

Asian & Pacific Islander National Cancer Survivors Network Summer Newsletter



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Asian & Pacific Islander National Cancer Survivors' Network Resource Guide

In 2005, APIAHF formally invited cancer organizations and advocates across the United States to submit service profiles to be compiled into the Asian and Pacific Islander National Cancer Survivors' Network (APINCSN) Resource Guide, an initiative that aims to enable AAPI cancer patients and caregivers as well as health professionals to access updated information about culturally and linguistically appropriate cancer programs and services. To recruit programs and advocates to submit information, APIAHF developed and distributed a resource guide directory form, which inquired organizations of their cancer services, ethnicities and languages accommodated, and regions served.

Since the release of the resource guide directory form, APIAHF has received

submissions from 140 cancer organizations and programs. Their service profiles were compiled into a booklet in July 2006 and are currently being disseminated to cancer service providers and programs. In addition, information about participating organizations and programs is accessible online at <http://www.apiahf.org>

Organizations and programs that provide cancer services for Asian Americans and Pacific Islanders are welcome to submit their information to be included in the online version of the National Cancer Resource Guide. For information about the Resource Guide and a submission form, or to request a copy of the resource guide, please contact Nicole Kang, Chronic Diseases Program Coordinator, at 415. 954. 9988 x 311 or nkang@apiahf.org.

AAPI Cancer Support Group Case Study

In December 2005, APIAHF first convened the National Asian American and Pacific Islander Cancer Support Task Force, a panel of health advocates and professionals selected by APIAHF to take leadership on various initiatives under the AAPI Cancer Survivors Capacity Building Project. One of these initiatives is the AAPI Cancer Support Group Case Study, a guide that will provide programs and organizations serving Asian Americans and Pacific Islanders, as well as prospective support group facilitators, with tools to create culturally and linguistically appropriate cancer support groups.

Throughout 2006, APIAHF and Task Force

members have been conducting group facilitator interviews throughout the country, specifically to inquire about their support group's history and structure, as well as the services they offer and populations they serve. In addition, support group facilitators were asked to provide a summary of success, challenges, and advice for other prospective support group leaders who seek to work specifically AAPI communities.

APIAHF is currently compiling the interviews into the Cancer Support Group Case Study that will be disseminated. Please contact Nicole Kang at nkang@apiahf.org for more information.

Pacific Islander Cancer Survivorship Educational Forums

In 2004, APIAHF was funded by the Lance Armstrong Foundation to develop the curriculum for and implement two Pacific Islander (PI) Cancer Survivorship Educational Forums in California. To ensure that the curriculum was tailored to respond to the needs and requests of PI communities, APIAHF conducted focus groups in Northern and Southern California for the Chamorro, Samoan, and Tongan communities during the first year of funding. Community responses revealed that there was a need for education around the topics of clinical trials and cancer support group development. In addition, the community voiced a need for cancer organizations and programs to share data and other information pertaining to cancer treatment and survivorship in the PI communities.

Using responses from the focus groups, APIAHF, in collaboration with Guam Communications Network, Samoan National Nurses Association, Taulama for Tongans, and NCI/CIS at Stanford, developed an educational program that was seen

into fruition at both Northern and Southern California PI Cancer Survivorship Educational Forums, which were held in Fremont, CA and Long Beach, CA respectively. The program included presentations from faculty from Stanford University and California State University, Fullerton, who presented cancer related data to the communities. In addition, there were three breakout sessions: clinical trials, cancer support groups, and Pacific Islander survivorship issues, as well as a “talk story” session that welcomed cancer patients and survivors from the communities to share their experiences with cancer. Both Educational Forums were well-attended by community members and cancer advocates and received positive evaluations.

Contact Edgar Ednacot at 415-954-9988 x326 eednacot@apiahf.org for a copy of the Proceedings Report of Educational Forums.



**Northern CA Forum
Participants**



**Pacific Islander Cancer
Survivorship Educational Forum**

Excerpt from the Southern California Pacific Islander Cancer Survivorship Educational Forum



Survivors Panel in Southern CA
(back) Antonio Perez and Lucianne Latu (front) Suzanne Robert, Faye Henrich, Vaillili Enesi, Esther Tufele, and Leonaitasi Saiti

Suzanne Robert, Breast Cancer Survivor

Crying is part of the healing process. You cry because you're reliving it today.

At the age 34 in 1997, I was diagnosed with an aggressive form of breast cancer. In October of 1997, I found a lump in my right breast. My doctor sent me to get a mammogram, and I was by myself because I had lost my mom. Right before my first surgery, I found a lump in my left breast that had gone undetected. Everything was not clear so they had to do another surgery. They found another lump in the left breast; the doctors were shocked because they thought it was the same lump. The doctors didn't know what to do with me because there were three tumors. They were fighting with insurance because they didn't know who would get money for the surgeries. They were not concerned just about me. My husband had to do all the fighting for me.

1998 came around. It was a major surgery for me at the City of Hope. I finally told them that THIS was about my life-about my husband, job, etc. On January 9, 1998, my surgery was 12 hours. They told me that the only thing I could do was have a bilateral mastectomy. During that time, I thought "What's going to happen to my children?"-a mother is the only one who "knows"-they needed me. I had no parents. There's no cancer in my family. It was just me. I had no support.

After those surgeries (I've been through 18), I had lost my hair/appetite because of the chemotherapy. I felt like giving up. There was a wing at the City of Hope-I saw this little girl wheeling out her chemotherapy IV. She had a Cinderella dress and no hair. Her face was so puffy. She came up to me and said, "Don't I look beautiful?" when I was about to give up. I said, "You look so beautiful" and thought to myself that I'd never give up. I said to myself "At least I had 34 years of my life; this little girl hasn't". I told myself that I'd fight it to my last breath. I was going to surround myself with positive people/positive things.

For me, it was the song "I Hope You Dance" that kept me going. I hope it keeps you going.



APINCSN Founders
Susan M. Shinagawa
Rev. Frank Chong



A Book of Hope: Stories of Healing to Honor AAPI Cancer Survivors

APIAHF was funded by the Center of Disease Control to develop “A Book of Hope: Stories of Healing from Asian American and Pacific Islander Cancer Survivors”, a publication created with the purpose of educating the AAPI community about cancer survivorship and to stir hope in patients and survivors about survivability. To recruit survivors Asian American and Pacific Islander communities, APIAHF first issued a “Call for Stories and Photographs” in January 2006 to local community and national cancer organizations and programs. In response, 14 cancer survivors from various communities, stretching from the Pacific Jurisdictions to the Mainland, stepped forward to share their stories of survivorship.

In the Book of Hope, each survivor shares his/her journey with cancer, including his/her experience

with initial diagnosis and treatment and success and challenges encountered during cancer treatment. In addition, each survivor provides recommendations for providers on how to approach the treatment of AAPI patients. The essence of the book, however, comes in the messages of hope that each survivor shares that reflect his/her perspectives on their journey with cancer as well as the love and encouragement that they wish to share with undergoing similar experiences.

The Book of Hope will be published and released in October 2006. For more information about the book and/or to request a copy, please contact Nicole Kang at nkang@apiahf.org.

AAPI Cultural Strategy Exchange Teleconferences

APIAHF has scheduled Cultural Strategy Exchange teleconferences for 2006 to address issues pertaining to cancer survivorship and cancer resource availability impacting AAPI communities. In previous years, APIAHF brought such issues to the surface through discussions on AAPI Patient Navigator Programs and AAPI Clinical Trials. For the 2006 conference series, APIAHF utilized a new approach to addressing AAPI issues by shaping each teleconference to be community specific, primarily to engage community advocates and members in more in-depth discussions about relevant topics. Communities that were highlighted in these teleconferences included: Pacific Islanders, Southeast Asians (Cambodian, Thai, Lao, Hmong, Vietnamese), and South Asians.

In March, APIAHF held a Cultural Strategy Exchange Teleconference focused on the Pacific Islanders. Featured speakers included Lola Sablan-Santos, Executive Director of Guam Communications Network, and Sala Mataalii, Founder of the Samoan National Nurses Association, who led a discussion on their experiences working with cancer patients and survivors. Their discussion focused on cancer treatment and survivorship issues in Pacific Islander communities and their

recommendations for health care providers and organizations working with Pacific Islander patients.

In April, APIAHF conducted a teleconference focused on the Southeast Asians. Featured panelists were Mai Tran, an APINCSN Steering Committee Member and Support Group Facilitator for the American Cancer Society, and Maichew Chao from Families in Good Health of Long Beach, CA, who shared their experiences with working with Vietnamese, Lao, Hmong, and Cambodian communities. They focused primarily on the status of programmatic and policy initiatives that focus on Southeast Asian (SEA) health, the challenges and barriers that SEA patients face in obtaining cancer and general health care, and their recommendations on how physicians and cancer program staff can synergize to create a better healthcare delivery model for the communities. Both of these teleconferences yielded participants from various regions of the United States and fostered information exchange and networking opportunities.

In September, the South Asian Cultural Strategy Exchange will take place. For more information, please contact Nicole Kang.



The Robert Family



Luci Latu & Leafa Taumoepeau



The Lin Family

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We're on the web!
<http://www.apiahf.org>

The Health Forum is a national advocacy organization dedicated to promoting policy, program, and research efforts to improve the health and well-being of Asian American and Pacific Islander (AAPI) communities. Founded in 1986, the Health Forum approaches activities with the philosophy of coalition-building and developing capacity within local AAPI communities. We advocate on health issues of significance to AAPI 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 AAPI health.

2006 AAPI National Health Summit

APIAHF will be hosting the AAPI Health Summit on September 14-16, 2006 at the San Jose Marriott in San Jose, CA. The Summit, a 2 ½ day event that will bring together policymakers, public health and health care providers, researchers, and community voices, will feature plenary sessions that will address strategies to eliminate health disparities and improve access for AAPI communities. In addition, there will be ten individual tracks that will focus on a wide range of topics and communities, including cancer survivorship.

For information about the AAPI Health Summit's Cancer Survivorship Track, please refer to www.apiahf.org or contact Roxanna Bautista at rbautista@apiahf.org.

