117 patients at St. Vincent Hospital.

In Chinatown, many cancer patients receive care at local oncology clinics such as Dr. Kin Lam's office. Therefore, ACS-AI decided to collaborate with Dr. Lam in providing additional care through a trained patient navigator, Ms. Victoria Wang. In turn, Dr. Lam generously provided a private room in his clinic specifically for the patient navigation program to let patients speak openly with the patient navigator about their concerns and anxieties, ask for guidance/resources and receive counseling. Since February 2010 Ms. Wang has provided support to 108 patients.

In April, ACS-AI placed Chinese-speaking patient navigator Mr. Berlin Lee at Radiation Cancer Center of the New York Hospital Queens to help Chinese cancer patients during treatment and link them to ACS-AI hosted patient programs and local community services.

Page 4 In addition, ACS-AI launched the first-ever Korean-speaking Patient Navigation program in

New York. In May 2010, two trained Korean-speaking Patient Navigators, Mrs. Soon Lee and Mrs. Dong Hae Shim started their services at the Radiation Cancer Center of the New York Hospital Queens, and Dr. Yunhee Chung's clinic, a renowned oncology clinic in the Korean community, respectively. Both were exceptionally helpful in providing support and guidance in a culturally appropriate manner to Korean cancer patients. Since it's launching last September, the Koran Patient Services Program has received overwhelming response from the Korean community. To this day, they have helped 75 patients in their battle against cancer. For more information, please contact Jessy Lau at jessy.lau@cancer.org.

Minnesota Cancer Survivor Support Group by Marie Tran

Cancer affects all races at all different ages. Having cancer is hard, and if you are an Asian American living in Middle America, getting cancer support sometimes can be harder. Being in Minnesota, where Asian ethnic groups are many but in small numbers, makes it difficult to have resources allocated appropriately to the needs of our cancer survivors. More often, we are not even being counted because of insufficient data collection and reporting. There are support programs at most cancer centers for cancer survivors only if you can navigate the system and can communicate in English.

Because of our 10 years spent educating the community about cancer awareness, preventive screening and early cancer detection, we now have many cancer survivors with different diagnoses of cancer. Currently, our Susan G. Komen for the Cure funded Southeast Asian Breast Cancer Outreach Project includes a breast cancer survivorship support component. In February 2010, the Cancer Education Program staff from the Vietnamese Social Services of Minnesota facilitated a support group for our cancer survivors. On February 4th, more than 20 survivors and caregivers attended the first cancer support group. Some were newly diagnosed and still in treatment, while others had been survivors for five years. They were very happy because most knew each other and now they shared one thing in common - surviving cancer. Another group of 11 participants met on March 20th. We are still in the pilot phase of organizing the support group. Feedback from participants are still being collected and analyzed for program planning. We hope to have the group meet on a more regular schedule. There is one Vietnamese support group and one-on-one support is provided to the Chinese and Karen (Burma) cancer survivors.

We are taking small steps, but we hope to find ways to sustain these support services. Thus far, the participants are very enthusiastic and willing to share their experience with each other rather than hiding their cancer from others. We have come a long way from people thinking of cancer as a death sentence. Now we are moving in a more hopeful and positive direction.

For more information contact:

Marie Minh-Hien Tran, Coordinator
Vietnamese Social Services of Minnesota
1159 University Ave W, St. Paul, MN 55104
Phone: (651) 917-2945
Email: mariemhtran@vssmn.org



Cancer Support Group in Minnesota

Arizona CATCH Leadership Training

by Brianna Loughridge

From April 8-10, 2010, members of the Asian American, Native Hawaiian, and Pacific Islander communities convened at St. Joseph's Hospital and Medical Center in Phoenix, Arizona for a 2½ day Community Advocacy & Training in Cancer & Health (CATCH) Leadership Training sponsored by the APINCSN. A diverse group of 27 individuals representing various cultural organizations, healthcare facilities, social service agencies, and academic programs from areas around Arizona and California attended.



CATCH Leadership Training attendees and staff

St. Joseph's Comprehensive Cancer Center generously provided attendees and presenters with appetizing breakfasts, lunches, and snacks for the 2 ½ days. Asian Pacific Community in Action (APCA) supplied support and aided in the recruitment of special speakers for the event. This program was the 4th episode of an on-going nationwide leadership training funded by the Centers for Disease Control and Prevention and administered for APINCSN by the APIAHF.

Local leaders in the fields of medicine, cancer, communications, data and epidemiology, policy advocacy, and ethnic cancer support groups are speakers at the training so participants can access knowledgeable experts right in their own "backyard" for more assistance.

Together, this group engaged in five training modules, headed by highly experienced professionals. In Module I, Dr. Heyoung McBride, local radiation oncologist, educated participants about cancer and APINCSN Co-Founder, Susan M. Shinagawa discussed the effects of the data and U.S. policies in cancer rates for AAs and NHPs. In Module II, Cara Liu of CBS 5 News, Abe Kwok of The Arizona Republic, and Doug Hirono from APCA discussed how to work with the television and online and print mainstream and ethnic media to communicate a clear message. In Module III, Dr. Tim Flood of the Arizona Department of Health Services framed the importance of understanding and using data to advocate change. Module IV coached participants how to use the data from the previous module for political reform. Lastly, Module V allowed participants to engage in dialogue with cancer survivors and support group experts Lou Quitugua, Judy Lai, and Dorothy Vaivao to discuss the challenges and strategies taken to help others diagnosed with cancer in various AA and NHPI groups.

Our trainees appreciated the hands-on and interactive nature of the CATCH Leadership Training. After the various presentations, trainees were able to participate and apply their advocacy skills.

"Inclusions of local professional journalists and Department of Health officials really bring interesting, exciting and relevant perspectives to the training... LOVED this training and learned a lot. Great job putting together the speakers for this training. Thank you!"

Thanks again to St. Joseph's Hospital and Medical Center, APCA, and to all CATCH Leadership Training participants and speakers!

JOIN APINCSN!

APINCSN is a network of cancer survivors, their family members, caregivers, 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 and NHPI) communities. Please join us in growing this national network 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 cancer issues through speaking events, networking, coordinating survivorship resources, and promoting cancer survivors into national policymaking and research committees.

Network Membership Benefits:

- Connection to a network of experts
- Collaboration on 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
- Opportunities to provide feedback and determine cancer priorities
- Communication of national health policy and advocacy action alerts
- Receive APINCSN Newsletters and subscription to 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.

Cancer Health Briefs

Cancer health briefs were created to provide information and cancer data on Asian Americans, Native Hawaiians and Pacific Islanders (AAs and NHPIs). The demographic data are from the U.S. Census Bureau's American Community Survey 2006 (except where otherwise noted). AA and NHPI data are disaggregated in tables to show the population change from 2000 to 2006.

Ethnic specific health briefs provide data on the ethnic population, cancer statistics, and prevention and detection practices. Chinese Americans, Japanese Americans and Tongans ethnic health briefs are currently available. Health departments, hospitals and community organizations can learn more about the health and cultural issues that affect these groups through these health briefs.

The state cancer health briefs include population groups that appeared as "Asian alone" or "Native Hawaiian and Other Pacific Islander alone". The state health briefs that were created for: Arizona, Arkansas, California, Colorado, Florida, Georgia, Hawai`i, Illinois, Massachusetts, Minnesota, Nevada, New Jersey, New York, Oregon, Pennsylvania, Texas, Utah, Virginia, Washington and Wisconsin. Health departments and community organizations can utilize this data on cancer among AAs and NHPIs, along with resources, such as health services and cultural organizations, in their state.

To read the health briefs, please go to the APINCSN website: www.apincsn.org

The image shows four covers of cancer health briefs. From top to bottom: 1. KANSAAS: KAHAKU TONGA AMELIKA MOE KANISAA. 2. CALIFORNIA: KAHAKU TONGA AMELIKA MOE KANISAA. 3. HAWAII: KAHAKU TONGA AMELIKA MOE KANISAA. 4. HAWAII'S MINORITY POPULATION: KAHAKU TONGA AMELIKA MOE KANISAA. Each cover features the APIAHF logo and text in both English and Hawaiian.

Calendar: July– December 2010

July:

UV Safety Month

September:

Childhood Cancer Month

Gynecologic Cancer Awareness Month

Health Literacy Month

Leukemia and Lymphoma Awareness Month

National Ovarian Cancer Month

National Prostate Cancer Awareness Month

October:

Liver Awareness Month

National Breast Cancer Awareness Month

National Mammography Day: Oct 16

November:

Lung Cancer Awareness Month

National Family Caregivers Month

National Marrow Awareness Month

Pancreatic Cancer Awareness Month

Great American Smokeout: Nov 18



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 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 twelve 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 communities.

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

APIAHF/APINCSN

450 Sutter Street, Suite 600

San Francisco, CA 94108

www.apiahf.org , www.apincsn.org

(415) 954-9988