

Asian & Pacific Islander National Cancer Survivors Network News

Message from the Director

Roxanna Bautista



The Asian & Pacific Islander American Health Forum (APIAHF) has many accomplishments to share from our Asian American and Pacific Islander (AAPI) Cancer Survivors Capacity Building Project. We have conducted seven focus groups in Washington D.C., Hawaii, Massachusetts, Washington, and Minnesota to assess cancer services available for AAPI communities. In addition, we have conducted a national online survey to fill in geographical gaps not addressed by the focus groups which yielded over 100 responses. Results from the survey and focus groups will be compiled into a recommendations report and disseminated through our Asian & Pacific Islander National Cancer Survivors Network (APINCSN) membership, APIAHF website, and to cancer organizations and advocates. Three peer to peer strategy exchange teleconferences were also held to address the issues of AAPI cancer support groups, clinical trials, and patient navigation. In addition, APIAHF has been successful in developing a database of 100 cancer services and programs to be compiled in a printed and soon to be online AAPI cancer resource directory. Relationships with AAPI community-based organizations (CBOs), mainstream organizations and health departments have also been built to better address cancer within our communities.

Although we have faced challenges in our project, we are determined to ensure that our activities are responding to the needs of AAPI communities. In the next year of our project, APIAHF will work with experts in the field of cancer survivorship to develop a case study addressing best practices and challenges in developing cancer support groups for AAPIs. In addition, APIAHF will create an advocacy publication entitled “The Book of Hope” highlighting the impact of cancer in AAPI communities and stories from AAPI cancer survivors. APIAHF will continue to have strategy exchange teleconferences and the topics will include cultural considerations of cancer within specific AAPI communities. The AAPI Cancer Resource Guide will be made available online and will be searchable by users looking for cancer services. Lastly, APIAHF will continue to recruit for individual and organizational membership for the APINCSN.

APIAHF continues to see the importance of developing stronger collaborations with local, state, regional, and national AAPI and mainstream cancer organizations to include AAPIs in their reach and services. APIAHF is committed to helping people who have been impacted by cancer and strives to provide information to assist our communities in living longer and stronger with cancer.

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Year 2 Focus Group Highlights

APIAHF and its Consortium Partners recently implemented a series of focus groups in Washington, Hawaii, and Minnesota to assess Asian American and Pacific Islander (AAPI) I community needs in regards to cancer and survivorship. The focus groups gathered cancer survivors, community members, and health care providers to exchange information about existing support services, discuss challenges and barriers in patients' access to cancer-related services, and brainstorm methods by which to address patient needs and concerns. The insightful feedback of patients and providers at these sessions have deepened APIAHF's and consortium partners' perspectives on appropriate care for AAPI cancer survivors and strengthening efforts to develop groundbreaking, relevant programs and resources.

WASHINGTON

The first focus group was convened on May 10, 2005 in Seattle, Washington. The focus group expressed concerns about the availability of culturally appropriate and cost-effective health care. Most participants agreed that it was challenging to find physicians who provide cancer information to them that was easy to understand and dedicate more time during office visits to answer their questions and concerns. In addition, participants expressed frustration in finding credible cancer

“Participants expressed frustration in finding credible cancer resources and information online.”

resources and information online. Despite concerns about the number of challenges faced in accessing reliable physicians and information, participants acknowledged that the availability of comprehensive information distributed through the cancer-focused websites was helpful in guiding their treatment and recovery process. In addition, members of the group strongly attributed their healing progress to their participation in programs that promoted fitness and health education, the guidance and support of fellow cancer survivors and family members, and spiritual practices.

Focus group participants from this session recommended the development of a web-based database through which patients can access: 1) lists of hospitals and physicians that specialize in cancer care; 2) information about language-specific programs and resources; and 3) contact information of cancer survivors and resource persons. Additionally, it was suggested that organizations strongly advocate for increased coverage of cancer screenings by insurance companies and access to services for the uninsured.

MINNESOTA

The second in our series of focus groups gathered in Minneapolis, Minnesota on May 23, 2005. The discussions that emerged primarily focused on issues of cancer treatment and survivorship in Hmong, Vietnamese, and Cambodian communities. Among the number of concerns addressed was the issue of language and cultural competency. Participants expressed concern around the lack of resources, such as interpretation services and print materials, that could successful convey important treatment information to patients. Focus group participants also mentioned the lack of physicians that can accommodate to specific cultural and linguistic needs in treatment. In addition, there was an extensive discussion on issues related to healthcare costs. Participants mentioned that costs for visits,

screenings, cancer treatment, and post-treatment follow-up exceeded their ability to pay, regardless of whether or not they had health insurance coverage. Furthermore, there was also discussion about the lack of advocates in Hmong, Vietnamese, and Cambodian communities who are able to assist in the development of culturally appropriate programs.

Recommendations that emerged from this session included suggestions to increase access to information about health insurance and coverage for those under 40 years of age, a group that has been noted as needing the most financial assistance. Additionally, there was a call to develop more educational programs that could provide the community with basic knowledge of cancer, cancer treatment, and other available services geared towards preventing the onset of other chronic diseases in AAPI communities. Focus group members also emphasized the need for medical facilities to integrate their ethnic-specific medical paradigms into the delivery of health care. Often, AAPI communities prefer their care to be collectively shaped and administered; patients appreciate it when doctors consult with and empower their loved ones to have a role during the treatment and recovery process. Most notably, participants pushed for stronger advocacy efforts to be spearheaded by physicians and other health care providers.

HAWAII

The last set of focus groups was held on June 16, 2005 at the Pacific Global Health Conference in Honolulu, Hawaii. This focus group was primarily aimed towards cancer program staff working in the Pacific Islander jurisdictions. The participants discussed the barriers in Pacific Islander regions that have prevented Pacific Islander patients from participating in support groups and from seeking timely and appropriate cancer care. Such barriers include cultural belief models that discourage individuals from discussing their diagnosis and treatment if individuals “do not feel sick”. Other barriers include the lack of non-governmental organizations and comprehensive cancer centers that provide primary and cancer treatment, respectively. More notably, focus group members emphasized that the low usage of available health care can be attributed to high rate of poverty lack of insurance coverage.

“There were recommendations to develop materials in various Pacific Islander languages”

Although participants acknowledged the recent introduction of gender-specific support group programs and cancer control initiatives, the overall consensus was that the need for funding, treatment services, and educational programs is crucial. Focus group members recommended that, especially for the Pacific Islands, efforts must be made to transform cultural beliefs that may advocate false pretenses about cancer. Moreover, there were recommendations to develop materials in various Pacific Islander languages and brainstorm methods to create support groups. Finally, there was a call to advocate for the availability low-cost and free of charge cancer services.

For more information about the focus groups, please contact Amy Wong at awong@apiahf.org or (415) 954-9988 ext 305.

In September, APIAHF moves to its third year of the AAPI Cancer Survivors Capacity Building (CSCB) project. During the upcoming year, APIAHF will be working to increase the number of cancer resources through the continued development of a sustainable network of cancer programs and support groups serving AAPI communities. It is a priority for APIAHF to devote efforts to build the capacity of cancer survivors and programs that advocate for culturally appropriate support services and develop materials aimed to increase survivorship awareness in the community. In addition, the project will continue to provide capacity building assistance and support to AAPI serving cancer support groups, AAPI serving community based organizations, health departments, and national cancer programs. In keeping with our goal to improve cancer awareness, screening, early detection, and survivorship for AAPI communities, APIAHF will be working on the following activities in Year Three:

Book of Hope

Based on focus groups and informal key informant interviews with cancer survivors, cancer programs, and community members, the overall AAPI cancer survivorship population has little experience in advocating for survivorship issues and needs. As a first step to engage AAPI cancer survivors to talk openly about their cancer experience, APIAHF will be developing the Book of Hope to promote cancer survivorship and raise awareness about AAPIs thriving with cancer. The Book of Hope will include photos and personal stories of cancer survivors, families, and their caregivers. It can be used as an educational material since there will be information included to highlight facts about cancer, prevention, early detection, and survivorship.

AAPI Cultural Strategy Exchange

APIAHF will convene regularly scheduled teleconferences that focus on specific AAPI ethnic groups. Teleconference topics will focus on cancer survivorship support issues, cancer related legislation directly impacting AAPI cancer survivors, and other cancer resource related concerns. The teleconferences are intended to encourage communication, collaboration between programs, and dialogue around culturally appropriate methods in working with AAPI communities around cancer and survivorship.

Online AAPI Cancer Resource Guide

The AAPI Cancer Resource Guide will be made available on the APIAHF website for community members to be able to access updated information about cancer programs and services.

AAPI Cancer Support Group Case Study

APIAHF will be working with the National AAPI Cancer Support Group Task Force to compile case studies of the various AAPI cancer support groups conducted throughout the United States. The Case Study can be used to assist local programs and organizations to develop support groups appropriate for the communities.

APIAHF will continue to outreach and recruit organizations, community members, and cancer survivors to be involved with the Asian & Pacific Islander National Cancer Survivors Network (APINCSN). The benefits of Network membership include access to AAPI specific cancer information, resources, and materials; one-on-one technical assistance and training on cancer and survivorship programming; free copies of any cancer related materials produced by APIAHF, e.g. AAPI Cancer Resource Guide, Book of Hope; and opportunity to provide feedback and determine priorities around AAPI survivorship.

As the AAPI Cancer Survivors Capacity Building project moves forward with this exciting year, we hope that you will get involved with our activities. If you are interested in becoming an APINCSN member or have questions about the AAPI CSCB project, please contact Amy Wong at (415) 954-9988 ext 305 or Nicole Kang at (415) 954-9988 ext 311 for more information.



AAPI Cancer Resource Guide Available Fall 2005!

AAPI Cancer Resource Guide

The APIAHF has been funded by the Center for Disease Control and Prevention to develop a resource guide that contains information about culturally sensitive and linguistically appropriate healthcare resources for AAPI cancer patients and survivors. Comprised of information from AAPI focused community organizations, national cancer programs, and health department programs, the resource guide specifically aims to navigate cancer patients and survivors towards cancer prevention, detection, and survivor support services. The resource guide will be distributed in print form in October 2005. In addition, a searchable online form of the resource guide will be accessible through the APIAHF website in 2006.

Since the APIAHF's initial call for resource guide submissions, we have received over 125 forms from organizations and programs nationwide. As the APIAHF prepares to finalize the compilation of information to be featured in the print form of the resource guide, we invite your organization to submit a form to be included in the publication. To receive a resource guide form or to learn more about the resource guide, please contact Nicole Kang at (415) 954-9988 ext 311 or nkang@apiahf.org.

AAPI CSCB Consortium Updates

The Association of Asian Pacific Community Health Organizations (AAPCHO), Family Health Center of Worcester (FHC), and Kalihi-Palama Health Center (KPHC), APIAHF's Consortium Partners, have been instrumental in the compilation of resources for the APIAHF Cancer Resource Guide and recruitment of membership for the Asian and Pacific Islander National Cancer Survivors' Network. In addition, our Consortium Partners have participated in monthly teleconferences with APIAHF to exchange recommendations and strategies in regards to programming for cancer survivorship and facilitated focus group sessions focused on assessing needs in regards to cancer treatment and survivorship in the AAPI community. AAPCHO, FHC, and KPHC are also committed to recruiting for the National AAPI Cancer Support Group Task force as a part of the AAPI Cancer Survivors Capacity Building Project.

Apart from APIAHF activity, our Consortium Partners have been actively advocating and developing programming for specific AAPI communities. KPHC is currently developing an online resource guide that will provide patients in greater Hawaii with information about local cancer treatment and support services. In addition, KPHC continues to provide cancer education, screening, and patient navigation services to its patient population. FHC continues to provide capacity building assistance to AAPI organizations and individuals in Massachusetts by offering assistance to support the development and promotion of support groups.

Contact our Consortium Partners at KPHC (amacabeo@kphc.org), FHC (tam.lefhew@umassmed.edu), and AAPCHO (nagbayani@aapcho.org)

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The Asian & Pacific Islander American 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 APIAHF 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 US Census data analysis, and convene regional and national conferences on AAPI health.



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