

# Asian & Pacific Islander National Cancer Survivors Network

## Autumn Newsletter



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### 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 this newsletter, excerpts from six cancer survivor's story about his/her journey with cancer will be shared. These six survivors are part of the Steering Committee of the Asian & Pacific Islander National Cancer Survivors Network. Their complete stories will be in the finalized Book of Hope.

The Book of Hope will be published and released in December 2006. For more information about the book and/or to request a copy, please contact Edgar Ednacot at [eednacot@apiahf.org](mailto:eednacot@apiahf.org).

### Susan M. Shinagawa, Japanese American, Breast Cancer Survivor

*Excerpt from Book of Hope*

"What was worse was dealing with the medical system. My biggest headache was with the insurance company. Four years after chemo, I had to get the hospital to stop sending me bills. I had had three to four biopsies on the other breast following the first breast cancer, and I was still getting billed for the approved surgery of the initial biopsy. I had medical leave after the surgery and was doubly covered with my military insurance, but the insurance companies and the hospital had conflicting information. I was being charged \$13,000 a month for chemo. I was also dealing with doctors. My regular doctor was out of town, so another doctor took over. If I had any problems, I was to talk to this other doctor. I had thrush, black outs, and rashes, which I should have been reporting as they happened, but I was saving it up for the in person appointments with the doctor. At these appointments I had my blood drawn, white blood cell counts, and chemo dosages were determined. I had some questions and I shared my serious issues, but the doctor didn't have any time. He just ordered tests and prescribed medications. Later, I got a copy of my appointment records and saw that the doctor had written that I, the patient, was hysterical and needed psychological counseling. I had to deal with people like that."

"It's not how much life you have, it's the quality of life you have. For women, you are not alone. A large number of women, including myself, have also gone through this, and most are more than happy to talk, share, cry, and let you know that you are not alone. I knew I could get through it. Find somebody to talk to, or a group to talk to, and you can get through it. I don't want to give false hope, but I know you can live the best life you can, and you can die with dignity."



**APINCSN Co-Founder**  
Susan M. Shinagawa

## Jina Peiris, Sri Lankan, Breast Cancer Survivor

*Excerpt from Book of Hope*

"I found my lump in the shower and not through a mammogram. I told my doctor and asked him to do a biopsy and it was done. Three days later I knew it was cancer. When I was diagnosed with cancer, I felt very lonely and scared. I didn't know what to do and whom to reach for advice or help. I didn't know anyone who had breast cancer in my community. I knew that cancer is not something that people would discuss. I wanted to talk to someone. I wanted to know if this was a death sentence."

"The needs of Asian cancer patients are varied. Health care providers need to be trained and educated about different cultural and linguistic environments and aspects. Most doctors are not trained to talk to Asian women. Asian cultures are different. Every country has different ways of looking at things. There are issues with language, insurance, medications, not knowing who to talk to, and being denied because of your accent. We need culturally and linguistically appropriate educational materials in different languages. We need interpreters and translation available. We also need information about financial assistance for cancer treatments as well as for the family. We need support groups. We need to know how to find a good doctor, where we can go for second opinions and other recommendations for treatment, and where to go for support."



## Christopher Pablo, Filipino, Chronic Myelogenous Leukemia Survivor

*Excerpt from Book of Hope*

"When the diagnosis was given, my wife and I were in the exam room. The oncologist sat in one corner of the room, and delivered the message to us in a business like fashion. We had met with a hematologist and we were already expecting something bad. Still, it was pretty shocking to receive that news. I was just numbed by it all. There was that fear of dying and leaving behind my wife and children. I was concerned more about them than I was about myself, because they are the people relying on me."

"Two months after my diagnosis, I was practicing on the driving range of a golf course. I found a messenger at the driving range. I picked up a golf ball from the bucket and put it on the mat, preparing myself to hit it. There was a message of hope on it. It said, "Beat Leukemia." This eventually became a front-page story."

"Accept hope from things that you don't even expect. It's worth it. This journey was the biggest blessing, besides my wife and kids. I learned a lot and it wasn't a death sentence."



## Jackie Young, Korean, Breast Cancer Survivor

*Excerpt from Book of Hope*

"Because I was in the limelight politically, the Star-Bulletin, the local paper, had heard I was going through treatment and asked to do a story. I said, "Sure," and I took off my wig. It didn't bother me to take it off because I just thought of it as, "This is the way it is." The doctors told me my hair would grow back, so I thought it was part of the process and I was okay with the baldness. I was surprised to see that I had made the front page of the newspaper, in color, and with my bald head. After the interview, I received a lot of calls from women who didn't know that I had cancer and who said I was brave for showing my bald head. I got a lot of comments about that and I got faxes and cards."





**APINCSN Co- Founder**  
*Rev. Frank Chong*

## **Rev. Frank Chong, Chinese, Nasopharyngeal Cancer and Squamous Cell**

*Excerpt from Book of Hope*

“I’m an unusual case because I’m a long-term survivor of 33 years. There are things that I’m going through that many others haven’t. Some of the long-term survival issues that I’ve had to deal with have to do with all kinds of complications with my head and neck. The neck is filled with different muscles, nerve endings, and blood vessels. In 1988 through 1990, my carotid arteries started to shut down due to radiation damage, and it was serious. The radiation also badly damaged my neck muscles, and I’ve had occasional muscular problems such as hardness and cramping in my neck that radiates into my chest. Sometimes, I feel like I’m having a heart attack. Another major issue has to do with my oral health. Most people who have head/neck radiation have damaged salivary glands, they get dry mouth, and their taste buds are badly damaged. Your teeth disintegrate as well. Also in the head/neck area is the thyroid gland, which plays a part in controlling blood pressure. I’ve occasionally had problems with low blood pressure. In the last 5 years, I’ve developed Bell’s Palsy, which is essentially loss of muscle control on the side of the face. Whether it’s related to the radiation or not, though, no one knows.”

“Cancer is probably the most dramatic experience that anyone could have. It’s dramatic in that it’s a turning point in one’s life and it’s a challenge. Cancer is both physical and metaphysical. It is spiritual and existential because it forces one to find one’s place in time and space and to make peace with one’s maker.”

## **Xiem “Mai” Tran, Vietnamese, Breast Cancer Survivor**

*Excerpt from Book of Hope*

“I remember very vividly, in May 1999, I went to Walgreen’s to buy some vitamins and the store had a campaign—if people bought a rose, the money would go to cancer research. I thought to myself that if the month of May had 31 days, I should buy 31 flowers. I bought 31 flowers dedicated to this cause, because I was thinking of breast cancer and had hope that no one would get cancer. I didn’t think that I would be the one that would get cancer.”

“In terms of treatment, I chose to undergo a clinical trial that lasted 12 weeks. Everyone, family and friends, were against me going into the clinical trial. I still did it. I chose a trial that was in its third stage, plus there weren’t a lot of Asian women in the research. I knew that if I participated, I would be very disciplined and it might increase my chance of avoiding a recurrence. The clinical trial involved a different medication that was not that different from the mainstream treatment.”

“I learned a lot from the support group, especially emotional support. I realize that some other had it worse. There was a young man in his 30s that cried when he saw the rest of us laughing at a meeting. So we talked to him and asked him what was going on with him. He had lost his hair and his daughter thought that he looked like a monster. We gave him a hug and gave him some tips, some ways to talk with his daughter. He was much better the next week. This was just another example of the healing process that each had to go through. In 2002, I was happy to set up a Vietnamese support group for cancer survivors and patients just like

the ones I went to in the Wellness Community.”

“What I recommend for other cancer patients is that they become more educated so that they are not too scared and that they know where to get help and information. I also recommend that they contact an outreach group, because the staff are willing to make follow-up phone calls and home visits. A support group is definitely a must, especially during chemotherapy. It’s a place where people can go and feel that they belong. I especially recommend this for Asian patients. Our culture teaches us to share in the joys but not in the sorrows. Asian patients need a place to learn how to open up and get help.”



## Families, Caregivers, and Friends Supporting Cancer Survivors Photos from the Book of Hope



### APIAHF Cancer Survivorship Mentorship Program

On September 14, 2006, APIAHF released a Call for Proposals for the Cancer Support Group Mentorship Program, an effort of the Asian and Pacific Islander Cancer Support Capacity Building Project (APICSCB). The goal of the mentorship program, which provides one-time funding of up to \$10,000, is to provide community based-organizations, health clinics, social service organizations, and cancer survivors/advocates with the opportunity to develop local AAPI specific cancer support groups. Awardees are assigned mentor organizations or support groups to assist in the development of the activities and to provide peer-to-peer support in developing the support group. The proposals for this program were requested by October 9, 2006 to undergo review with the Mentorship Program's Grant Review Committee, which was comprised of health professionals from national AAPI serving organizations.

In November 2006, APIAHF and the Cancer Support Group Mentorship Program Grant Review Committee were pleased to award three organizations funding from December 2006 to June 2007 to develop support groups in various regions of the continental United States and Pacific Jurisdictions. Guam Communications Network of Long Beach, CA has been awarded \$9,000 to facilitate the development of Chamorro in-language support groups on Guam. Center for Pan-Asian Community Services, located in Atlanta, GA, was awarded \$6,000 to develop a psychosocial Korean support group. Finally, Herald Cancer Association in Houston was awarded \$5000 to develop the first Chinese support group in Fort Bend, TX to accommodate the needs of cancer patients in the growing Chinese population in the region. These support groups will be mentored by more established cancer support groups and will be provided technical assistance and training as needed.

For more information regarding the Cancer Support Group Mentorship Program, please contact Roxanna Bautista at [rbautista@apiahf.org](mailto:rbautista@apiahf.org) or 415-568-3304.

## 2006 APIAHF AAPI National Health Summit– Cancer Survivorship Track

On September 14-16, 2006, the Asian & Pacific Islander American Health Forum hosted the AAPI National Health Summit in San Jose, CA. This conference, attended by nearly 600 health professionals and community advocates from the continental United States and Pacific Jurisdictions, featured specialized tracks and forums that addressed public health and health policy issues to AAPI communities. One of the tracks featured during the Summit was the Cancer Survivorship Track, which was developed by the Chronic Diseases Program of APIAHF.

Prior to the beginning of the Cancer Survivorship Track, the Chronic Diseases Program hosted a grant writing training to officially release the program's Call for Proposals for the Cancer Support Group Mentorship Program, a grant opportunity for 501 ( c ) 3 organizations to develop culturally and linguistically appropriate support groups in priority communities and regions. Various organizations attended to learn about the opportunity and to gain skills on proposal writing.

### Cancer Survivorship through the Eyes of Survivors and Providers Panel



The first workshop of the track was titled “Cancer Survivorship through the Eyes of Survivors and Providers”. Four cancer survivors, who were each paired with a health care provider on the panel, shared a specific issue encountered during their cancer experience and each health care professional provided the medical perspective of each issue. Featured cancer survivor speakers included Lucianne Latu (Tongan bone cancer survivor), Suzanne Robert (Chamorro breast cancer survivor), Jina Peiris (Sri Lankan breast cancer survivor), and Jackie Young, PhD (Korean breast cancer survivor). The featured healthcare provider speakers included Evaon Wong-Kim, PhD, MPH, MSW (Chinese Social Work Clinician, Professor, Researcher), Victor T. Tofaeono, MD, FACS (Samoan Surgeon, Medical Administrator, Health Researcher), Nitin K. Shah, MD (Asian Indian Neuro-anesthesiologist, Internist), and Giang T. Nguyen, MD, MPH (Vietnamese Family Med Physician, Public Health Researcher).

The second workshop was titled “Improving Access to and Utilization of Cancer Care Continuum through Community Based Participatory Research.” In this workshop, representatives from Asian, Native Hawaiian and Other Pacific Islander, American Samoan, and Muslim community based participatory research cancer projects highlighted their activities in addressing their respective communities’ health concerns along the cancer control continuum. Featured speakers included Moon S.C. Chen, Jr., PhD, MPH (Asian American National Cancer Awareness, Research, and Training), Jacqueline H. Tran, MPH and Alek A. Sripipatana, MPH (Weaving an Islander Network on Cancer Awareness, Research and Training), Victor T. Tofaeono, MD, FACS (American Samoa Community Cancer Network), and Magda A. Shaheen, MD, PhD, MS, MPH (The Muslim Breast Cancer Project).

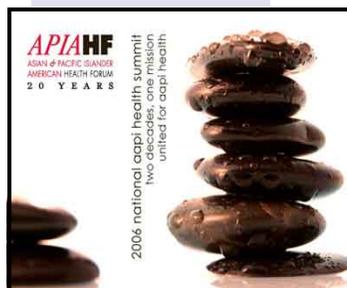


### Improving Access to and Utilization of Cancer Care Continuum through CBPR Workshop

The third workshop was titled “Tools and Strategies for Developing AAPI Ethnic Specific Cancer Support Groups” and Chinese and Samoan cancer support group facilitators shared their experiences in developing a cancer support group for the communities they serve, and provided tools and strategies to participants interested in starting their own community support group. A Samoan cancer survivor and support group participant also spoke and discussed about her participation in the support group and how it has helped her heal. Featured speakers included Lei-Chun Fung, MPH, MSW (Chinatown Public Health Center) and Marina Tupua, RN and Vailili Enesi, RN (Samoan National Nurses Association).

The last workshop was titled “Develop National AAPI Cancer Survivorship Agenda” where the Cancer Survivorship Track participants assisted APIAHF staff in categorizing and prioritizing the various recommendations that were gathered during each of the workshops to be developed into a National AAPI Cancer Survivorship Agenda.

The attendees found all sessions informative, applicable to their work in their communities and were able to network with Asian American, Native Hawaiian and Pacific Islander health advocates from around the country. They also contributed to the discussions and provided recommendations during the sessions, which will be disseminated in 2007.



## Asian and Pacific Islander American Health Forum

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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.

The APINCSN Online Cancer Resource Directory is a compilation of organizations that offer cancer services for Asian American and Pacific Islander (AAPI) communities. The APINCSN Online Cancer Resource Directory provides detailed information about some of our network members, the AAPI 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.

This online directory is comprised of a listing of network members and organizations who expressed interest in promoting their resources to the community through a listing in this guide. Each organizational listing includes the following information: contact information; cancer services; cancer/site served; language services; ethnicities served; regions covered; and fees for services.

This online directory is searchable by type of service, location, and languages spoken. If you find any errors in or would like to update your entry for the APINCSN Online Cancer Resource Directory, please contact us. We are open to suggestions to improve the usability of the online directory to best meet your needs.

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](mailto:rbautista@apiahf.org).

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