



In the initial cover design which appeared in the 2002 and 2003 PATH Needs Assessment Report, a stained glass window was displayed with some cells left empty for future voices. In this publication of Voices from the Community, those cells are now filled.

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INTRODUCTION

Breast and cervical cancer are the leading sites of cancer for Asian American and Pacific Islander Women.

Breast cancer is the leading site for cancer incidence and mortality for Asian American and Pacific Islander (AAPI) women in the nation (Jenkins and Kagawa-Singer, 1994). Although AAPI women as an aggregate group have a lower incidence of breast cancer, mortality rates are increasing (American Cancer Society, 2001). Cervical cancer rates for many AAPI women are significantly higher than for white women; for example, Vietnamese women develop cervical cancer at five times the rate of white women (Miller et al., 1996). Unfortunately, AAPI women have the lowest breast and cervical cancer screening rates compared to all other ethnic groups (American Cancer Society, 1998), and few programs have specifically targeted these women to promote and sustain regular screening practices (Kagawa-Singer & Pourat, 2000, Chen et al., 2004).

The REACH 2010-Promoting Access to Health for Pacific Islander and Southeast Asian Women (aka PATH for Women) project was a five-year effort to increase breast and cervical cancer screening for seven AAPI communities in Los Angeles and Orange Counties, California. Los Angeles and Orange Counties have the largest Pacific Islander and Southeast Asian populations in the nation, yet there exist very few resources and providers focused upon these communities. Started in 1999, the PATH for Women project focused on the Cambodian, Chamorro, Laotian, Samoan, Thai, Tongan and Vietnamese communities to reduce disparities in breast and cervical health. The PATH for Women project is a collaboration of six community organizations and two universities consisting of very dedicated staff and community leaders. The project is a community-based participatory action research project. It was developed, implemented and evaluated with the integral role of the community organizations and its members in collaboration with the academic research team.

TABLE 1: POPULATIONS TARGETED BY PATH FOR WOMEN IN LOS ANGELES AND ORANGE COUNTIES, 2000		
API Population	Los Angeles County	Orange County
Cambodian	34,032	5,359
Guamanian or Chamorro	5,188	2,318
Laotian	3,569	3,208
Samoan	16,163	4,555
Thai	24,151	3,822
Tongan	2,627	610
Vietnamese	89,080	151,164
TOTAL	174,810	171,036

\* Source: U.S. Bureau of the Census, 2000 Census of Population and Housing, Profile of General Demographic Characteristics (DP-1), Summary File 1 – 100% data. Data shown is for race alone, or in any combination with any other racial group.

The REACH 2010-PATH for Women project is comprised of 6 key community partner organizations: Families in Good Health/St. Mary Medical Center (Cambodian and Laotian); Guam Communications Network (Chamorro); Samoan National Nurses Association (Samoan); Special Service for Groups, Inc. (Thai), Tongan Community Service Center/Special Service for Groups, Inc. (Tongan); Orange County Asian and Pacific Islander Community Alliance (Vietnamese); and PALS for Health/Special Service for Groups, Inc. (Language access issues). Each organization provided bi-lingual and bi-culturally skilled staff who participated in far-reaching, high impact trainings to provide resources and information to the community on breast and cervical cancer and language access issues regarding health care. Individuals in the roles of community health workers, health educators and coordinators, worked within their respective communities to provide culturally and linguistically sensitive information and resources. PALS for Health was a leader for the project in providing information and resources for language rights issues and helped to improve health care access for our communities.

The PATH for Women project employed a five-component approach for Pacific Islander and Southeast Asian communities: community education, community training, provider training, screening, and policy. Working with very diverse communities, PATH for Women developed tailored strategies within each component to meet the needs of the community members. The processes included coalition capacity building (developing resources within the partner agencies); development of culturally and linguistically appropriate language materials [ranging from brochures to t-shirts and digital video disc (DVDs)]; trainings (including anatomy, legal aspects of cancer, social services, etc); education to providers and community members; and relationship building within and across communities to increase access and awareness of the needs of these seven populations.

REACH 2010-PATH for Women's **VOICES FROM THE COMMUNITY** is a compilation of stories from the PATH for Women project as told by the many community-based project staff, including coordinators, health educators, and community outreach workers. They are the individuals who reach out to their communities every day to provide education, resources and hope to the many women they serve. Each of the staff from the PATH for Women project partner agencies wrote their own story in which they highlight the unique efforts they made to document the enormous community needs, the strengths and challenges of their work, the accomplishments that have been achieved thus far, and the ways in which they persevered over the course of the entire effort. Some of the stories focus mainly on education, outreach and navigation efforts to give the reader invaluable insights into the detailed processes involved in such labor-intensive work. Some of the stories focus on the organizational context in which programs were developed. And some of the stories are more policy oriented, introducing the reader to the systemic and environmental influences on health. All authors were encouraged to write on what they felt was important to highlight in their work. Each piece in this collection thus represents the personal experiences of the PATH for Women partners, and is an important illustration of the tremendous efforts, tenacity, and skills that are required to launch and sustain such deeply participatory efforts in diverse communities.

In sum, the PATH for Women project addressed health disparities in breast and cervical cancer among AAPI women. Over the course of our five-year effort, our community partners have developed strong relationships, created and linked numerous resources, and promoted and facilitated positive behavior change for better health. These are the stories from the individuals who made the entire effort such a success.

# Voices

FROM THE COMMUNITY

HENG LAM FOONG

Heng received her bachelor's degree in Communication Arts in New York. After several years in print and broadcast media, Heng moved to Los Angeles and began her career in social services as the Program Director of SSG/PALS for Health Program, a private, non-profit program that provides health care interpretation, interpreter training, language proficiency testing, language access education, and language rights advocacy.



During her ten years at PALS for Health, she led many innovative measures to bring culturally and linguistically appropriate health care to limited English proficient (LEP) communities of Southern California. Trained and guided by practical experience in policy work, Heng helped develop Los Angeles County's first language rights campaign aimed at educating health care providers and limited-English proficient (LEP) individuals about their responsibilities and rights to linguistically appropriate health care under Title VI of the Civil Rights Act of 1964. Under her leadership, PALS for Health also partnered with 4 other statewide community agencies and clinics to develop the Connecting Worlds Training for Health Care Interpreters curriculum and an accompanying language proficiency testing for health care interpreters.

Raised in a multilingual household, Heng passionately supports meaningful access to health care and is a member of Los Angeles County Department of Health Services' Cultural and Linguistic Workgroup, Community Advisory Council for Care1st Health Plan, and a board member of the Los Angeles County Susan G. Komen Breast Cancer Foundation.

## INTERPRETATION SERVICES PROMOTES MEANINGFUL HEALTHCARE ACCESS

### **I. Brief background information on the organization and community**

Established in 1993 as a program of Special Service for Groups, Inc., PALS for Health has worked for 10 years to improve the quality of life for limited-English proficient (LEP) Asian and Pacific Islander (API) communities by providing an array of services that help to break down cultural and linguistic barriers to health care access. In March 2003, with funding from The California Wellness Foundation, PALS for Health began adapting our API language access model to meet the needs of LEP Spanish-speaking health consumers in Los Angeles County. Our capabilities are reflected in our six projects that have been tested and proven through our demonstrated effectiveness in the health



PALS for Health staff.

care arena where language accuracy is vital. They include health care interpretation, written translation, interpreter training, provider and community training, women's health, and language rights advocacy. Our community-based mobile interpreting service, which currently encompasses Spanish and ten API languages and dialects, is one-of-a-kind in Southern California, and free to LEP health consumers.

### **II. When did the organization begin to implement breast and cervical cancer services?**

PALS for Health was developed as a health care interpreting project in the HIV/AIDS arena, and has slowly evolved to the entity it is today due to growing patient and provider needs. In 1995, with support from the Office of Minority Health (OMH), we expanded our HIV/AIDS health care interpreting project to cover all areas of health care. The following year, due in part to the OMH grant as well as additional support from the national Susan G. Komen Breast Cancer Foundation, PALS for Health began the development of its women's breast health project to initially increase in-language outreach, education and screening of Thai women.

Two individuals played key roles in the development of this project. They are Chulee Ikeda and Zul Surani. Mrs. Ikeda, a community leader, worked closely with the Thai community through Wat Thai and the Thai Nurses Association. Mr. Surani, who managed UCLA's Iris Cantor Center for Mobile Mammography, had been collaborating to offer no-cost screenings through the Breast Cancer Early Detection Program (BCEDP) to female temple goers. Through PALS for Health's involvement in the API Task Force of Partnered for Progress, the Los Angeles County partnership of BCEDP, we were asked to offer language interpretation services at these screenings.

This three-way community/provider partnership led to the eventual formation of a breast health education project at PALS for Health where female interpreters representing the Thai, Cambodian, Vietnamese, and Mandarin speaking communities were recruited to develop a culturally and linguistically appropriate workshop to offer educational information on mammography, breast self-examination, and breast cancer risk factors, and to dispel myths about the disease. These educators, who included Suan Stapataynon, Ann Luecha, Sara Mam, Vouchmeng Sieng, Bangtam Nguyen, Tsai-Ling Ding and Jui-Chuan

Yeh, met with PALS for Health and a consultant, Karen Quintiliani Hodgson, during evening meetings that spanned six months. Finally, thanks to the efforts of Ms. Chrissy Kim of the American Cancer Society, all educators enrolled in and completed the American Cancer Society's Special Touch training, which prepared these women to teach breast self examination techniques.

Soon, women who signed up for mammography screenings at Wat Thai, and consequently Wat Pa, received breast health education and language interpretation. The Iris Cantor Mobile Mammography Van also accompanied us to sites within the Cambodian, Chinese and Vietnamese speaking communities. Again, limited English proficient women received no-cost education and screening services. This project was later joined by new educators and interpreters including Waraporn "Nid" Tiaprasith, Srinapha "Noi" Vasunilashorn, Nisarot Kotchasak, and Monica Sor.

Once the Asian breast health education component was in full swing, PALS for Health started to focus on seeking partnerships within the Pacific Islander community, where few culturally and linguistically breast health services were available. Since the Tongan Community Service Center is also a program of Special Service for Groups, a meeting was scheduled with Program Director Sioana Finau and Program Coordinator Illaisaane Fehoko. The Tongan Breast Health Project was funded partially by a grant from the Susan G. Komen Breast Cancer Foundation and with a mini-grant from Partnered for Progress. Ms. Finau and Ms. Fehoko helped to adapt the breast health education training into Tongan, and completed American Cancer Society's Special Touch training.

This wonderful community relationship soon led to partnerships with the Guam Communications Network and the Samoan National Nurses Association, where we were introduced to Lola Sablan-Santos, Juana Sanchez, Sala Mata'lii, Ofeira Lutu, and Marina Tapua, among other wonderful individuals. Thus began the Pacific Islander Breast Health Collaborative, which in the span of one year increased the State of California's BCEDP screening numbers by one hundred percent (100%).

### **III. Highlights of barriers and successes to the topic of interest**

Through REACH 2010-PATH for Women partner agencies we learned that language is consistently one of the top three barriers to health care for many community members. Within our target communities, little was known about language rights, as outlined by federal laws such as Title VI of the 1964 Civil Rights Act, and few providers understood their legal obligations to offer in-language services through bilingual staff or interpreters. For example, in August of 2002, staff from the PALS for Health program worked with the Thai Project Coordinator of PATH for Women to advocate for the inclusion of a LEP cancer patient who was refused participation in a local clinical trial because consent forms were not available in Thai. Upon learning that the clinical trial was supported by federal funds, we persuaded the director of the clinical trial to translate forms into Thai and to permit the participation of the LEP patient. This is one of several examples which support the need to conduct outreach and education on language rights to patient and provider groups alike.

Working with Jackie Tran and Susan Lee (PATH Program Manager and Program Specialist), an initial training on language rights was facilitated for all PATH for Women partners. Held on November 29, 2001 at Guam Communications Network, the training featured speaker Brock Evans from the Region IX Department of Health and Human Services Office for Civil Rights, and Rommony Chung, Consumer Health Educator at PALS for Health. Partners learned about the LEP Guidance, Title VI of the 1964 Civil Rights Act, and the consumer health education project of PALS for Health that provided LEP patients with in-language training and the "I Speak" card.

PATH for Women also collaborated with the Office for Civil Rights, Asian Pacific American Legal Center and the National Health Law Program to conduct two public trainings, one for community-based organizations, and another for health care providers. Guest speakers, including Karin Wang, Esq. of the Office for Civil Rights, and Teresita Bautista, Director of Interpretation Services at Highland Hospital in Alameda County, introduced local, state and federal language rights laws, discussed reimbursement models, health care interpretation projects, best practices, and answered questions on all of the above. Both trainings were conducted at the Carson Community Center in July and September of 2002.



**PALS for Health and Alas Para Tu Salud  
(a program of PALS) staff.**

Last but not least, PALS for Health waived tuition fees to the 48-hour Connecting Worlds Training for Health Care Interpreters© (CW), for all PATH for Women partners. Although many of our partners are bilingual and often are used as interpreters during screening and follow-up exams, they had not received any formal training on health care interpretation. The CW curriculum, which was developed over the span of three years in partnership with four other community based programs/clinics representing Northern, central and Southern California, provided a good introduction to this complex field. Funded by The California Endowment, the curriculum covers key topics including roles of the interpreter, standards of

practice for health care interpreting, medical terminology, and offers ample time for practice sessions. All participants are required to complete a pre-test and pass a final written and oral exam. PATH for Women partners from the Samoan National Nurses Association and Guam Communications Network enrolled a total of seven participants, all who passed with flying colors!

These aspects are small but important pieces of a larger and ideal picture of quality health care delivery. To ensure that LEP patients receive care that is equal and meaningful, much needs to be done to affect individual, systemic and policy changes. Community based programs such as PATH for Women can only accomplish these changes with the full support of community members, health care providers, and policy makers.

## **VI. Future plans for the topic and process**

Although advocates have worked to improve accessibility to linguistically and culturally appropriate health care for over a decade, patient education on their language rights is still in its infancy. LEP patients often tend to be immigrants still steeped in a culture where health care providers are viewed as persons of authority, and to question authority is to go against the grain of cultural respect. Many LEP patients are afraid to ask for interpreters, and to file a formal complaint if they are denied care due to their inability to speak English, or the provider's lack of interpretation services. Said one LEP patient when asked what she would do if no interpreter was available, "I would go (to my doctor) anyway but I wouldn't understand anything (Thai woman)." If progress is to be made in increasing language access in health care, the LEP community needs to allow their collective voices to be heard. Anecdotes that highlight language barriers as told by advocates, although still moving, does not have the same impact as stories shared firsthand by LEP patients themselves.

As systemic change slowly takes place, there needs to be programs that continue to offer a multifaceted approach to decreasing the language barrier for LEP patients. Programs that offer no-cost or low-cost interpretation services provided by trained interpreters, patient language rights education, and provider trainings on the importance of accurate communication are all vital. As many LEP patients fear retaliation for speaking up, they will also need assurances that no harm will come to them if they testify to policy makers, or speak up in public about their language challenges. Programs that include effective public speaking trainings on health care law and health system navigation can be helpful in allaying some of these fears.



# Voices

FROM THE COMMUNITY

SITHARY OUN LY

Sithary is a Health Worker for the Cambodian community for Families in Good Health/St. Mary Medical Center in Long Beach. She reaches out to Cambodian women to encourage them to get mammograms, breast exams and Pap smear test.

This is the story of my life and why I came to America. In 1975 Cambodia fell into the communist regime and was ruled by Pol Pot. About 3 million out of 7 million people were killed by starvation, torture, and massacre. In 1979 during the invasion of the Vietnamese communist government, many Cambodian survivors fled to the Cambodia and Thailand border. My family is one of those refugees. Unfortunately the war was extended to the border and I was separated from my mother, brother and sisters during the shooting and bombing. I escaped to Thailand alone and frightened. I was put to live in the orphanage and lived in the Thailand camp as a refugee. In 1980 I was brought to America by a group of Churchgoers and I grew-up in a Christian home, which is different from my parents' belief in Buddhism.



From my own experience I faced execution and death so many times as a little girl, but hope and belief of the all mighty has saved my life. I am determined to fight against obstacles, endure pain and suffering because it makes me stronger each day. Now, I am working hard to give back by helping and educating the community, to understand and provide awareness of breast and cervical cancer and to appreciate life by going to see the doctor and having exams. It can save lives.

## BEYOND THE OUTREACH

My name is Sithary Oun Ly. I work for Families in Good Health at Catholic Healthcare West St. Mary Medical Center in Long Beach, California as a Cambodian Community Health Worker. I conduct outreach across language and cultural barriers to ensure that women receive proper medical treatment in the vital areas of breast health and reproductive care. The Breast and Cervical Cancer project is part of a Southeast Asian and Pacific Islander Collaborative funded by the Centers for Disease Control and Prevention Foundation through The California Endowment. The project name is REACH 2010-PATH for Women (Racial and Ethnic Approaches to Community Health 2010-Promoting Access to Health for Pacific Islander and Southeast Asian Women). Families in Good Health is a collaborative partner on this project and is based at Catholic Healthcare West St. Mary Medical Center in Long Beach, California, serving Laotian and Cambodian women.



Sithary conducting outreach at a temple.

Families in Good Health (FIGH) at CHW St. Mary Medical Center, is a multilingual, multicultural health and social education program that strives to provide quality outreach and education services to the Southeast Asian, Latino, and other communities in Long Beach. It was established in 1987, as a joint venture between the St. Mary Medical Center and the United Cambodian Community, Inc. - creating a partnership between community and health care. FIGH's mission is to build capacity within the community to enable them to make informed choices and to access needed health and social resources. FIGH conducts numerous health and social education programs that focus upon health promotion and disease prevention.

Beginning in 1975, first generation Cambodian refugees began settling here in the United States, escaping from war and political turmoil. Many chose to live here in Long Beach, California because of the excellent weather and similar climate to the tropical zone in Cambodia. There are two seasons, monsoon and dry season. Cambodia is located in Southeast Asia and is bordered to the north by Thailand and Laos, to the East and the South by Vietnam, and to the West by the Gulf of Siam and Thailand. The Capital is Phnom Penh and the country's population is approximately 11 million. The official religion is Buddhism. The official language is Khmer.

Most of the older Cambodian individuals have a difficult time adjusting to the new life and new culture in the United States. The major problem is speaking English. Due to the lack of education, older men and women often have difficulty memorizing and learning English. Often, they feel frustrated because they cannot communicate to an English speaking person. As a result, they tend to work at low paying jobs that don't require English speaking to perform those jobs. For this reason, many Cambodians like to live in small or large groups among other Cambodians so that they can form a community. In these groups, they can ask neighbors for help in accessing things such as healthcare. Unfortunately, very often they cannot get help because it is not available. It is very sad that they have to live and endure this silent torture, which they have to face everyday.

Our program at Families in Good Health at CHW St. Mary Medical Center has many unique programs that can assist people in the community in accessing healthcare. One of those programs is REACH 2010-PATH for Women, which provides outreach and education on early breast and cervical screening and patient navigation for patients through the healthcare system. This is a brief summary of my experience with PATH for Women and the challenges and benefits of community outreach.

When this program began three years ago, it was very difficult to outreach to the Cambodian women in the community because of deep cultural and language barriers. About 95% of elderly women had never seen a gynecologist in their lifetime due to lack of knowledge and information, economic hardships,

language challenges, cultural barriers and embarrassment of going to see male doctors. Overall, there are many obstacles that have prevented women from seeking healthcare and prevention. Many have even told their children to learn to be ashamed and to try not to see the gynecologist too often. It was very hard for us, the community health workers, to reach the women as a result of these cultural barriers. They refused to listen to any explanations or educational awareness about women's health such as breast cancer, cervical cancer, Pap smear test, breast self-exam and mammography.

As a Cambodian community health worker, sometimes the ignorant attitudes and the rejection burns me out, but I refuse to walk away or give up the job that I love doing. I conduct outreach at Buddhist temples, businesses or markets, community organizations, and community events. We set up tables at outreach sites with vital information on breast and cervical cancer, and answer any concerns that relate to health. We also currently conduct education classes at community organizations and at other community sites that are available to us, sharing breast and cervical screening techniques, screening sites, and facts and statistics on breast and cervical cancer.

Personal outreach efforts: Outreach to men and women is not as easy one might think. For example, at health fairs or at any event, some information tables stand empty while others have a long list of people who have signed up for health information. From my own experience, I always stand in front of the information table. I motion and call to the people walking by and show them the give-away incentives. At the same time, I have the opportunity to talk about breast and cervical cancer by using a soft gentle tone of voice to build relationships, but always respect the decision of the person to whom I am speaking. I never force them to listen or do anything that they do not want to do. For example, we do not force them to drop everything just to listen to what we have to say or chase after them. People in the community do not like disrespectful people. They like people who are willing to listen and understand them.

At one particular site where I conducted an educational class, many Cambodian men and women were enrolled in special programs to help mitigate the devastating effects on their lives from the holocaust, torture, killing, separation and loss of family members under the communist leader, Pol Pot. They were being helped for social needs, but no one ever taught them the awareness and prevention of breast and cervical cancer, which every woman should know. For the first time in their lives, men and women heard about the discussion of breast and cervical cancer. The information is so personal that I was afraid to talk or discuss in public with the group of men involved. However, I as a woman and as a survivor of the "Killing Fields," told the group, "If you survived the Killing Fields, you could survive anywhere. Don't let anything or anyone stop you from seeking preventive care or treatment. If you need help on how to get health care or treatment, please call me." One lady in the group heard the information. She was crying and said, "I wish that my husband is here listens to the health educators about women health. When I told him that I have pain, he said that I complain too much. He even said that the doctor is not God, can not cure everything. If I'm sick just stay home and rest, that what he told me."

About 3 million out of 7 million Cambodians died under the rule of communist leader Pol Pot from April 17, 1975 to January 7, 1979. Many Cambodians were killed by starvation, torture, and massacre -- this is what the world knows as the "Killing Fields". Many Cambodian survivors fled the country as refugees and now live in countries such as Australia, France, Canada and the United States.

Building trust is a fundamental element of outreach. As a human being, most of us understand very well and keep reminding ourselves not to trust the unfamiliar face or unknown person because of our personal experiences. This is why it so difficult for us to outreach to men and women in our community. When we asked men and women to write down their name, age, address and phone number, they would immediately reject us. They would ask, "What for? Why do I need to give my name? Are you going to report me to the government?" In spite of these odds, we strive to be successful and we constantly outreach to the same places until men and women understand our goal in educating the community about the high risk of breast and cervical cancer rates in the United States, especially Southeast Asian women, namely Cambodian women.

One method to reach the community was the media, primarily Cambodian television. The Cambodian TV media commercial about breast and cervical cancer that we developed played a big



**Outreach at a community health fair.**

role in helping to outreach to 35,000 households in Los Angeles County. We worked very hard in outreaching and building relationships with the community and with the individuals. The people in the community knew who we were and respected us because we worked at St. Mary Medical Center. They believed that we had real jobs and that we are not scamming them. It took time to gain their trust. When the women placed their trust in me, I felt comfortable speaking about men and women's health in public. I could persuade them to come and see a doctor for a breast exam, a mammogram and a Pap smear test. The concepts of mammograms and Pap smear tests are completely unfamiliar to Cambodian women who were not born in the United States. I made sure they were comfortable with the setting, the staff and the doctors. One doctor's appointment could easily take up to three or four hours which required a lot of patience. But I was very happy to do it because it means they are receiving the important exam.

Compassion, caring and commitment are the keys to success. Outreach alone cannot solve the problems that Cambodian women face in their everyday lives. Another issue is access to health care. The women who cannot speak, read and write English and cannot read or write Khmer have many obstacles. Khmer language materials about breast and cervical cancer are worthless to those women who cannot read. This is why we need to spend more time in educating these women, and utilizing TV media as a way to reach and to educate other women that we cannot reach directly. Many of the women said that they understood the important messages that we taught them, but that they could not get to the hospital or clinic because they do not speak English, cannot drive or read signs. Some of the women live alone and some live with their children, but their children go to work or attend school. Some women live with their husbands, but their husbands do not support them. The difficulty in accessing health care is a problem that I cannot ignore. So, I made the commitment to serve women and to ensure that they get the proper health care by providing them services such as making doctors' appointments, translation, helping with paper work, transportation support, and counseling. The women who have joined our program are very happy with our services.

We also provide support and care for your loved one, which is an important way of getting access to health care. One woman diagnosed with breast cancer was stressed out every time she went for chemotherapy. Sometimes when we were not available, she would skip chemotherapy because no one else could provide her with transportation. She received no support from her husband. When we learned that she was skipping treatments, we went to her house and discussed her symptoms with her husband, but her husband was very upset with us for coming to his house. He said, "You all don't need to come to my house to stir-up this problem. My wife is not critical. I don't have time to take her to the doctor because I am working during the day." We apologized and explained about his wife's diagnosis of breast cancer, which is the number one killer disease and that he needs to care for her. We explained about our role and how he can help by doing his part, by providing his wife with love and support. If she needed help in getting to the hospital, he had to take her. Finally, the husband understood and promised to help his wife get to her doctor's appointments.

Having compassion to help the helpless has always been one of my inner strengths. I'm very happy to help the women when they call me for help. I was with one woman just prior to her surgery to remove lumps from both of her breasts. She was afraid that she wouldn't wake up. She said, "Please tell my husband that I love him and tell him please take good care of the children." I told her everything is going to be fine. I was with her, holding her hand at her bedside and I stayed there to console her after the surgery, assuring her that she would recover and return to her family. It was a long day for me to be in the hospital with the patient. Although I was tired, I have to be strong for all the women that are enrolled in our program so that they can be strong for themselves.

Reaching Cambodian women is based on relationships. If one woman is successfully treated, she will tell her family, neighbors and friends, who will then contact us for the information and they will get their exam. This is part of the success of our program, PATH for Women, being a part of the community and letting them know that we are here to help.

# Voices

FROM THE COMMUNITY

JUNE CRUZ MILLIGAN

LINDA GUEVARA

LOLA SABLAN-SANTOS

LOURDES FLORES QUITUGUA

June Cruz Milligan has been a resident of California for over 40 years. The involvement she has with her Chamorro community stems from the example set by her parents who were actively involved in the events the Chamorro people celebrated. She is an active member of the Chamorro Community Council of California and the I Famalao-an [Chamorro women's club], she also volunteers her time and energy to many of the other surrounding Chamorro organizations. Having a chance to work in her community has been a rewarding experience in helping to bring information needed to her Chamorro community and becoming an advocate for women's health.



Linda Guevara was born on Guam and relocated to Long Beach in 2001. She joined Guam Communications Network in February of 2004. She enjoys working with everyone at GCN. She is involved with the PATH project, helping with the cervical cancer project, and also with the CARES project. Linda is very active with the patients (medical referral) that are out here from Guam. She visits with them at the Weingart Guesthouse, and has become an advocate for women's and men's health, especially to the Chamorros.



Lola Sablan-Santos is the Executive Director of Guam Communications Network (GCN), a California based non-profit 501 (c)(3) organization and multi-service agency serving the Chamorro/Guamanian population in Southern California. She has been involved in Breast Cancer education and outreach for the past eight years and has been instrumental in development and implementation of outreach and screening programs for Pacific Islander women in Los Angeles and Orange Counties. Currently, she serves as the Chamorro community project director for the PATH for Women breast and cervical cancer education and outreach program and is the co-principal investigator for the Chamorro breast cancer research project. In addition, Lola has coordinated the development of bilingual educational literature on breast cancer awareness and breast self-examination in Chamorro, Samoan and Tongan. She has also coordinated the creation of a Pacific Islander media print campaign promoting the utilization of the State of California's Breast Cancer Early Detection Program.



Lourdes Flores Quitugua was born in Guam and moved to the United States at the age of eleven where she is currently residing. She started working with GCN in 2001 as a Health Educator for the Breast Cancer Research Project targeting Chamorro women who are 50 years and older in Southern California counties of Los Angeles and Orange in comparison to the women in the Northern California counties of Alameda, Solano and Santa Clara. She is also involved with the PATH for Women along with HAPAS (Health Access for Pacific Asian Seniors) REACH 2010.



# KINALAMTEN I FAMALAO'AN CHAMORRO

## CHAMORRO WOMEN'S WAYS

There is an understanding in the Chamorro culture that we are responsible for each other. That word in the Chamorro language is inafamaolek, which means interdependence that is based on genuine reciprocity and respect.

### 1 – Motivation

The REACH 2010- Promoting Access to Health for Pacific Islander and Southeast Asian Women project offered an opportunity of reconnecting to our roots in a way that we have not known before. From the examples demonstrated by our parents, we were raised with the Chamorro traditions of embracing familia [family], hinengge [faith] and nenkanno [food]. Family involvement was extended through the Chamorro community in terms of how we supported one another through chalek [laughter] and lagoon [tears]. Faith held an unwavering spiritual belief that was witnessed in the Fandanggos [weddings] and the Lisayus [rosary for nine nights of prayers] for the matai [dead] celebrations, both in birth and in death. Food is an expression of thanksgiving that is also shared amongst our people and allows us to remember our origins.



Educational workshop session.

### 2 – Goals

We would really like to see our Chamorro Manelo-hu [sisters] become health advocates for themselves, as well as for their families without feeling guilt. We would like for them to overcome their difficulties in talking about their bodies and for them to realize that by empowering themselves, they set the example for future generations of Chamorro women to follow. It is common for our Chamorro women to put themselves last when it comes to taking the necessary prevention steps of maintaining a healthy life style. She carries within herself this quiet strength to accomplish the needs and challenges for her immediate family and extends herself to the community as well.

A tragic story comes to mind of a Chamorro woman that recently passed away from breast cancer. Even though she had health insurance, she didn't believe in practicing monthly self-breast exams or going for yearly mammograms. She chose to see the Suruhana [a traditional healer/witch doctor] for treatment over her primary care physician when she experienced pain and found a lump in her breast. When she became very weak, she finally went to see her physician. She was immediately hospitalized and within days, died from complications of advanced breast cancer. It is stories like this that add to our passion of helping to bring breast cancer awareness into our Chamorro community.

In order for us to ensure that our culture is incorporated into our Chamorro health care, we have to accept the responsibility of becoming an active participant with health care advocacy for the underserved and the forgotten populations. This responsibility is not meant to solely fall on the shoulders of the Chamorro women, but on the entire Chamorro community as a whole. We all need to look out for one another, always lifting each other up and leaving no one to suffer in silence.

### 3 – The Realities

Initially, our community outreach and education strategy was designed with the Western approach: lectures, presentations and forums. As well intended as they were, we soon realized that the Western



way was not working and was not being accepted by our community. We only had a small number of women who attended our activities. As a result, we had to re-think our strategy using a culturally tailored framework. We had to be culturally sensitive, especially when involving the manamkos [elders]. Words such as susu [breast] or punket [cervix] were not spoken in front of our manamkos [elders] or in public. Our manamkos [elders] considered it desatenta [very disrespectful] and even isao [sinful] to have these words mentioned in their presence. In their upbringing, these words were associated with sex that was not openly discussed. We also learned that no matter how well we thought we knew our manamkos and our community members, unless we were in their peer group there were boundaries that were established that we could not cross.

The English language and word association was another challenge we faced. Although the majority of Chamorros speak and read English well, they also have a different interpretation of words, often asking Hafa kumekelek-na? [What is she saying or what does that mean?]. This statement is often heard from our elderly Chamorro community, especially when it involves doctor visits. The mother of one of our authors, for example, has been living in Southern California for many years, and one would think she would not have any problems understanding her doctor. However, in fact, she does and she feels intimidated because she doesn't understand half of what he says to her, often relying on her daughter to rephrase what her doctor has said.

Words in the context of lectures and workshops are perceived as formal and westernized, and any activity that utilized these words is considered "boring" to attend. Also, when Chamorros hear the word 'lecture', they automatically think of themselves being scolded or reprimanded. When the word 'workshop' is heard, they envision doing all sorts of extra work. In addition, the use of questionnaires and exit surveys are considered intimidating by most of our women. Many are reluctant or have refused to complete these forms for fear that they would enter the "wrong" answer. Subsequently, we utilize words such as "chat sessions", "story telling" and "discussions" to entice their participation.

#### **4 – The Activities**

In developing our new strategy we concentrated our outreach efforts on working with established social and organizational networks and on developing in-language educational materials. Chamorros, as a rule, gather in small groups. These groups mainly consist of immediate and extended family members or groups of people within the same age, gender, or cities/villages, and meet frequently to pass on information of a difunto [death of community member] or to plan gatherings for patto [new birth in a family], umásagua [marriage], nobena [prayers for intercession to the patron Saints of the family] and other activities hosted by the family. These types of gatherings provided us with many opportunities to meet and outreach to our target populations, as well as to promote the PATH for Women project and its activities. We would faisen [ask] group assistance in gathering support for our activities. We have been able to outreach to our community through the development of in-language and culturally focused education materials, such as our Susu Chart that provides an explanation with diagrams of how to do self-breast exams, our Para Hagu [For You] cervical cancer awareness brochure, the Manelo-hu [sisters] newsletter on women's health and wellness, and our Tronkon Niyok quilt which displays the names of the Chamorro breast cancer survivors and memorializes those that have passed away. These materials have been important tools in our outreach activities and have also been enthusiastically received by our women and by our community. We have been told numerous times that these materials promote cultural self-esteem and pride amongst our community members. Also, our in-language materials were considered to be a first for our community, with many individuals remarking that our island of Guam did not offer in-language educational materials.

Another important component of our revised outreach strategy was incorporating cultural/religious celebrations as outreach venues. These celebrations included ma-takpangi [infant christenings], Gupot [Guam's Liberation Day from WWII that is celebrated by all the Chamorro organizations], Corpus Christi [Christ the King – a religious event practiced on Guam where all the churches celebrated their village Patron Saint which is practiced in the U.S. mainland as well] and other religious events such as Pasqua

[Easter] and Natibidat [Christmas]. The Chamorro community is scattered throughout the United States and around the world, and therefore it is not uncommon for family and friends to fly or drive long distances to attend special events that local Chamorro families and organizations hold throughout the year.

Our final component was promoting “fun.” Chamorros love to have fun. We utilized fashion shows, Laughlin turnaround bus trips, in-home theme parties (Cookie Lee Jewelry, Party-Lite Candles, Tupperware, etc), bowling tournaments and picnics, all of which piggybacked our education and outreach activities. We learned that as long as it was fun, the women would come.

## 5– The Successes

We didn't realize the extent of our accomplishments until we began listing them and getting phone calls requesting copies of our materials from Chamorros that had seen or heard about it from other Chamorros. The circulation of three newsletters called the Manelo-hu [sister] extended beyond the Los Angeles and Orange County areas and was also made available in an electronic version. We produced several in-language educational materials that were culturally tailored for the Chamorro community, including brochures for breast and cervical cancer awareness, a chart for breast self examination, a quilt displaying the names of Chamorro breast and cervical cancer survivors and memoriam, the Malle Calling, and a reminder postcard campaign to promote annual mammograms and pap smears. We also conducted awareness campaigns and disseminated information on the Patient's Bill of Rights and Responsibilities and information on Advanced Health Care Directives/Durable Power of Attorney beyond the education on breast and cervical cancer.

In addition, we found that through the PATH for Women project, as well as the development of our activities and materials, we provided a bridge for Chamorro women to cross and empower themselves with information and tools to teach other Chamorro women for generations to follow. When the Tronkon Niyok quilt was first created, we had a difficult time getting our breast cancer survivors to go public. Then, one by one, they came forward, creating and developing a special bond amongst themselves which allowed them to openly share their survivor stories and emphasize the importance of healthy life styles that Chamorro women need to practice.

Another example of mobilizing the women took place in September of 2003. Fifteen Chamorro community health advocates attended the California Breast Cancer Research Project conference at the San Diego Convention Center that represented Northern and Southern California. At the conference, the group displayed in-language breast cancer and cervical cancer materials developed through the PATH for Women Project and the Guahu I Suruhana Breast Cancer Research Project. A quilt entitled “Tronkon Niyok” was also on display, which honors the Chamorro women breast cancer survivors and those who have passed away. This was one of the first ever trips that involved community women in participation at a research conference which became a fun event that allowed opportunities to share and learn from others.

In March of 2004, twelve Chamorro women were given the opportunity to travel to Washington D.C. to attend the Intercultural Cancer Council's 9<sup>th</sup> Biennial Symposium on Minorities for the Medically Underserved & Cancer. Travel and accommodation scholarships were provided through the generosity of I Famalao'an, Chamorro Community Council of California, National API Cancer Survivors Network and Guam Communications Network. Attending the ICC Symposium was the first time for ten out of the twelve ladies. One of the ladies who attended is a breast cancer survivor and was included in the opening ceremony. She was the only Chamorro breast cancer survivor representative, which held a



GCN staff and community members at the BCRP Conference in San Diego, CA.



special meaning for all of us. These types of events exemplify the mobilization and involvement of the community in their own health and well-being.

In addition to the outreach and education, our staff has procured breast prosthesis, wigs and other accessories for breast cancer survivors who requested these items and had no known resources available to them. Our staff had received numerous telephone calls from women residing on the islands of Guam, Rota, and Saipan as well as women from Southern California with inquiries on breast prosthesis, bras, wigs and turbans. These calls prompted our staff to identify resources that would donate these items to GCN to distribute into the community. As a result of our staff's tenacity and patient advocacy, we received several large donations of the requested items from local vendors. The donations were sufficient for us to establish a new service delivery program under the PATH for Women project.

## **6– Most Memorable Experience**

One of the most memorable experiences was during a trip we made as facilitators to meet some of the Chamorro women from Northern California in 2001. A group of us met a woman who may have been one of the oldest and longest known breast cancer survivors in our community. She told her story of the struggles and challenges she went through. During her story, it dawned on many of us that she was the first Chamorro woman that we had ever heard talk about having breast cancer. She gave us a Chamorro face to put on breast cancer. She also helped us to realize how our Chamorro community does not talk openly about illness and disease. We all were empowered by this woman and felt that if she had the courage to talk about what she went through with breast cancer, the least we could do is break through the barriers posed by our community to increase more awareness of the impact of breast and cervical cancer to our Chamorro community.

The PATH for Women project has provided GCN with many opportunities to increase the awareness of breast and cervical cancer within our Chamorro community and to address the health care needs of women living with cancer. In addition, the PATH for Women project has provided employment opportunities for our Chamorro women as well as opportunities to be involved in participatory research and patient advocacy that would not have been otherwise available. All of these opportunities are also credited with the improvement seen in the socio-economic environment of the local Chamorro community and with the connectedness of Chamorro women residing in Southern California, within the United States, and on Guam and its surrounding islands of Rota and Saipan.

# Voices

FROM THE COMMUNITY

MAICHEW CHAO

Maichew is currently at Families in Good Health as a Program Coordinator. Families in Good Health (FiGH) is a Department of St. Mary Medical Center in Long Beach. FiGH is a multilingual, multicultural health and social education project that strives to provide quality outreach and education services to Cambodian, Laotian and Latino communities in Long Beach. FiGH's mission is to build capacity within the community to be able to access needed health and social resources.



Maichew conducts numerous health and social education programs that focus upon health promotion and disease prevention including older adult immunizations, physical activities, tobacco, and breast and cervical health.

Maichew works on research projects in collaboration with UCLA, Special Service for Groups and Orange County Asian and Pacific Islander Community Alliance, with projects focusing on breast and cervical health for Laotian and Hmong communities.

Maichew was a refugee from Laos and began volunteering as soon as she arrived in the USA in 1979 from refugee camp in Thailand. Maichew began by volunteering with the new refugees who needed assistance to help them start their new lives in the United States. From that experience, she was hired as Community Outreach Worker for the Southeast Asian community in Long Beach. Maichew has been with FiGH since its inception in 1987 and has helped to create healthier communities with her work.

## FAMILIES IN GOOD HEALTH

Beginning in the 1980s, large waves of Southeast Asian refugees settled in the city of Long Beach, including individuals from Vietnam, Cambodia, and Laos. The 2000 Census identified approximately 8,648 Lao and Lao/Hmong currently residing in Los Angeles and Orange Counties. Demographic characteristics of Lao and Lao/Hmong in these cities depict extremely low levels of socioeconomic resources; approximately 100% of Hmong, and 80% of Laotians live in low-income tracts.



FiGH/SMMC staff conducting community outreach.

Families in Good Health (FiGH) formerly known as Southeast Asian Health Project is a multilingual, multicultural health and social education program that strives to provide quality outreach and education services to the Southeast Asian and Latino communities in Long Beach. It was established in 1987 as a joint venture between St. Mary Medical Center (SMMC) and the United Cambodian Community, Inc. creating a partnership between community and health care. FiGH/SMMC is a department at SMMC and has a mission to build capacity within the community to enable individuals to make informed choices and to access needed health and social resources. FiGH/SMMC conducts numerous health and social education programs that focus upon health promotion and disease prevention.

The project opened its doors as a prenatal outreach project in 1987, using bilingual and bicultural health advocates to create bridges for access to health care. Since then, the agency has developed multiple health promotion programs, such as tobacco control, assistance for the elderly with adult immunization education, childhood immunizations, breast and cervical health, cultural competency training, child care training, prevention programs for teen pregnancy, and fish contamination education.

In July 2001, Families in Good Health/SMMC conducted a community needs assessment as part of REACH 2010-PATH (Promoting Access to Health) for (Pacific Islander and Southeast Asian) Women. The data from the study identified a strong need for breast and cervical cancer education, patient navigation, and research in the Lao and Lao/Hmong communities. In July 2002, the primary goal of the Lao component was identified to improve the health and well-being of Laotian, Lao/Khmu and Lao/Hmong communities by increasing the awareness of breast and cervical cancer through outreach education, patient navigation, and referrals.

Program activities varied according to the unique cultural aspects of the Laotian community, as well as the skills of the community health advocates. Understanding the nuances of the Lao culture, the Laotian community health advocate produced a flip chart in Lao along with other breast and cervical cancer educational materials. Individuals also helped Laotian women through patient navigation via phone service and face to face services, provided interpretation, translation, transportation, and referrals. Families in Good Health/SMMC also mobilized a community advisory board to provide community feedback and materials development feedback. The board consisted of Lao community leaders, which included a Temple leader, Church leaders, and healthcare providers.

### Barriers to Health Care

The lack of education and knowledge on breast and cervical cancer and the need for screening and early detection are a major barrier for Laotian women. The lack of knowledge, combined with cultural barriers, multiply the obstacles that Lao women face in health care. Lao women have never

heard about mammography, clinical breast examination, breast self-examination or cervical examination (Pap smear). Lao women generally do not receive prenatal care or deliver their babies with assistance from medical providers because birth is seen as a natural life event, not a health-related event. So, Lao women typically never see a practitioner to examine their bodies, especially their intimate parts. In fact, most women deliver their babies at home. Here in the United States, when women have prenatal care, they also receive clinical breast and pelvic examinations, which for Lao women are often new and strange experiences. In Laos, women do not even know that breast or cervical cancer can be fatal. Even after migrating to the United States, they still are not educated about mammograms or cervical exams. Women who have been in the United States for a while may have heard mammography and Pap tests, but they are still very hesitant to get screened. Culturally, they do not seek health care unless they are having symptoms.

Language and lack of transportation, childcare and health care insurance are other major obstacles. Most older Laotian women do not speak English or speak English poorly. Thus, language prevents Laotian women from seeking health care. When women choose to get care, they still have to face the challenge of the lack of interpretation and translation services, oftentimes resorting to use their children as interpreters; this situation has resulted in misdiagnosis and subsequently, the wrong treatment being prescribed. Many Laotian women also do not know how to drive and do not know how to use public transportation. Family members who can drive are often working. The older women usually baby-sit their grandchildren at home so their children can go to work, and many women don't carry Medi-cal or health care coverage. Another barrier is that Lao women prefer to see providers who can speak the same language so that they can communicate with ease. There is not one single Lao obstetrician/gynecologist in Los Angeles and Orange Counties.

These are the types of challenges that FiGH/SMMC staff attempt to address in their outreach education. The Lao community has its complexities and is very diverse. For example, there are Lao/Hmong, Lao/Khmu, Lao/Mien and low-land Lao. Most of the Lao ethnic groups and the first generation of refugee men and women don't read or write in their own language. When FiGH/SMMC staff conducted outreach education, the staff had to spend more time with each individual client in order to explain details in a way that the client may understand. Each time the staff member provides education on breast and cervical health, she also encouraged the clients to get screened. In general, the staff hears in response, "Oh, I don't have pain or problem with my breasts or my private part, I don't need to be screen it is too embarrassing," or "I am too old to get the screening." Many Lao/Hmong women said their husbands do not want them to get screened and so the women cannot get screened without their husband's permission. The staff had to persuade and encourage each woman at least three or more times in order for the woman to change her mind about getting screened.

One case example is a Lao refugee woman, 55 years old, who died from breast cancer in Long Beach three years ago. Before she died, FiGH/SMMC conducted a focus group with her family and neighbors regarding breast and cervical cancer. After the focus group, we encouraged all the women who attended to get their breast and cervical screening. At that time, this woman was not very ill, and she refused to have her breasts screened. When she eventually became obviously ill, her family initially tried to treat her with herbal medicine and traditional healing, but when she could not be cured, the family took her to the hospital. The doctors found out that she had breast cancer. The doctor treated her but she died shortly afterwards. The doctor informed the family that she died because her breast cancer had spread throughout most of her body. She had so many lumps in both her breasts that there was no way that the doctor could save her life because it was too late. After she died, the family still did not believe that her death was caused by breast cancer. In fact, the family believed that she died from evil which had eaten her inside organs. They believed that this evil originated from a man who had a hidden evil inside of him that arose from a prior conflict with their family. They believed that as a result of this situation, he sent his evil to eat her body organs and cause her death. Laotian women of all ethnicities have never heard of and have never been educated about breast cancer; nor have they had breast cancer screenings in their own county. For these reasons, it is very difficult for our people to understand and believe in early

detection to save their own life. Cultural beliefs and experience influence their health behaviors. Therefore, it is important for us to conduct outreach and education. For instance, the death in this case may have been prevented if the family had known about available services.

As a REACH 2010-PATH for Women partner, FiGH/SMMC has developed Lao-appropriate educational materials such as in-language brochures and a flip chart. FiGH/SMMC conducted breast and cervical health education throughout the Laotian, Lao-



**Breast Cancer Survivors.**

Hmong, Lao-Khmu and Lao-Cambodian communities. FiGH/SMMC also conducted one-on-one breast and cervical cancer education through home visitations and group presentations at different community sites by using the flip chart, brochures, breast model and cervical model. FiGH/SMMC staff conducted outreach education events at temples, churches, and markets throughout the communities. We also participated at community events such as Lao New Year celebration, Hmong New Year celebration, Buddhist Temple holiday events and church special events.

Women were encouraged to get screened and to utilize patient navigation, interpretation, translation and transportation services. Sometimes, the women had their hands held by our outreach workers while getting their pap smears or were accompanied into exams and mammography rooms. The purpose was to make them feel secure and to help both the patient and provider understand each other, thereby better enabling the provider to meet the patient's needs. FiGH/SMMC followed up with those patients who had positive tests to ensure that the women received appropriate care and treatment. Women who didn't have health insurance received assistance in applying for Medi-Cal or Medicare and/or receiving free screenings through the state Breast Cancer Education and Detection Program (now known as Cancer Detection Services – CDS) and Family PACT (Planning, Access, Care and Treatment).

The Laotian community is relatively small and very low-income. They have few community resources and are scattered throughout Los Angeles and Orange Counties. The community does not have any type of ethnic media to disseminate information. Therefore, FiGH/SMMC has had to do outreach education the hard way: door-to-door, face-to-face, and one-on-one in order to educate community members and encourage them to get early screening. For example, door-to-door outreach and person-to-person education is one of the most effective methods of reaching community members. FiGH/SMMC staff need to be in their homes and at community and ethnic events. FiGH/SMMC will continue to educate the Laotian, Hmong and Khmu women and to provide patient navigation. We hope that those women who received help from FiGH/SMMC will encourage other Laotian women in the community that FiGH/SMMC was not able to reach. We encouraged the women that we met to share the breast and cervical cancer brochures with other women in their neighbourhoods and to get screened by themselves or to contact us for assistance. We hope that by providing our community members with information, they will be equipped to help other women in the community.

# *Voices* FROM THE COMMUNITY

DOROTHY ETIMANI SCHMIDT-VAIVAO

Dorothy Etimani Schmidt-Vaivao, Program Coordinator born and raised in Auasi, American Samoa. Worked with the Samoan National Nurses Association (SNNA) since its inception in 1996. Happily married to Joseph Vaivao and proud mother of Marina, Carmen, Christopher, Hannibal, Joseph, Edmund and Keneti. Dorothy is going to be a grandmother, this August, welcoming her first grandchild.



## SAMOAN CANCER SUPPORT GROUP

Samoan National Nurses Association (SNNA) is an organization of nurses, both retired and active. SNNA was founded in 1996 and became a non-profit organization in 2000. Its mission is to serve the Samoan community throughout the United States in providing quality health education, recommendations, resources, guidance and services, and to raise awareness of health issues in encouraging and assisting individuals through health promotion and disease prevention programs. The Samoan community is one of the largest Pacific Islander communities in Los Angeles County. SNNA began its outreach of breast and cervical cancer to the Samoan community in the year 2001 and expanded into the other Pacific Islander communities such as Tongans, Native Hawaiians, and Chamorros in the year 2002.



Samoan Cancer Survivors support group.

Samoan National Nurses Association, in collaboration with the REACH 2010-PATH for Women program, established a Samoan Breast Cancer Support Group in January 2001. SNNA started a cancer group because we felt that there was a need in our community for such a setting. We needed to let our women know that they are not alone, that there are other women just like themselves living normal lives as breast cancer survivors. Families of survivors or survivors themselves needed to know that there was a place for them to share their fears and concerns. In our culture, women are taught to be strong; letting others know that you're sick is a sign of weakness or a curse, which is one reason why so many women do not seek medical help. The support group meeting was an opportunity to give women an understanding about each other's current and past experiences. Survivors and family members were reluctant in the beginning to share their feelings and emotions about breast cancer due to cultural barriers. They are not encouraged to talk about their illness because it's perceived as a sign of weakness or taken as a complaint or burden on the family. But over the course of the past three years, they have been able to express themselves freely.

The first ever support group of its kind in both the United States and Samoa is facilitated by Marina Tupua, a registered nurse (RN), and coordinated by a retired assistant nurse breast cancer survivor Vailili Enesi. This group averages 12 participants each month, including survivors and family members of survivors. Participants range in age from 18-75 years old. SNNA's goal is to provide a comfortable, safe and cordial meeting place in the community where our Samoan women can: 1) Meet once a month and be able to access information, both providing and receiving support; 2) Procure information about other women's experiences; 3) Learn about trends in breast cancer treatment and alternative therapies; 4) Discuss their fears about breast cancer and their reluctance to get screened, diagnosed and treated; and, 5) Be encouraged to get screened, diagnosed and treated. The meetings take place the last Thursday of each month at SNNA's office.

Breast Cancer survivor Tutasi Peleti stated that she's grateful for SNNA's support group, because she is able to share and learn new things at the same time from her peers. She feels that if her story makes a difference to one woman or family member, then it's worth sharing. The late Mrs. Elizabeth Tauu was one of the first members of SNNA's support group; she expressed that she was thankful for the support group and especially to facilitator Marina Tupua for always taking the time to take her to appointments and treatments. She was also thankful to the support group for always being there to bring the meeting



to her home when she was too weak to attend the monthly meetings. Another survivor, Lolini Vaimaona, who has gone through two surgeries, has also shared how grateful she is for the support group. Lolini and her mother travel quite a distance, from La Puente to Carson for the monthly meetings. One example of the kind of support group members gave to each other is the time group members drove out to Lolini's home after she came out of the hospital from her last surgery. She's thankful to SNNA for having this support group. Aside from providing support to one another, survivors are also encouraged to share their personal stories in SNNA's breast and cervical cancer forums, newsletters, radio media and small group outreach.

There are 16 known Samoan survivors of breast cancer in Los Angeles County. Members were recruited through SNNA's breast and cervical cancer outreach programs. A questionnaire was given to each woman asking for a brief history of breast and cervical cancer. These questionnaires enabled us to identify survivors and their family members who were later contacted. Through word of mouth, active members have also recruited other members.

The support group, together with SNNA, has successfully put together a Breast Cancer Survivor Booklet that highlights the stories of five survivors and the importance of prevention measures. Through a questionnaire, the community was asked about their feelings regarding this brochure. Many felt that this brochure was excellent, especially because it featured Samoan women. The brochure made breast cancer a reality for them and emphasized that breast cancer is a concern for the Samoan community as well. The group has also successfully completed a quilt, which depicts each member of the group's personal feelings about breast cancer. On Valentine's Day, Easter, Thanksgiving, Christmas and New Year's Day, the group has outings or potlucks with a particular theme about which members ponder. Individuals share how the theme and holiday relates to them. During these special gatherings, usually a lot of emotions and tears are stirred, and this is one of the reasons why this group grows closer and becomes personal like family.

SNNA feels that it's in the best interest of the community to have this service continue and be available to the community. The group continues to make it their priority to reach out to other survivors and family members through word of mouth. Members are encouraged to bring a survivor friend or family members to their monthly meeting. SNNA plans to continue with the breast cancer support group after REACH 2010 ends because it has successfully met its objectives and goals that were set forth.



Quilt created by Samoan cancer survivors.



# Voices

FROM THE COMMUNITY

WARAPORN 'NID' TIAPRASITH  
SRINAPHA 'NOI' VASUNILASHORN

Nid is the Program Coordinator for the REACH 2010 Promoting Access to Health (PATH) for Pacific Islander and Southeast Asian Women and Healthy Asian Pacific Seniors (HAPAS) project. As program coordinator Nid develops culturally and linguistically appropriate materials for education and outreach on breast and cervical cancer, immunizations, cardiovascular disease and diabetes mellitus, conducts outreach presentations to community members and providers, establishes mobile screening events, and advocates for the rights of community members in accessing health care. She also serves as a patient navigator and assists patients through the health care system; linking them to financial support and referral services. Nid has also been pivotal in establishing a Thai language cancer support group in collaboration with Hollywood Presbyterian Hospital, where she assists in the support group facilitation. Previous to the REACH 2010 projects, Nid has also worked in the community assisting women of domestic violence. Nid is an active community member and has been integral in developing outreach strategies that are effective and appropriate for the Thai community in Los Angeles County.



Srinapha 'Noi' Vasunilashorn is a REACH 2010-PATH for Women partner for the Thai community. She is a recent graduate of California State University, Northridge (CSUN) with a major in philosophy and is currently working towards a master's degree in Public Administration at CSUN.



Noi is an interpreter/translator/trainer for PALS for Health (a medical language interpretation and translation service). She has also been working for the Los Angeles Unified School District (LAUSD) as a Textbook Clerk/Office Assistant for the past six and a half years.

## TOGETHER WE CAN MAKE IT HAPPEN

During the 50-year history of Thai immigration to the U.S., most Thais have chosen to make their home in Los Angeles County. The very first group of Thai immigrants was comprised of students who stayed for a short period of time and returned home after completing their studies. A small percentage of these students stayed in the U.S. and started families. The second tide of Thai immigrants to the U.S. came to Los Angeles about 30 years ago. This sprawling city is considered by many recent Thai immigrants to be a gateway to this country. The primary reason for settling in Los Angeles was the ready availability of jobs. Owners of Thai restaurants and garment factories were willing to hire Thai immigrants. Unfortunately, a large number of Thai immigrants are not proficient in English and are forced to work under slave-like conditions with pay that is significantly less than minimum wage.



Outreach with mobile mammography and Pap smear unit.

Many recent immigrants and Thai immigrants still encounter multi-faceted problems: language barriers, living in substandard housing, and lack of preventive healthcare and health insurance due to low income. One of the major problems encountered by Thai workers is a lack of healthcare. Many female garment workers encounter breast and cervical health problems associated with breast and cervical cancer (e.g., irregular breast shape, nipple discharge, and vaginal bleeding). These women not only have physical health problems, but also emotional problems, such as anxiety and concern about language barriers.

Pacific Asian Language Services for Health (PALS for Health) and Special Services for Groups (SSG) recognized these problems and planned to lessen this unnecessary burden. SSG/PALS, in collaboration with the UCLA Iris Cantor Center funded a mobile van with the state Breast Cancer Early Detection Program (BCEDP) between 1997-2000, offering free clinical breast exams (CBE), and mammograms to low-income and uninsured women. The breast health outreach was funded by multiple agencies, including the Office of Minority Health between 1997-1999, The Susan G. Komen Foundation between 1998-1999, and the California Wellness Foundation between 1998-2000. Heng L. Foong, Program Director of PALS for Health, Chulee Ikeda, a community leader, and Zul Surani of the UCLA Iris Cantor Center Mobile Van were key individuals who played significant roles in the development of the project. To everyone's disappointment, the UCLA mobile van service ended a few years later due to the lack of funding.

Fortunately, REACH 2010-PATH for Women was introduced to the Thai community in 2000. Shortly afterwards, PATH for Women in collaboration with Pacific Coast Medical Services assumed the role of providing breast cancer screening for Thai women at major events and at the Thai temple in North Hollywood during every first Sunday of the month. The free screenings attract a lot of attention from Thai women in Los Angeles and Orange Counties.

REACH 2010-PATH for Women is well recognized among the Thai community. People know us via the Thai media and outreach. For example, besides breast cancer screening, outreach within the Thai community took place every month at main events. The PATH for Women health articles regarding breast and cervical cancer and general health issues were published in 3-5 Thai newspapers twice a month or every week in 2004. Sometimes, the PATH for Women program was broadcasted via Thai radio stations and television channels, sharing similar information as the newsprint. Information on

breast and cervical cancer was also made available to the community in VCD and DVD format, in the Thai language.

PATH for Women staff member, Waraporn “Nid” Tiaprasith, has played an important role in direct services by navigating, interpreting, providing personal and moral support, and seeking available benefits for free treatments such as Outpatient Reduced-cost Simplified Application (ORSA), Ability to Pay (ATP), Cancer Detection Section services (formerly known as Breast Cancer Early Detection Program-BCEDP) and Breast and Cervical Cancer Treatment Program(BCCTP) for Thai women and their families. It is common to hear women confide in and show great appreciation to Nid. In one case, a single female Thai cook who was diagnosed with breast cancer said, “After Ms. Nid interpreted the test result to me that I had breast cancer, I only stared at her face because I couldn’t believe it. Ms. Nid approached me, held my hands, and hugged me to give me moral support. I felt the warmth and didn’t feel lonely any more. At least, I have Ms. Nid and my friend, Nong, who understand me and support me. I am deeply grateful to Ms. Nid.” Another woman with both breast and cervical cancer said, “If I didn’t know Ms. Waraporn who arranged to have treatment for my tumor within 2 weeks, my life would be critical and everything would be too late.” These are some of the highlights of our success; patients are very happy with our immediate attention and healthcare navigation. As a result, they refer us to their friends and families for their breast and cervical healthcare needs.

In spite of our vigorous outreach and efficient staff like Nid, barriers and obstacles at the medical sites still exist in terms of access. Obstacles at the medical sites include long processes of registration and application for free treatment benefits (ORSA, ATP, BCEDP now known as Cancer Detection services and BCCTP), and navigating the health care facility. Usually departments and buildings are separated from each other and spread out geographically, and interpretation services at each office are often unavailable. Other barriers to healthcare access for women include long working hours and the prioritization of their families’ needs. They often do not have the option to take time off from work for doctor’s appointments. Also, women need support or approval from their husbands or family members before seeking screenings or preventive treatments. Instead, most women wait until they are seriously ill before agreeing to see a doctor. Some Thai women still believe in traditional treatments or no treatments. For example, not realizing that birth control pills are harmful to a person with cancer, many Thai women will smash birth control pills and mix it with water believing that when applied to their hair, this mixture will make their hair grow faster and look better during chemotherapy. Transportation is also a problem for most Thai women. To resolve the long process of registration, and application for free treatment benefits and treatments, changes have to be made by the medical sites. For example, related screening and treatment services should be offered at the same hospital. Currently, CBE and screening may sometimes be located at one hospital, but diagnostic and breast biopsy services will be located at a different hospital. And then surgery will be located at yet another hospital. In addition, registration processes should become more streamlined for patients, so that the patient does not repeat the same process at each hospital.

As PATH for Women ends in October 2004, Thai Health Network USA will still try to provide screening and treatment to women in the areas of breast and cervical cancer. In the future, we will incorporate more gynecological cancer screenings. Education in women’s health and outreach at major events and community sites will continue. Liaison and negotiation with reputable and efficient hospitals/ medical sites for the Thai medical personnel employment have been implemented and will continue. The highlight of our future plan is to organize a survivor speak-out program for both Thai women and



Community outreach at a beauty salon.

mainstream women regarding breast and gynecological cancers on Thai television stations focusing on survivors of 5 years or more. The program will air every other week and will also incorporate men. Meanwhile, patient navigation will also continue. We plan to continue these efforts by depending on free media, such as Thai newspapers and Thai television, and self-funding until new funding becomes available.

On behalf of PATH for Women partners and the Thai community, we would like to sincerely thank Mary Anne Foo/Executive Director, Jacqueline Tran/Program Manager, Susan Lee/Program Specialist of PATH for Women; Heng L. Foong/Program Director of PALS for Health, Marjorie Kagawa-Singer/Associate Professor in the School of Public Health and Asian American Studies Center at UCLA, Sora Park Tanjasiri/Associate Professor in Kinesiology and Health Sciences at CSUF, and Tu-Uyen Ngoc Nguyen for helping to save many women's lives from breast and cervical cancer and improving their lives in Los Angeles. Also, many thanks to PATH for Women partner Ratchaneewan Meesri for her hard work and dedication to outreach, education, media efforts, and patient navigation in the Thai community.



Assisting with paper work at a mobile mammography screening.

# *Voices* FROM THE COMMUNITY

PETA FAKASI'I'EKI

Born and raised in Tonga and migrated to the United States in 1990. Peta has worked in the Tongan Community Service Center as a Program Coordinator for the REACH 2010 - PATH for Women team since June 2002. Peta conducts workshops on breast and cervical health and assists women with access to screening services. Peta is also very involved in the community and has served as president for Tongan women's organization of the Tongan United Methodist Churches in Los Angeles for the past 3 years.





# TONGAN AMERICAN WOMEN’S NEED FOR LINGUISTICALLY APPROPRIATE MATERIAL ON BREAST AND CERVICAL CANCER

As a result of the growing Tongan population in Los Angeles, the Tongan Community Service Center (TCSC) was established in 1988 to provide much-needed social services to the Tongan community in Los Angeles County. The Community Center is the single most effective agency in providing culturally and linguistically competent services to the Tongan community, and in targeting underserved and overlooked populations in the areas of interpretation and translation. The Tongan Community Service Center has also established partnerships with larger organizations around projects directed towards the needs of the Tongan Community. The Tongan Community Service Center is a program of Special Service for Groups (SSG).

REACH 2010-PATH (Promoting Access to Health) for Pacific Islander and Southeast Asian Women began in 1999, a five-year project funded by the Centers for Disease Control and Prevention (CDC) Foundation through the generosity of The California Endowment. This project was developed to focus on breast and cervical health disparities among Pacific Islander and Southeast Asian Communities in Los Angeles and Orange Counties. REACH 2010-PATH for Women expanded from a breast screening program that was developed in 1997-1998 with PALS for Health. Through the work of Sioana Finau and Ilaisaane Fehoko, a breast screening project was initiated for the Tongan Community through a small mini-grant from Partnered for Progress. This small mini-grant (\$5,000) brought the UCLA Iris Cantor Mobile Van to the community and allowed for community members to receive mammography screening. As a result, in-language materials were created; with time, this small project has grown into the larger PATH for Women project, which now addresses both breast and cervical health in the Tongan community.



TCSC staff.

In 1999-2000, focus groups, interviews and community meetings were held to identify breast and cervical health needs in the community. Information was provided that helped to shape the strategies of the REACH 2010-PATH for Women project. In 2003, a breast and cervical cancer survey was conducted among 182 women in Los Angeles county to better assess the knowledge, attitudes and beliefs of the community women. The age of women interviewed ranged from 35 to 83 years. From these surveys and meetings with the community, Tongan Community Service Center was able to identify specific health needs and developed strategies to address these needs.

REACH 2010-PATH for Women identified various needs; one of the greatest was the need for culturally and linguistically appropriate educational materials. Small surveys conducted through workshops were administered to Tongan women, aged 35 and older, residing in the county of Los Angeles, through a network of social ties and organizations, including church groups, senior citizen clubs and through the Tongan Community Service Center’s own education programs. Comments gathered clearly highlighted the need for materials. Groups were then asked to evaluate whether verbal or written materials would be a more effective means to outreach. All women agreed that brochures, flyers and questionnaires translated into the Tongan language would be the most appropriate outreach strategy.

In addition, the women also identified health care and health education access as areas of concern. Tongan women also identified several other reasons for their lack of knowledge and desire to seek

precautionary action or treatment for breast and cervical cancers. Issues such as cultural beliefs, limited access to health screening, low socio-economic status and many other factors impacted their access to seeking care in a timely fashion. Having identified this, we sought to understand why.

Most Tongans who migrated from Tonga have a tendency to rely on their families already rooted in the United States or any other country outside of Tonga for assistance. To communicate with doctors or nurses, you have to speak the language of the care provider or you need to have an interpreter. Aside from insurance, we also have to look at the financial situation of the family to understand the priorities and needs of the family. A major area of concern, in regards to health care, was centered on the lack of translated materials and access to medical services provided with translation. Having identified this, TCSC has sought to develop culturally and linguistically appropriate materials on breast and cervical cancer to outreach to the community, and address this aspect of healthcare.

As early as 1997-1998, materials were translated into Tongan to provide information and resources to community members. Materials were often translated from existing brochures and made into flyers to disseminate at workshops and screening events. Over the years, Tongan language brochures on breast and cervical health have been developed, some of which are the first of their kind in California. The brochures are an opportunity to share breast and cervical health information with the Tongan community, but also a means to share the Tongan language and culture with the other communities. The imagery and words used for the brochures were carefully chosen to not only educate, but also to appropriately reflect the beliefs and practices of the community. Education was integrated into the Tongan culture, such as weaving messages into tasks such as making tapa, meeting with Church members, learning about healthy eating, and creating recipes from our local island foods and exercise. Creating culturally and linguistically appropriate materials takes much more skill than just translating the words into the language; one must also place thoughtful meaning into the words of the language. Only through understanding and respecting the culture, beliefs and practices of our community are we able to reach women in our communities.



Outreach at Tongan cultural event.

While Tongan Community Service Center has been able to address some of the needs identified by the community, there remains much more to do. Much improvement needs to be made in increasing community education regarding the need for early breast cancer screening. A vital need exists to launch aggressive outreach and education programs to educate the Tongan community about the importance of early detection. Unfortunately, there are few breast cancer educational materials developed specifically for Tongan Americans, and we urge the creation of programs to develop materials that are culturally, linguistically, and educationally appropriate for Tongan American women. One of TCSC's future community projects is quilt making. We are planning to invite women from the Tongan community to make a quilt that displays a local mulberry plant (grown on the island of Tonga) that would symbolize addressing breast cancer through early detection.

# Voices

FROM THE COMMUNITY

AUDREY BICH-THUY DOAN  
DIEP TRAN

Audrey Bich-Thuy Doan, Vietnamese Health Educator was born in Vietnam, left her country for studies majoring in Business Administration in Switzerland, then moved to Canada for almost 30 years where she participated in several organizations and activities contributing to the development of education, culture and social standing for the community. Since 1997, she settled down with her family in southern California to be closer to her parents. Audrey joined OCAPICA as a Vietnamese Health Educator in 2002. She is implementing action plans to educate Vietnamese American women in OC about Breast and Cervical cancer. Audrey also works on various other projects that focus on education, youth, and safety. She has been pivotal in the development of in-language materials for all the projects she works on and has been on the Vietnamese radio and television bringing awareness to the above mentioned areas for the community.



Diep Tran is a Program Coordinator at the Orange County Asian and Pacific Islander Community Alliance for the Vietnamese Breast and Cervical Cancer Program, a component of REACH 2010-PATH for Women Program. She is also responsible for the post-production administrative activities of the Vietnamese American curriculum project and the Mendez v. Westminster curriculum guide. She earned a Bachelor of Arts in Psychology and a Bachelor of Arts in International Studies from the University of California, Irvine. In her spare time she enjoys spending time with her dog, Lucky, playing the piano, and doing crafts. She is also an aquarium hobbyist and loves to write poetry.





# THROUGH OUR EYES, THROUGH OUR HEARTS— THE VIETNAMESE WOMEN'S PATH STORY

Orange County is home to the largest Vietnamese American population nationwide, estimated to be 135,500 (2000 Census, with community estimates at 250,000-300,000 people), with approximately 60 - 70% of the community made up of refugees or immigrants. Little Saigon, which began in the City of Westminster as a Vietnamese enclave on Bolsa Street with small mom-and-pop shops and restaurants has evolved into a booming commercial and cultural center and had become the heart of the Vietnamese American community. Westminster, once divided by racial segregation until the late 1940s, is now a dynamic, ethnically diverse city with Little Saigon as one of its main attractions.

Although Little Saigon can boast of many success stories about top Harvard graduates and thriving entrepreneurs, there are also many hidden, untold stories as well, about refugees and boat people desperately fleeing their homeland, and their struggles to adapt and acculturate into a new homeland -- stories of poverty and the difficulties of surviving in America.

At first glance, when told that the Asian and Pacific Islander (API) owned businesses in Orange County contribute \$15 billion annually to the local economy, it is assumed that APIs are financially stable, and that as a whole they do not need any government assistance. A closer look however, shows that 72% of API owned businesses do not have paid employees (2000 Census), which typically signifies a small family-run business where family members work long hours (oftentimes 7 days a week), have no retirement or pension plan, and have no health insurance or health benefits.

Lack of health insurance is a major concern for the community. What does it mean to be Vietnamese American and have no health insurance or access to health care? This story, which is only one aspect of the community's story, represents the experience of two community health educators in regards to breast and cervical cancer issues for Vietnamese women in Orange County, particularly among those who are low-income, uninsured, and underinsured.

Why does the Vietnamese American community need breast and cervical cancer outreach? Vietnamese American physicians fill the local ethnic radio stations and newspapers with information and discussions about various health topics, and there are at least two Vietnamese American non-profit community clinics in Orange County. Unfortunately, even with these resources, Vietnamese American women are diagnosed with cervical cancer at a rate that is five times higher than for Caucasian women. Breast cancer is the most common cancer for Vietnamese women and the leading cause of death, and yet screening rates for both types of cancer remain low when compared to other ethnic groups. What are some of the barriers that prevent Vietnamese women in America from receiving screening and preventive treatments?

Health care is a family issue; therefore to understand the perception of health care and health care utilization, we need to look at the Vietnamese household. Oftentimes, when discussing barriers to health care for minorities and ethnic groups, the most commonly cited barrier is "culture." Rather than thinking of culture as inhibiting, we encourage trying to understand how the interplay of customs and family values can make it complicated for women to access health care. Raised to be modest, Vietnamese women are rarely openly educated about puberty, male-female relationships, or even about



Outreach at a community agency.

their body. First-time discussions have even take place just a few days before their wedding! Thus, even married women tend to be shy when talking about issues of sexual relationships or their body. Since modesty extends itself even into the predominately male doctor's office, women may not be referred to get mammograms or Pap smears by their own physicians, especially when the patient is elderly or when the physician was originally trained in Viet Nam. Asking a patient to have a Pap smear can be particularly embarrassing, because it may imply that she has been "promiscuous," and therefore she needs to get tested. Another problem is the lack of training on ethnic health issues in medical schools, which probably accounts for the traditional belief that Asians as a whole are the healthiest people.

Many also believe that talking about illnesses and diseases may bring them bad luck; therefore, they will not mention it until the symptoms are intolerable. There is also the expectation of women to sacrifice for their families and to place a higher priority on their family's needs before their own. This expectation may lead to months or even years during which a woman may ignore her own health care needs because she is taking care of her family.

Having no time off work or no sick leave is another major barrier for Vietnamese American women. For most of our women, Little Saigon is a "comfortable" place to work—the food, language, and people are familiar. The many food-to-go shops, small restaurants, and beauty salons primarily employ female workers, who receive low wages, no health benefits, and often must hold two or more jobs to make ends meet. According to 2000 Census, 25% of Vietnamese American households have three or more workers, which is double the amount of workers for all US families. Although Vietnamese-American household income earnings increased from \$29,770 in 1990 to \$45,000 in 2000, the per capita income was \$15,565 compared to \$21,587 for all Americans, and \$23,918 for White Americans. This disparity in income also reflects the disparities in health care access and utilization.

Other barriers such as transportation, language, the unfamiliarity with the complicated health care system, and lack of health insurance (Special Service for Groups, Inc. REACH 2010-PATH Needs Assessment Report, 2001) exist as well. Lack of health insurance is one of the major barriers to care. Although local community clinics may charge between \$5 - \$15 for an office visit, lab tests and medication are extra costs that the client must cover. A regular visit with lab tests can cost up to several hundred dollars for those who are paying cash. Many Vietnamese women cannot afford to spend this extra expense, which means they usually will not see the doctor until symptoms are unbearable.

With many barriers preventing Vietnamese women from accessing care, how can we as community advocates help to increase screening rates and health care utilization? The Vietnamese Breast and Cervical Cancer Project, a component of REACH 2010-PATH for Women, was developed to address the disparities in screening rates, health care access, and other issues pertaining to breast and cervical cancer for Vietnamese women. Our program aspired to increase the awareness of these two cancers by creating innovative ways of outreach, culturally sensitive materials, and in-language education through workshops.

The goals of the project initially seemed daunting to the two health educators. We knew our limitations. Neither of us had any background or extensive knowledge in public health, breast or cervical cancer, or how to develop a community program. Fortunately, by being a part of PATH for Women, we had abundant opportunities to attend trainings and conferences.

Along with the formal skills that we learned from the trainings and conferences, we also needed to blend in our own personal skills and experiences acquired while growing up as Vietnamese women. The wide age gap (about 25 years) between the two partners for the Vietnamese Breast and Cervical Cancer Project brought a mix of difficulties, learning, rewards, and lots of sharing. As we grew to know the community, we also grew to know each other. At the basic level of the program, it is very personal. Diep is in her mid 20s, with a fluency in computers and English, while Audrey is in her early 50s, with excellent skills in Vietnamese and communication. As with any close partnership, we had good and hard times, tears and laughter, and many moments of reflection and deep understanding about each other.

We began by developing in-language materials that described our program and the services we could offer. Having very little experience in materials development, we finalized and printed our brochure after

nearly 9 months. We began our outreach at major cultural events—TET (Lunar New Year) Festival, Le Vu Lan (Vietnamese Mother's Day), and the Moon Festival. Over the last three years, we distributed more than 2,500 flyers, brochures, and other educational materials. Although the interactions with community members were often brief, we were able to hear different stories about the health care needs of women and their families.

One of our most successful outreach strategies was our breast and cervical cancer workshops. Diep created a Power Point presentation, which included breast-self examination (BSE), clinical breast exam (CBE), mammogram, and Pap smear information. This tool was translated and presented by Audrey at two beauty colleges, a luncheon at King Harbor Seafood Restaurant, HOPE Community Center, several Head Start Centers, Boat People SOS, Nhan Hoa Clinic, adult day care centers, and several community health fairs.

The workshops offered us the opportunity to share detailed information about breast and cervical cancer within an intimate group setting. It is encouraging when participants share their experiences at the end of the workshop and encourage each other to get screened. We have received great support with our workshops. For example, we developed a close relationship with one breast cancer survivor. She works as a tailor by trade and is a mother and wife. This intelligent, courageous, kind hearted cancer survivor of seven years attended many workshops as our special guest to tell the audience about her experiences with breast cancer. She moved the audience as she shared the time she took a two-hour shower, crying, as she pulled out the last strands of her hair from her now completely bald head, due to radiation and chemotherapy. She even talked about her fear of losing her husband's love, because she was not "pretty" anymore without her hair. She left the audience with feelings of encouragement and hope, and with a very strong message to be active rather than passive about their health. For many of the participants in the workshop who had never heard a cancer survivor speak, she was the model cancer survivor, and became the essence of all the early detection and prevention messages.



Outreach at the Vietnamese Lunar New Year Festival (Tet).

We also received great support from the owners/managers of two beauty colleges: Advance Beauty College and Coastline Beauty College. Students included a mix of both females and males, who ranged in age from early 20s to late 40s. It was challenging to conduct workshops at the beauty colleges due to the large number of students. Some students continued working on their nail sets and would have side conversations, but overall, the majority of the students, even the men, found the workshops to be valuable and informative. The students asked general questions during the Q&A session, but what truly touched us was that they asked us personal questions afterwards and were willing to share their personal experiences about their health. For both of these workshops, we had the support of the National Association of Vietnamese Nurses, where volunteer nurses would help conduct part of the workshop, demonstrate BSE, and help with

the Q&A session. When we started to present at beauty colleges, other community-based organizations began to bring their health information to the beauty colleges as well. This helped to open doors to what would not be a traditional setting to conduct health workshops or presentations.

We have also presented workshops at several Head Start Centers. Audrey was invited to be on the Policy Council of Head Start Center in Orange County, and through this partnership, we were able to set up several breast and cervical cancer workshops at the school sites for Vietnamese mothers. Vietnamese staff at the schools created the flyer, recruited the women, and brought refreshments, too. The group size was smaller than the workshops held at the beauty colleges, with about 5-15 women in each. Since it was a small group and all the participants were women, Diep suggested having the women imitate the standing poses of BSE. Audrey imitated the steps and the women followed. During and after the presentation, women were asking questions and sharing their stories. We were able to pass around our breast and cervical models for the women to closely examine. The workshops were some of the best

experiences of our program.

Our outreach efforts with the workshops came after we were comfortable with our patient navigation process. After 9 months to a year, we learned about the different medical facilities, the services they provided, and got to know the staff working at those medical sites. We introduced our program and ourselves to several private physicians' offices, community clinics, and a medical center. Some responded more positively than others, but after several patient navigations, we began to work closely with Nhan Hoa Clinic, the first Vietnamese American community clinic in Orange County. Nhan Hoa has their own mammogram machine, which made it easier for women to get a Pap smear and mammogram in one visit. Nhan Hoa also opened their doors for us to do outreach for our events, like passing out flyers for our annual health fairs and for other events that were not always related to health. Nhan Hoa has been an important and integral partner. Although we have built partnerships and know the system, healthcare continues to change daily. Our experience with patient navigation keeps us updated with the changes that occur.

Patient navigation is rewarding. Diep remembers receiving a call from a woman who admitted that she initially did not want to call us because she was afraid that we might be rude to her. She had previously called a different breast cancer program, and the lady who answered her call was rude and curt. She also experienced similar situations with staff at government agencies. She admitted to having no health insurance and being low-income, but did not want to be treated like a "beggar." Her husband handed her our brochure and urged her to "give us a try." After making an appointment for her screenings, she hoped to meet us one day to thank us in person. She was extremely glad she called, and said she would refer her friends to call us as well. It is a deeply rewarding feeling to have patients share their gratitude and encourage us in their own ways.

Through our experience, most women who call for a Pap smear or breast exam are about 45 years or older. About 20% of our clients have been under 40 years of age. We have also attempted to outreach to the younger generation Vietnamese American women. Generally, they tend to be more open about their sexuality and their body than their mother's or grandmother's generation. For these women, the advantage of being born in America or raised here since childhood is that they have more access to health information via the internet, mainstream news outlets, and also through the school nurse or college health centers. We have conducted various outreach activities to younger Vietnamese women, such as passing out flyers that we designed for younger women at the local universities, shopping centers, and local high schools. We assumed that younger women would be more willing to call us for help with screening appointments, but we have received few calls from this group. We are unsure of the reasons, but some possibilities could include not wanting their parents to find out, not having enough time, feeling that they are young and healthy, or preferring to go to a mainstream organization, such as Planned Parenthood.

We have experienced similar difficulties in screening with younger women who are recent immigrants. We have conducted workshops at Advance Beauty College and Head Start Centers where most of the women were younger than 40 years old. After the workshops, many of these women asked us questions and spent time talking to us, but very few called to make an appointment for screening. We believe that this group may be occupied with work, starting a family, or with establishing their immigration status. We also believe that the low number of calls does not mean that they are not accessing care, but rather they do not need our assistance in making appointments for screening. They may be calling the clinics directly. We are unsure of the reasons, but we are thankful to be able to present workshops on breast and cervical cancer to younger women so they at least have the knowledge and can hopefully share it with their friends and family. We hope that in the future we can better reach and assist this community.

There are also other health issues that our clients often ask us about, such as diabetes, cholesterol, and even free general health examinations. To try to address these needs, OCAPICA, in partnership with Acacia Adult Day Services and the Office of Assembly Member Lou Correa organized a community



**Outreach at a community fair.**

health fair that provided free blood glucose, cholesterol, blood pressure, bone density, and mobile mammogram screenings. We called our health fair, Living Healthy, Living Longer... For the first year, twenty participating organizations distributed educational materials and information about their community programs. About 150-200 people attended this successful event! The second year was also a great learning experience. It rained the day of the health fair, but we still had a great turn out. This time, 27 different community organizations and businesses participated with about 130 community participants. Along with having mobile mammography, Audrey presented our breast and cervical cancer workshop at this health fair with the help of a Vietnamese nurse. Our 3<sup>rd</sup> annual health fair was held on May 1, 2004. There were 36 participating organizations and businesses, over 150 participants, and many generous donations, like food, water, and gifts for raffle prizes. This health fair received only positive feedback from community members, the media, and the participating organizations.

Our health fairs have greatly expanded, and we hope to see this fair become a regular health resource for the community in the future. Health fairs are a great venue to lead people into the health care system; however, we must continue to work with our community members to assure that they are linked with continuous services.

In retrospect, capturing the success of our program gives us a sense of great joy, but we know very well that more work needs to be done to decrease the health disparities for our community. This story has been difficult to express in writing and it is only a snapshot of the whole project. Many intricate and personal details were not mentioned in this story that contributed to the success of our program. Concluding it has been even more difficult. The experiences that we have gained working on the Vietnamese Breast and Cervical Cancer Program and working for OCAPICA is manifested in the gratitude of the patients, the reputation we built, and the friends we have made. This has been an experience of a lifetime.

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