



Pacific Islander Cancer Survivorship Educational Forum – Pilot Project Proceedings Report

Project Partners

Asian & Pacific Islander American Health Forum
Guam Communications Network
Samoa National Nurses Association
Taulama for Tongans



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This Pacific Islander Cancer Survivorship Educational Forum Focus Group- Pilot Project Proceedings Report has been prepared by members of the Asian & Pacific Islander American Health Forum Staff and the Pacific Islander community based organizational partners- Guam Communications Network, Samoan National Nurses Association, and Taulama for Tongans. Contributors to this document include: Roxanna Bautista and Nicole Kang. Photographs included in the book were taken by Richard Cavosora, Roxanna Bautista, and Susan M. Shinagawa.

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About the Lance Armstrong Foundation

The Lance Armstrong Foundation (LAF) inspires and empowers people affected by cancer. LAF helps people with cancer focus on living; LAF believes that unity is strength, knowledge is power and attitude is everything. From the moment of diagnosis, the LAF provides the practical information and tools people with cancer need to live life on their own terms. The LAF serves its mission through advocacy, public health and research. Founded in 1997 by cancer survivor and champion cyclist Lance Armstrong, the LAF is located in Austin, Texas.

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Background of APIAHF Pacific Islander Cancer Survivorship Educational Forum Project

The Asian & Pacific Islander American Health Forum (APIAHF) is a national health advocacy organization that promotes policy, program, and research efforts to improve the health and well being of Asian American and Pacific Islander (AAPI) communities in the United States. APIAHF advocates for health issues of significance to AAPI communities, promotes community-based capacity building and training, conducts research, disseminates information, and convenes regional and national conferences on AAPI health. APIAHF addresses cultural competency and language access in the areas of policy advocacy, HIV/AIDS, domestic violence, and chronic diseases through leadership development and capacity building assistance for community based organizations.

In 2004, APIAHF proposed to conduct the Pacific Islander Cancer Survivorship Educational Forum pilot project aimed to educate cancer survivors and health care providers about culturally relevant survivorship issues and provide information about cancer support programs and resources for Pacific Islander communities in Northern and Southern California. Activities in the two-year project included the convening of focus groups, conducting key informant interviews, developing the educational forum curriculum, and coordinating and implementing two educational forums. The project was specifically targeted for Pacific Islander cancer patients and survivors, community based organizations serving Pacific Islander communities, health care providers, and health departments. Pacific Islander cancer patients and survivors can advocate for enhanced culturally appropriate programs and resources at the local and state level utilizing the focus group findings and the forum proceedings.

In California there have been some programs addressing survivorship in AAPI communities, however, for specific Pacific Islander communities cancer support services and programs are still sorely lacking. While programs and services have been limited, there are some localized programs that are serving specific Pacific Islander communities that have been well received by community members. APIAHF contacted organizations serving Pacific Islander communities in California, of the three cancer support programs (which serve Samoan, Chamorro, Tongan, and Hawaiian survivors), all have indicated challenges in developing facilitator guides/program plans for their support programs, or adapting other organization's facilitator guides that are often not culturally or linguistically sensitive to the Pacific Islander communities or ignores certain groups within the Pacific Islander community. Organizational staff expressed their frustration in obtaining culturally and linguistically sensitive materials available for those who want to develop support programs and resources for Pacific Islander Communities. APIAHF and Organizational Partners have promoted and will continue to promote the development of culturally appropriate and unique support services and resources for all Pacific Islander communities, and will share the developed curriculum to assist other organizations interested in working with Pacific Islanders. APIAHF and Organizational Partners will continue to assist organizations, healthcare providers, and health departments establish Pacific Islander support groups, involve Pacific Islanders in clinical trails, and provide culturally competent services and referrals to Pacific Islander patients and survivors.



Through the recommendations and proceedings from this project, Pacific Islander cancer survivors can ultimately advocate for enhanced culturally appropriate programs and resources at the local and state level. This project has the potential to be adapted for Pacific Islanders in other regions of the country and in the U.S. affiliated Pacific Islander Jurisdictions. In addition, with APIAHF's expertise in leadership development and capacity building, APIAHF can enhance cancer support services, and thus improve the quality of life for Pacific Islander cancer survivors living with, through, and beyond cancer.



Opening Statements

Roxanna Bautista, MPH, CHES
APIAHF Chronic Diseases Program Director

Welcome to the Northern California Pacific Islander Cancer Survivorship Educational Forum. The Asian and Pacific Islander American Health Forum is excited to have gathered local Pacific Islander communities here today for this momentous occasion, an event that we have worked hard with our Pacific Islander partners, Guam Communications Network, Samoan National Nurses' Association, and Taulama for Tongans, to create, develop, and present to you all.

Two years ago, when The Lance Armstrong Foundation released their call for grant proposals, APIAHF had a vision. This vision was to educate cancer survivors and health care providers about culturally relevant survivorship issues and provide information about cancer support programs and resources for Pacific Islander communities. However, we knew that such a task called for collaboration with our Pacific Islander community partners, who had already made groundbreaking strides in narrowing the gap in health disparities for Pacific Islanders through the development of culturally and linguistically appropriate materials, support groups, research studies and data collection, and educational models, as well as their advocacy work.



The collaboration has been fruitful and inspiring. The enthusiasm and dedication of our community partners has inspired us to more strongly connect to the Pacific Islander communities to better understand pertinent health care issues and shape our policy, advocacy, and programmatic objectives so that Pacific Islander health care concerns are addressed. I am proud to say that our Northern California Pacific Islander Cancer Survivorship Educational Forum is a synergy of our collective efforts to improve the health and well-being of Pacific Islanders and hope that today will provide you all with the opportunity to learn more about pressing health issues as well as be empowered to initiate change in your communities.

Now we will hear a few words of welcome from the leaders of the Health Forum, Guam Communications Network, Samoan National Nurses Association, and Taulama for Tongans. Dr. Ho Tran will start and will be followed by Lola Sablan- Santos, Sala Mataalii, and Leafa Taumoepeau.

Thank you.



Ho L. Tran, MD, MPH
APIAHF President and Chief Executive Officer



As an organization, APIAHF is committed to incorporating components of the Asian American and Pacific Islander Health Agenda into our scope of policy, advocacy, and program work. We strive to promote to communities, health providers, and organization the importance of ensuring service accessibility through the development and provision of culturally and linguistically appropriate services and resources. We advocate for increased research and data collection on AAPIs and especially for the desegregation of Asian American and Pacific Islander data to allow experts to clearly pinpoint differences in health issues between those communities. We develop and support policies that push for affordable and equitable care for all. As such, the Health Agenda is not absent from today's programming, which will provide you with the tools to engage with and empower your communities to initiate change in cancer treatment and support services.

I hope that today's programming will inspire you to action
Thank you for coming and may you have a good day.

Good morning. My name is Dr. Ho Tran and I am the President/CEO of the Asian and Pacific Islander American Health Forum. It gives me great pleasure to welcome you all to the Northern California Pacific Islander Cancer Survivorship Educational Forum, a collaborative effort between APIAHF and our Pacific Islander community partners, who inspire us with their dedication, innovation, and hard work in caring for the health needs of their respective communities.



Welcome from APIAHF's Pacific Islander Community Organizational Partners

**Talofa
From Sala Mataalii**

President and Founder of Samoan
National Nurses Association



**Malo e Lelei
From Leafa Taumoepeau**

Executive Director of
Taulama for Tongans

**Hafa Adai
From Lola Sablan-Santos**

Executive Director of
Guam Communications Network





Northern California Pacific Islander Cancer Survivorship Educational Forum February 11, 2006

Cancer in Pacific Islander Communities

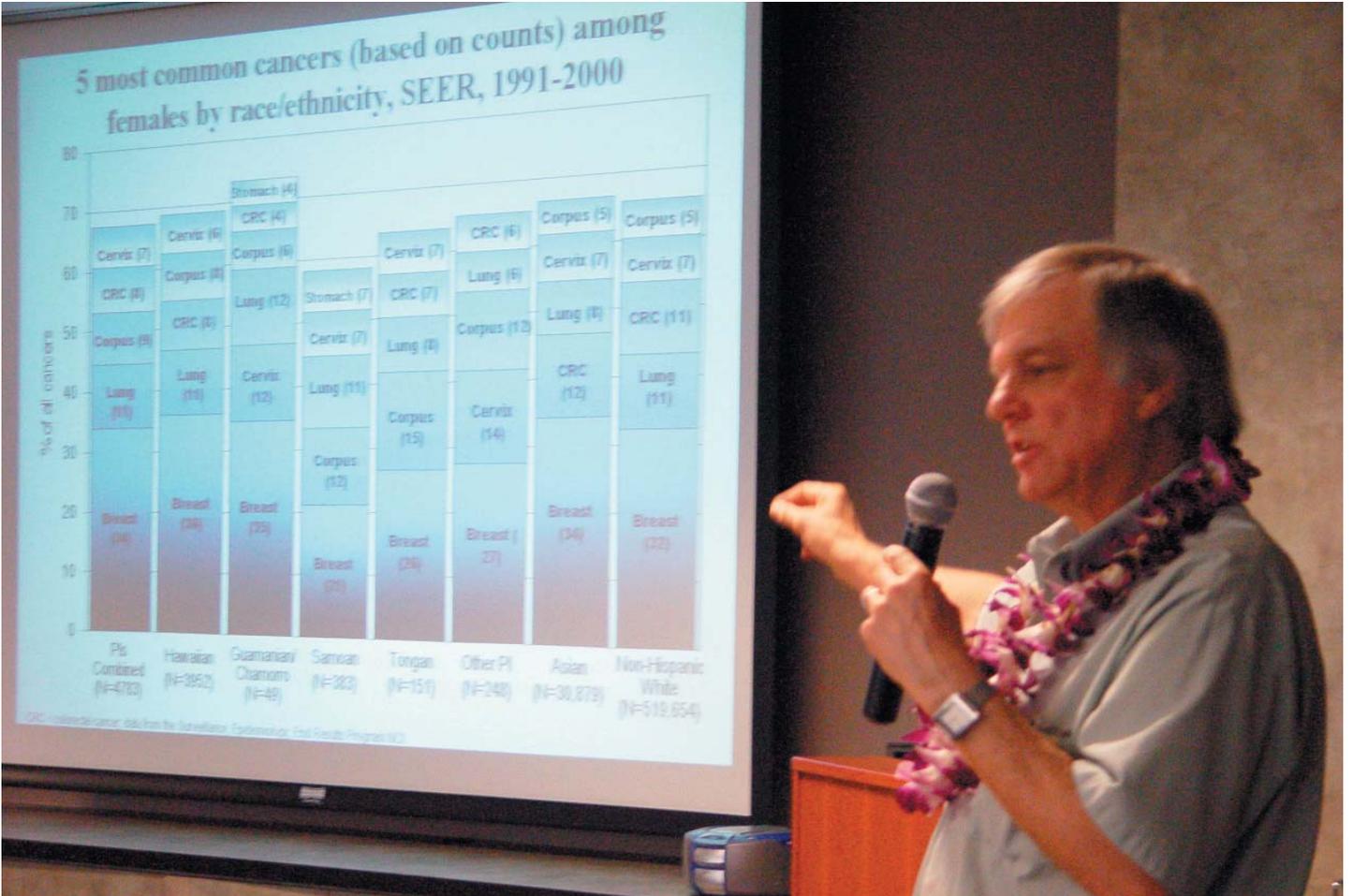
Dr. Dee West- National Cancer Institute/Stanford University

Dr. Dee West, principal research investigator for Cancer Information Services at Stanford, presented on the current state of cancer in Pacific Islander communities through his discussion of relevant cancer data as well as shared key recommendations for policymakers and stakeholders in regards to improvements for Pacific Islander cancer research and services.

Key points from Dr. West's presentation include:

- Misclassification is a common problem in the reporting of cancer cases by ethnicity. Because of this, Pacific Islander data is most often aggregated with cancer data of Asian Americans, therefore, leading to the "invisibility of cancer" within Pacific Islander communities and health professionals.
 - There are persistent barriers between Pacific Islander communities and access to care. These include:
 - 1) lack of free or low-cost healthcare services for the uninsured or those who have no source of care;
 - 2) lack of understanding of cultural modalities by which Pacific Islander communities operate by in their approach to healthcare;
 - 3) limited presence of traditional healers and complementary medicine models in healthcare plan for communities;
 - 4) lack of education about early detection and screening; and
 - 5) lack of financial assistance.
 - Community feedback reveals that there continue to be unfavorable perceptions of cancer; cancer is most commonly viewed as a punishment from God for "sins" committed during a lifetime or that "cancer is death".
- Recommendations for improvements in cancer research and treatment include: 1) mandate federal and state agencies to collect and develop better ethnic classification, demographic, and healthcare information; 2) understand the barriers that community members have in accessing clinical trials; 3) recognize Pacific Islander as an indigenous, distinct, and at-risk population requiring a flexible and culturally-sensitive health care delivery system; and 4) increase the number of Pacific Islanders being placed in health care organizations which serve Pacific Islander communities.

To request a copy of this presentation, please contact the Asian & Pacific Islander American Health Forum.



Biography

Dee West, PhD is the Chief Scientific Officer at the Northern California Cancer Center having previously served as the NCCC Executive Director for 10 years. Since 2004 he also has an appointment as Professor of Epidemiology at Stanford University where he serves as the Associate Director for Population Sciences in the Stanford University Comprehensive Cancer Center. Dr. West served as the Principal Investigator of the SEER cancer registries in San Francisco/Oakland and San Jose/Monterey for 20 years. He is also the Principal Investigator of the Cancer Information Service for the State of California and for a Breast Cancer Early Detection referral program for the State. He is also the past Principal Investigator of a Breast Cancer Family Registry in Northern California. He is a Co-Investigator on several

studies, including a cohort study of 133,000 teachers in California and the NCI CanCORS project, which examines quality of cancer care and quality of life for breast and lung cancer patients. Dr. West has published widely from registry data and from analytical studies. His main research focus has been on breast, prostate and colon cancers and research methods. Much of his research has been related to diverse patterns for cancer in many racial/ethnic populations and the reason for these patterns and how to reduce the unequal burden of cancer in many populations. Dr. West served as President of North American Association of Central Cancer Registries from 1995 to 1997 and as the North American Representative to the International Association of Cancer Registries from 1996 to 2000. Currently Dr. West is Chair of the National Coordinating Council for Cancer Surveillance.



Pacific Islander Cancer Survivors Stories

Leafa Taumopeau, Executive Director, Taulama for Tongans

Mother of Lucianne Latu, Tongan Survivor of Osteogenic Sarcoma



Zealand, my marriage was falling apart. The marriage ended. I don't know if that had anything to do with it.

Friends and family did not want us to go. They said, "It's a Tongan disease. We should treat it the Tongan way with herbs and home remedies." When the family heard that Luci was having her leg amputated, they became upset at me because it was my decision to take Luci out of Tonga.

It was okay when she was younger, but as my daughter got older, she started raising a lot of questions like "Why am I having cancer?" She was brilliant in elementary school, but then she went to high school, and things went down from there. She went from a bright student to one who almost did not graduate

I wish my daughter were here today. She should be the one talking to you right now. She was supposed to be here, but at the last minute, she could not be here. My daughter is 28 years old. She was diagnosed with osteogenic sarcoma at age eight.

from high school Children are cruel. Because she was an amputee, she was pushed aside and called a freak for having one leg. She fell into a deep depression. I didn't even know!

There are no facilities to detect or screen for cancer in Tonga, so we had to go to New Zealand for treatment. They amputated my daughter's leg above the knee and that was followed by aggressive chemotherapy. We were there for more than a year. While we were in New



She dropped out of college and went to work, but at work, many psychological issues (depression) came up. We tried everything; we went to psychologists and social workers. Nothing seemed to help Luci break free from her depression. She attempted suicide a couple times and began drinking. Sometimes, I would go somewhere and come back and the paramedics would be there. I wondered if that time was “it”. The whole family was suffering.

As a caregiver, I felt responsible. As she grew older, she asked “Why did you agree that I should lose my leg?” I said, “To me, was best. I did not want to lose you.” She said, “You should have asked, because I would not have wanted to lose my leg.” She blamed me for the cancer.

I started Taulama to deal with cancer because we’re dying from cancer and we don’t know why. Is it our diet? The bomb testing in the Pacific? We don’t know, but people are dying and they recognize that it’s from cancer. It’s difficult to pursue this interest because we don’t have enough money and resources to help ourselves, but there are so many Pacific Islanders who have been affected by cancer.

Biography

Leafa Tuita Taumoepeau, Executive Director of Taulama for Tongans. Ms. Taumoepeau was awarded the Cultural Competence Service in Action Award for 2005 for her work in the community, promoting, advocating health and this was presented at the Cultural Competence and Mental Health Summit XIII for 2005. She is married with 4 children. Leafa was educated at Tonga High School in the Tonga Islands and Auckland Business College in Auckland, New Zealand.



Juliane Lee
American Cancer Society
Chamorro Leukemia Cancer Survivor

In 1988, I was getting ready for my wedding. I suddenly came down with a high fever that lasted two weeks and a painful infection in my throat. I went to see my doctor and he insisted that it was just a bad case of the flu; he prescribed chicken soup, Tylenol, and bed rest. I believed him because I had learned to not question my physician. I then suffered a massive stroke and was paralyzed. I was diagnosed with acute myelogenous leukemia, a condition that affected the level of my platelets, causing the hemorrhage that led to the stroke. The treatment required high doses of chemo and bone marrow transplant.

My 6 siblings were tested to see if they were matches. When the doctors did not find a match, they asked they were my only siblings. My parents were insulted, but the doctors said, “The truth is you’d be surprised by the skeletons that come out of the closet at a time like this.” It turned out that I was the middle child of 7 siblings. My oldest sister was found to be a perfect match.

When I was diagnosed, I was looking for someone who had the same thing as me: someone who had a stroke. They said that there was no one, that my case was rare. But, through the Bone Marrow Transplant support group, I found someone. He was twenty-three. Years later he tracked me down and told me, “You saved my life.” I still go to the bone marrow transplant reunion every year.

Coming to terms suffering cancer was difficult to grasp. Would I understand and make sense of it all? Eventually, I went back to school to receive a degree in psychology, and created support groups for young adults and young stroke survivors. I am now a health programs manager with the ACS-it is my way of giving back and I am inspired by the stories I hear. Each day I know that this is where I should be.

Biography

Juliane Corn Lee was born & raised on Guam. After moving to San Francisco for college, she earned both her undergraduate and graduate degrees in psychology from the University of San Francisco. Her work in patient advocacy began after her own experience with the disease. In 1988 she was diagnosed with acute myelogenous leukemia (AML), and is now 17-years post bone marrow transplant. Currently she works as a Health Programs Manager for the American Cancer Society.



Esther Tufele
Samoan National Nurses Association
Samoan Breast Cancer Survivor

I was diagnosed before Thanksgiving of 2002 with stage IV breast cancer. When I found out, I did not know how to deal with it; both my mother and grandmother passed away of breast cancer. I came from a family of 13 siblings and I was the only one diagnosed with cancer. It made me a stronger person and has allowed me to educate others. I have a 27 year old son who is now on death row because his involvement with gangs. When my son found out that I had cancer, he did not know how to deal with it. I go to visit him often.

My cancer experience has taught me a lot in the way of becoming a stronger person to deal with my cancer. I am still learning how to deal with cancer every day. I've met many other beautiful people, which has given me the motivation to move on and educate the community.

I want to thank Sala for being my biggest mentor, to help me share my story. I look forward to another year of survivorship and hope that I can save at least one life. Thank you for allowing me to come and share my story.



Esther Tufele (left), Juliane Lee (right).

Biography

Esther Tufele is a Samoan breast cancer survivor, who has been very active in advocating for cancer support groups. Ms. Tufele has family members that have gone through cancer. She strongly believes in sharing stories within the Pacific Islander community, especially in a community that does not want to talk about cancer. Ms. Tufele regularly participates in the American Cancer Society Relay for Life. She loves to share her own story on her experience with cancer and always conveys her positive outlook on survivorship.



Alexandra Leon Guerrero
Student, Stanford University
Daughter of Chamorro Nasopharyngeal Cancer Patient

My first memory of cancer: I was probably about 10 years old and my uncle passed away from stomach cancer. I didn't really understand it, but from that moment on, cancer has always been a part of my life. My grandfather had B-cell lymphoma, and he went through two rounds of chemotherapy. The first round was successful, but it came back. The second round was successful, but it came back. He eventually passed away of cancer.

When I was 16 and away at boarding school, my father called me to tell me he had nasopharyngeal cancer. My aunt, who is a nurse, checked and found a lump in his lymph. They had it checked, and sure enough, it was cancer. Unfortunately, the facilities in Guam are poor for treating cancer, so he came to Stanford to get the cyberknife, which administers concentrated doses of radiation to specific areas. He had several rounds of chemotherapy, and was good for a year, and he went back home. Then he suddenly came down with debilitating headaches and wasn't sure what was wrong. He tested for cancer, but tests came out negative. He started getting sick; he had pneumonia, and it got so bad that he got admitted into hospital, where he slipped into a coma. I was in my freshman year at Stanford,



and I had to leave school to go back to the Philippines to visit my father. He came back out of a coma in 60 hours, thankfully, but we still didn't know why he was in it. It turned out that he responded sensitively to radiation therapy and that there was so much damage in his nasal/pharyngeal area that he had to get a feeding tube inserted. The cancer wasn't there, but the radiation had ruined his quality of life.

It was hard for my dad to go from a position of power as the President of the Bank of Guam to being so needy. It was difficult psychologically. It was hard for me as well, wondering if I'd lose my dad. I took a quarter off from Stanford to take care of my father with my mom. We needed to be there and support my father. In asking my father how he felt about the disease, he would respond that he would rather die than to live as he was. He didn't want friends to visit. I would spend time with him to help him. In asking him

how he gets through his days, my father responded "It's because of you guys. I want to keep fighting for you guys, to stay alive for you." He was getting better, but still had problems like controlling blood pressure that led to having difficulties breathing and sleeping.

I spent a lot of time with my dad, and didn't get to do much of the things that my peers were doing. They didn't understand why I was disconnecting myself, but I'm glad



that I got to spend time with my father knowing how precious that time was.

In October of 2005, he passed away in his sleep. It's been difficult for me to accept. It's good to know that he's no longer suffering, that he was at peace when he passed away. He came to Stanford the week before and watched a soccer game. He told us "I love you guys" as if he knew that he was ready to go. Personally, it's impacted me by encouraging me to eat healthier (vegetarian) and exercise because there is cancer in my family. I'm a Chamorro and want to become a doctor and go back to Guam to impact my community.

Biography

Alexandra Leon Guerrero is a 21 year old undergraduate student currently in her junior year at Stanford University. She is majoring in Human Biology with a concentration in the biology and human experience of cancer. She was born in San Francisco, but was raised on Guam by her Native Chamorro father and Spanish mother. Having had several close family members either suffer from or die of cancer, she is personally connected to the issues that surround cancer and how the disease can affect both the patient and their family. After Ms. Guerrero graduates from Stanford, she plans to go on to medical school and then eventually return to home to be a doctor on Guam.



Afternoon Breakout Sessions

Breakout Session 1 – Clinical Trials

Rachel Mesia and Aida Negrón, National Cancer Institute

NCI CIS Overview was provided.

What is clinical trial, what is its importance and what can we do?

Objectives:

- Define clinical trials
 - Identify types of clinical trials
 - Identify at least 2 NCI clinical trials resources
 - Understanding the importance of clinical trials CIS
 - US and territory wide scope (includes Puerto Rico and Virgin Islands)
 - Cancer education for underserved populations
 - Public and cancer information
 - Main phone numbers, questions & online resources
 - Partnership programs- cancer partnership for underserved populations; communication and information for those in health disparities
 - Ulani's story
 - o Chronic myelogenous leukemia (CML)
 - o Successful story, Ulani wants to several times a week
 - o She gleevec drug halted disease
 - o She asked "am I going to be a guinea pig?"
 - o Minorities more willing to participate if educated about it
 - What are clinical trials?
 - o Studies involving people
 - o They answer scientific questions
 - Types of Clinical Trials
 - o 5 different types
 - o Not always about treatment and prevention
- (1) Treatment
 - a. Study effectiveness
 - b. What is the best way to administer drugs?
 - (2) Cancer Prevention Trials
 - a. Enroll high risk people (such as those with breast cancer in the family)
 - b. Enroll healthy people with high cancer risk
 - c. Selenium and Vitamin E for prostate cancer prevention
 - d. Many positive results because past studies of Selenium and Vitamin E prevents other diseases
 - (3) Early Detection/Screening Trials
 - a. Colorectal cancer screening
 - b. Sigmoidoscopy effective in detecting colorectal cancer and is a successful method in screening
 - c. Prostate cancer diagnosis
 - (4) Quality of Life/Supportive Care Trials
 - a. Method to relieve pain of patient
 - b. Cultural level- spiritual incorporation of culture into therapy
- c. Current study- pet (?) therapy on pain



Cancer Prevention Brochures

- People at high risk for cancer
- More information about what you have to do to get involved
- Sometimes physicians do not give all the information
- Need to provide all the information at possible

Patient Protection

- Ensuring safeguards
- Human rights- historically, “studies” have been negative and killed their “subjects” such as the Nuremburg and Nazi scientists, Tuskegee
- There are federal regulations
- Putting people in danger is unacceptable

Informed consent

- Discussion and explanation of trials to participants in understandable language; right to make independent decisions and right of patient to leave the study; must be language appropriate
- Randomization is a problem, but it avoids bias. Cancer patient in placebo group gets best possible treatment if available. Informed consent is ongoing. Patients have right to receive all information available.
- Institutional review board (scientific); evaluate legal and ethical merit of protocols of clinical trials; two panels monitor and approve trial; data & safety monitoring; if data not recorded properly, may shut down that clinical trial

Risks and benefits

- Patients must be informed
- New treatments not always better than standard care- must highlight this
- Potential drugs are not guaranteed
- May not work for every patient
- Insurance does not always pay for clinical trials

- Will receive at a minimum, the best standard treatment
- If new treatment proven to work, patients may be among the first to benefit
- Control group given experimental drug, if it is found to work

Clinical trials—the basic workbook is in the folder/binder?

- For basic understanding
- Information on the process
- Barriers, exercises and reviews

Easy to read brochures

- For cancer patients considering clinical trials
- For Medicare recipients
- What are your rights?
- Risks and benefits
- What does Medicare pay for?

Videos

- Cancer clinical trials: because lives depend on it
- Patients involved in clinical trials give their first hand experience

Only 3% of U.S. adults with cancer participate in clinical trials. 70% of children with cancer participate in clinical trials—maybe because parents are involved. Only 0.5% of U.S. population (Hawaii and Pacific Islands) have been involved in an NCI-sponsored cancer treatment trials

Why do so few cancer patients participate in cancer clinical trials?

- Fear
- Distrust
- Financial concern
- Don't know about them
- Lack of access
- Suspicion of researchers



Doctors might not promote clinical trials because:

- Lack of awareness of appropriate clinical trials
- Believe that standard therapy is best
- Concerned about more paperwork
- Don't want to go against physician's wishes

General barriers to participate (Pacific Islanders)

- History of oppression
- Behavioral risk factors
- Ineffective cancer control
- Fear, apprehension to research
- Lack of awareness
- Lack of access
- Lack of transportation
- Cultural values and beliefs
- Language and literacy barriers
- Economic issues

Clinical trials & minority population

- Low representation
- Research information for specific ethnic groups
- Opportunities for better treatment and care

How can we increase minority participation?

- Increase awareness
- Increase participation

More information: go to www.cancer.gov and 1-800-4-CANCER

Biography

Rachel J. Mesia is the Partnership Program Coordinator for the National Cancer Institute (NCI) Cancer Information Service (CIS) and Outreach Program Coordinator - Stanford Comprehensive Cancer Center. She has worked in local Bay Area college health education programs and HIV prevention. Prior to joining the NCI CIS and Stanford, she worked as a capacity-building assistance staff with the Asian & Pacific Islander American Health Forum. She has experience with collaborating and serving various organizations and networks that target ethnic minorities. Ms. Mesia earned a Master's Degree in Public Health from San Francisco State University and is an active member of the California Family Health Council Board of Directors.

Aida Negron, CIS Partnership Program Coordinator at the UCSF Comprehensive Cancer Center, has a Master's Degree in Public Communication from the University of Puerto Rico in San Juan. After graduating, Aida worked in various aspects of public relations, marketing, and health promotion for several non-profit and government agencies. After moving to the Bay Area in 2002, Aida worked as a Program Coordinator & Manager for Planned Parenthood Golden Gate. She also worked as a Health Communication Project Coordinator for UC Berkeley's Center for Community Wellness, where she still provides services as a group facilitation consultant. Aida does freelancing work as a Spanish translator & proofreader. In addition, she remains active in serving non-profit organizations through her volunteer work with Planned Parenthood Golden Gate and Mobilization Against AIDS, collaborating with programs that specifically target women and the Latino/a community.



Breakout Session 2—Pacific Islander Support Groups

Lola Sablan-Santos, Guam Communications Network
Sala Mataalii, Samoan National Nurses Association

This session was designed for Guam Communications Network and Samoan National Nurses Association, two Southern California community based organizations with support groups that serve the Chamorro and Samoan communities, respectively, to highlight their experiences with developing and implementing programming to cater to the needs of Pacific Islander cancer patients and survivors and to invite community feedback into determining improvements that can be made to existing support group models. Sala Mataalii of the Samoan National Nurses Association and Lola Sablan-Santos of Guam Communications Network specifically highlighted the history of their support groups, the successes and challenges they encountered in creating and launching their support groups, and their recommendations for prospective support group facilitators who wish to serve Pacific Islander communities.

The crux of the discussion rests in the groups’ discussion of the triumphs and difficulties that they have experienced with their support groups. In terms of successes, both groups have garnered continued interest since their inception and attribute this to their shared underlying mission, which is “Food, Fun, and Fellowship”. Ms. Sablan-Santos mentioned that it is important to integrate

such an approach for the dual purpose of creating a safe, comfortable space for patients and survivors to share private issues about themselves and to foster camaraderie among participants, who would otherwise choose to remain isolated with their conditions. Another key success defining the support groups include the empowerment

that the attendees gain by participating in the support group; in addition to becoming more proactive in supporting and advising other group members, many participants become involved in outreach and advocacy activities to promote cancer awareness in their communities.

Coupled with the successes that both groups have encountered are also longstanding challenges.

Although interest in the

support groups has been high in the community, it has been difficult to for the groups to effectively promote the concept of “survivorship in the communities. Because cancer continues to be considered as taboo or synonymous with death, the role and importance of support groups are often met with skepticism. In addition, it was difficult at one point for both groups to secure the commitment of participants; many community members had expressed interest in attending, but were “no shows” because of community-wide awkwardness with the concept of survivorship or other factors.





Biography

Lola Sablan-Santos is the Executive Director of Guam Communications Network (GCN), a community-based and multi-service agency headquartered in Long Beach. She has been involved in cancer education, outreach and advocacy for over 10 years. In 2001, she served as Co-Principal Investigator, along with Dr. Tanjasiri, in the 3-year California Breast Cancer Research Program (CBCRP) funded project entitled, “A Network-Based Intervention for Chamorros in Southern California and is currently and is currently involved as one of the Chamorro partners in the WINCART (Weaving an Islander Network in Cancer Research and Training) project. Ms. Sablan-Santos has served as a member of the CARE Program Advisory Committee with the Association of Asian Pacific Community Health Organizations (AAPCHO), Asian & Pacific Islander National Cancer Survivors Network (APINCSN) Steering Committee Member, Orange County Breast Cancer Partnership, Executive Council and API Task Force, the Partnered for Progress, API Task Force, the State of California Breast Cancer Early Detection Program’s API Committee and Media Ad Hoc Committee. She currently serves as the Chairperson for the State of California’s Office of Multicultural Health Community Council. Ms. Sablan-Santos is one of the co-founders of the Pacific Islander Health Care Collaborative and the Media Alliance for Pacific Islanders.

Sala Mataalii, RN, MSN, MBA/HCA, MA is a founding member and president of the board of Samoan National Nurses Association (SNNA). She constantly works to improve the lives of those around her and the life of the community she resides in, and is a recognized leader in Pacific Islander communities. Through Ms. Mataalii’s leadership, SNNA has gained a respected reputation for delivery of services, commitment of its staff, and a dynamic dedication to improving the quality of life for Pacific Islander families and their communities. Ms. Mataalii has served as an Asian & Pacific Islander National Cancer Survivors Network (APINCSN) Steering Committee Member. As a community organizer, she has supported community health initiatives, and joined the struggle to reverse the trends of disparity in breast/cervical/ prostate cancer, diabetes, obesity, cardiovascular, and disability in our people. As a cultural leader she brings recognition as a positive role model through her presence at and development work for cultural celebrations in our community.



Breakout Session 3—Cancer Survivorship Issues Asian & Pacific Islander American Health Forum

This session was designed to provide participants with an overview of APIAHF’s report on cancer survivorship issues in Pacific Islander communities; the report, which was a compilation of community feedback in regards to cancer service accessibility and quality, was presented at full length and opportunities were given to participants to discuss and contribute to the report.

The main topics of the discussion primarily centered around the issue of insurance. Participants shared that community members continue to underutilize prevention and treatment services because of the lack of insurance coverage. The rates of insurance premiums and/or the lack of understanding surrounding insurance policy has deterred patients from seeking timely, appropriate care. In addition, participants discussed the nature of

patient-provider relationships; community members continue to express concern that mainstream hospitals, health care organizations, and doctors do not a) provide translation services that can alleviate the communication gap between patients and healthcare staff; b) understand and uphold the cultural factors that patients abide by in their approach of health care; and c) encourage the trust of patients, which prevents them from sharing the details of their medical history and feeling that they may have about their prognosis and treatment. Finally, participants discussed the issue of prevention. Many community members still do not grasp the importance of early detection and attribute their lack of understanding to the dearth of culturally and linguistically specifically outreach educational programs that inform communities





Southern California Pacific Islander Cancer Survivorship Educational Forum March 18, 2006

Cancer in Pacific Islander Communities

Dr. Sora Park-Tanjasiri, California State University at Fullerton



Sora Park-Tanjasiri, Principal Investigator of WINCART (Weaving an Islander Network of Cancer Awareness, Research, and Training) at California State University Fullerton, presented on cancer's impact on Pacific Islander communities and the efforts of Pacific Islander specific research endeavors, such as WINCART, in establishing an infrastructure to further educate PI communities about cancer and to ensure continued work on community needs through the establishment of partnerships, research, and educational programs.

Key points from Dr. Tanjasiri's presentation include:

- Although there are 100,000 Pacific Islanders in Southern California alone, Pacific Islander communities remain invisible to policymakers and researchers because of ethnic misclassification on the Census and aggregation with Pacific Islander data with Asian American data.
- Among Pacific Islanders as a whole, cancer is the second leading causes of death. This can be attributed to the fact that many cancer cases in Pacific Islander communities are diagnosed at late stages.
- WINCART is a five year effort that aims to increase awareness, research, and training for Pacific Islanders in Southern California. Through partnerships with CBOs that work with Samoan, Chamorro, Tongan, Marshallese, and Native Hawaiian communities, WINCART aims to promote community education for cancer control, improve access to and utilization of existing cancer services among Pacific Islanders, facilitate community-based participatory research studies that address the unique cancer needs of Pacific Islanders, and to increase the number of Pacific Islander researchers through training, mentorship, participator research projects.

To request a copy of this presentation, please contact the Asian & Pacific Islander American Health Forum.



Biography

Sora ParkTanjasi, DrPH, MPH is Associate Professor in the Department of Health Science at California State University, Fullerton. Her work focuses on the community health needs of diverse populations, particularly Asian Americans and Pacific Islanders (APIOs). She is the Principal Investigator of WINCART: Weaving an Islander Network for Cancer Awareness, Research and Training, which is a five year, NCI funded collaborative with eight community-based non profit organizations and 4 other universities. Dr. Tanjasi is also the Co-Principal Investigator on a two year NIH funded study to increase cervical cancer screening among Thais, a three year study

to map pro- and anti-tobacco influences in Cambodian and Chamorro communities, a four year project to decrease breast, cervical, colon, prostate and liver cancers among Chinese and Koreans, and a five year CDC-funded effort to increase breast and cervical cancer screening among Southeast Asian and Pacific Islander women. Dr. Tanjasi received her masters and doctoral degrees in Community Health Sciences from the UCLA School of Public Health.



Pacific Islander Cancer Survivors Stories

Vialili Enesi

Samoa National Nurses Association

Samoa Breast Cancer Survivor

I'm a six year survivor.

I just love to tell my story because I've been telling my story since after my surgery. Wherever I go, Sala said I have to tell my story. I also told my story to Lance Armstrong Foundation in DC.

I retired from nursing in 1998. If you're a nurse, you know to have a mammogram every year. I went to get a mammogram in 1999. The doctor called me because they saw a white spot in my breast. I went to his office and I asked him why the spot didn't show up in the last mammogram. The spot in my right breast was not a lump, just a calcification; at that last test, I was told to wait 3-5 months or a year to see what it was.

In 2000, Sala and I went to a conference in Oakland; everyone kept asking if I was okay and if something was wrong. I told a woman named Gail what was wrong and she encouraged me because she had the exact same thing. Two days after I came back from Oakland, I call my doctor and told him that I'd like to have my surgery. The doctor asked me to come in and he asked if I had a husband and children. I told him I had no husband. I asked him if I could have a second opinion. I saw another



doctor and they did another ultrasound and biopsy. All the findings they had were the same and showed that the thing was a calcification. I wasn't scared. I didn't think why I had this. I was thinking that the Lord was testing my faith. If this was the way He was testing me, it was okay. I told my surgeon and family physician that I was going to have the surgery. I kept thinking about how I was going to tell my children. The day before my surgery, I told my daughter to tell all the kids (two sons and one daughter) to come to the house so I could talk to them about something. I told them "Tomorrow, I will have surgery. All I need from you is prayer and support.

I need your support for the surgery I'm going to have." They asked me to wait, but I told them, "No, I'm having it tomorrow".

While I was in the room getting ready for the surgery, the minister came inside my room and said a prayer. I thought to myself that I was ready for the surgery because I had strength. I knew my Lord would cure me from this disease. I had surgery, stayed in the hospital for 2 days, and came home.



I've been trying to help my Samoan community. I even told my story to the Samoan radio. That's how EVERYONE knows—even my relatives, because I didn't tell anyone but my children and my friend Sala.

I didn't experience the chemo and any radiation. I didn't take any pills. It was just like that—just my prayers and that's it. So now, I'm a survivor.

The moment that we are diagnosed, we are victims—every lady should have an early mammogram and a self-breast exam.

Biography

Vailili Enesi, RN has been a breast cancer survivor for over 5 years. She is a strong advocate of cancer treatment and prevention. She uses her story to help other survivors and has been sharing her story for a long time. She did not go through treatment for cancer. Ms. Enesi is a retired nurse and member of Samoan National Nurses Association. She is a strong recruiter in SNNA support groups. Additionally, she was one of the first interviewees of the Lance Armstrong Foundation Cancer Symposium.



Esther Tufele
Samoan National Nurses Association
Samoan Breast Cancer Survivor



I was diagnosed in November 2002. I found the lump, and I didn't start mammogram testing until I was 41. It was devastating and I didn't know why it happened to me. My mother and grandmother passed away from cancer.

I have 7 brothers and 5 sisters. I became the only one with breast cancer. Not one of my siblings is here today. I wish they were. But, I'm glad I found a family in SNNA.

In November, I'll have reached my 4 year survivorship mark. There is so much to tell and so much to share. Do

your breast self-exams. When I found my lump, I was like, "Oh my God". I called my doctor and they did a biopsy and ultrasound. They put me through chemotherapy and the cancer didn't shrink; it grew. They cut it out along with my breast. I had chemotherapy and surgery and was put through radiation. No one thought I'd survive it because I'm the biggest cry baby. I can't tolerate pain. I survived, but I lost all my hair. I came through the experience and I hope that my story will help at least one person. I love everyone that I've met along the way. It's been beautiful (even though it's not fun to have cancer). It's invigorating; I get to meet all these nice people and share my story. If I get to meet people and share my story, it's worthwhile for me. This will make me strong so I can deal with other personal stuff.

Biography

Esther Tufele is a Samoan breast cancer survivor, who has been very active in advocating for cancer support groups. Ms. Tufele has family members that have gone through cancer. She strongly believes in sharing stories within the Pacific Islander community, especially in a community that does not want to talk about cancer. Ms. Tufele regularly participates in the American Cancer Society Relay for Life. She loves to share her own story on her experience with cancer and always conveys her positive outlook on survivorship.



Antonio Perez Chamorro Prostate and Stomach Cancer Survivor



I was diagnosed in 1994 with prostate cancer. I was operated in 1996. I'm taking it 5 years at a time. It's my second 5 years. If I make it to August, I'm in the ballpark.

Don't be scared-those doctors out there are good. Put your hand in him and their nurses and everything, because if you don't, you'll be a dead duck. Once you learn more about prostate cancer and all that, you're okay.

For my second cancer, my blood count went down from 14 to 6. They kept me there for blood transfusions for two weeks. They found that the cancer in my stomach was growing. I spent 6 months in chemotherapy and radiation-I didn't lose my hair. I go every 90 days, so this time, my doctors told me to see him in 4 months. This

is my second year on my second stomach cancer; they removed 75% of my stomach (I went from 220 lbs to 150 lbs). Seven of my lymph nodes are cancerous and the other 4 are cancer-free. I was in the military and I handled a lot of stuff, but I don't know how exactly the cancer showed up.

When you're sick, go see the doctor because there are good ones out there. If you're not satisfied with one, go see another one. I've been with my urologist for almost 20 years and mine is from UCI. I thank my God Almighty for keeping me here. Cancer doesn't know anyone. It will show up and bite you in the rear. Before, I got scared, but now, I take it one day at a time. That's how I measure it. Go see the doctor-don't wait until cancer hits you in the inside. I had one brother with colon cancer until it was too late-the cancer killed him.

If you go to church, pray for everyone.

Biography

Antonio F. Perez was born and raised on Guam. At age 18, he joined the United States Air Force. During his years in the military he was stationed at various Air Force Bases including Guam, Japan, Alaska, Goose Bay Labrador, Oregon, Montana, California and his final base at Ellsworth, AFB, South Dakota. After retirement, Mr. Perez moved to Long Beach, CA with his wife Rose and son, Jesse. He worked at the Long Beach Naval Station Commissary and then the Long Beach Shipyard and retired as a supervisor, after 20 years. In August 1996, after a physical examination, Mr. Perez was diagnosed with prostate cancer. In 2005, during a routine examination for Agent Orange Disability, Mr. Perez underwent an upper and lower gastrointestinal examination and was diagnosed with gastric adenocarcinoma cancer.



Suzanne Robert
Guam Communications Network
Chamorro Breast Cancer Survivor

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

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

1998 came around. It was a major surgery for me at the City of Hope. I finally told them that THIS was about my



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

After those surgeries (I've been through 18), I had lost my hair/appetite because of the chemotherapy. I felt like giving up. There was a wing at the City of Hope-I saw this little girl wheeling out her chemotherapy IV. She had a Cinderella dress and no hair. Her face was so puffy. She came up to me and said, "Don't I look

beautiful?" when I was about to give up. I said, "You look so beautiful" and thought to myself that I'd never give up. I said to myself "At least I had 34 years of my life; this little girl hasn't". I told myself that I'd fight it to my last breath. I was going to surround myself with positive people/positive things.

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



Biography

Suzanne Robert was born in 1962 in Tamuning, Guam and raised in Inarajan and Toto. On November 12, 1997 she was diagnosed with stage II invasive ductal carcinoma, an aggressive form of breast cancer. Even though she was unable to work during her treatment she still continued her volunteer work with young athletes. Some of the recognition that Ms. Robert has received includes being selected as a 2002 “Torchbearer” Winter Olympic Games Torch Relay. She is an avid speaker regarding her personal experiences after her diagnosis with breast cancer respective to inner strength, health care and self advocacy. She also helps other women through her presentations on breast cancer awareness, early detection and the importance and techniques of self examination. Ms. Robert is a Head Start Teacher and has been with Irvine Unified School District for over 14 years. She is also a junior at California State University, Fullerton, where she is working on her Bachelor of Science degree in Child and Adolescent Development.



Faye Henrich
Guam Communications Network
Chamorro Breast Cancer Survivor



I'm a 7 year survivor.

Every year, I had a mammogram. Every year, they didn't know that the spots were.

In 1999, I was all clear to move from SD to Fairfield to take care of my mother. As I was lying down with my mom, I felt a lump on the right breast and the lump was as big as my index finger and it wasn't moving. At the time, I had just retired as a teacher and I was figuring out what I wanted to do after teaching. My sister had called and said to come take care of my mother because she was going downhill and I had to help take care of the grandkids.

When I was picking up my mother, I had found out that I had overused my hand, discovered that I had carpal tunnel. I went to primary doctor and asked him to touch the lump and he referred me to a surgeon. When I went to the surgeon, he had asked me about my mammogram, and I told him that I had it the previous month. He told me



to get a biopsy-the test was positive. My options were a reconstruction, mastectomy, or lumpectomy. I told him to take it out. I said no reconstruction because God gave me those breasts and I didn't want something to change them.

I had Stage II cancer on right breast. 25 lymph nodes were taken out, but all were negative. I had a scary bump on my left breast. It looked like a lot of calcifications; because I was such a high risk, I wanted it to be taken care of and the doctor told me to have a lumpectomy. When it came out, it was diagnosed as Stage I cancer. Due to the fact that I had chemo and not radiation on my right breast, I had radiation on my left breast.

I don't want to talk about how cancer attacked me because I was good about mammograms. But, I want to talk about nutrition. I'm involved in a wellness program in San Diego.

We need to learn how to eat correctly. We Guamanians eat so many carbohydrates-we forget about fruits and vegetables. I want to tell my other breast cancer survivors that we need to eat five fruits and five vegetables every day. Please eat a lot of fish. Salmon/sardines have a lot of omega 3s. Eat a lot of them and you're going to feel SO healthy.

Breast cancer is not a killer if we know how to protect it and know how to go about it. It's this reason that I'm very fortunate to be a speaker up here and to share what I really feel is important.

Biography

Faye Henrich was born and raised on Guam. She received her Bachelors degree in business education at the University of Guam. She was a business education instructor and dean of education at several colleges in San Diego and retired in 1998. In 1999, Ms. Henrich was diagnosed with stage II breast cancer and had a radical mastectomy. She is currently on a clinical trial. She has participated on several advocacy efforts such as Guam Communication Network's Southern and Northern California breast cancer panels, Susan G. Komen's Race for the Cure, and the Brighter Side.



Lucianne Latu Tongan Osteogenic Sarcoma Survivor

I was diagnosed with osteogenic sarcoma in 1987. I was 8 years old. As a result of the cancer, I had my right leg amputated. I only have a third of my thigh left.

I have a difficult time considering myself as a survivor. For Pacific Islanders, we're very humble people. Survivorship is too big of a hat to wear. Even though I've been cancer free for 19 years, I think the blessing about having cancer is that I had it at such a young age. At 8, my biggest crisis was if I could be the king of four square or finish my homework on time to play outside. The last thing I was thinking was whether or not I was going to live or die.

I didn't know how to give up at age 8. I just dealt with it and we as human beings, we can adapt. I have to say that none of it would've been possible if it weren't for the Almighty and my mother, who is my biggest advocate. As Tongans, we're fatalistic people. If we get sick, God meant for it to happen. The fatalism is a hard wall to penetrate. It's hard to reeducate and change that way of thinking.

I was a tomboy when I was younger. One day, my mom asked me if I had gotten hurt. I had the feeling of constantly wanting to stretch out my leg. There was a tumor was a size of a golf or tennis ball right above my knee. Then and now, Tonga does not have the background or technology to deal with such a huge disease. We're still behind the times. I was lucky that we even had x-rays. There were no tools to do a biopsy.

We decided to go to New Zealand for treatment. I got a biopsy and they found it was cancer. I was transferred to an oncology ward and spent 9 months of 1987 there. After 4 months of chemo, the tumor wasn't shrinking. The doctors said that I would survive for 3 months. A mother knows; a mother would place herself between a child or a

train to save her life. My mom believed that it was better to have a part of missing than all of me gone.

I only received chemotherapy. As a young girl, I cried more about cutting my hair than losing my leg. Growing up, having this physical limitation wasn't easy. If anything, the battle of cancer was a lot easier than the stigmas and narrow-mindedness. To me, it was part of life-in elementary school, I looked different and not many people accepted differences. High school was hard, too. It took me a long time to start wearing clothes that showed my prosthesis.

With Tongans, we have a weird way of twisting words. "I'm so sorry to hear that" comes out as "What a waste". That was probably the biggest hardship that I had. I started to resent my mom because she made the decision to have my leg amputated; I asked her why she didn't just let it be, because it was so much easier than letting me deal with that on a daily basis.

She sees my struggles and wonders if she made the right decision to me. It's the worst feeling for me to see my mom feel that way. But now, I understand her. I got tired of having to justify my existence in this world. You take it, you leave it. This is who I am.

I'm in a league of my own. It's life. One of the things that I want to say is that all of the things that have happened, good or bad, have been a blessing because they've brought me to today.

If it doesn't kill you, it only makes you stronger. I'm still going through the grieving process because I see the videos of myself as an eight year old girl, just seeing the life and not knowing what was ahead. I refer to her as



different because I see that little girl and feel she was stronger than the person that I am today. I miss that courage.

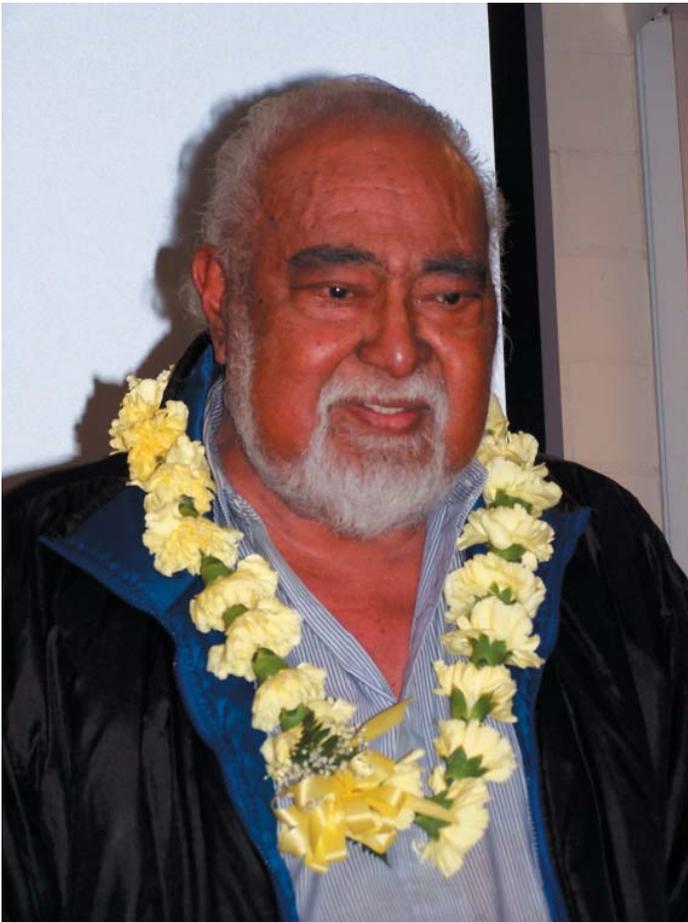
But I'm living.

Biography

Lucianne Latu was 8 years old when she was diagnosed with osteogenic sarcoma (bone cancer) in 1987 in Auckland, New Zealand. She has been cancer-free for the past 19 years and still going strong. As a result of the cancer, she had her right leg amputated back in 1987, but regardless of that “physical limitation,” it does not slow her down one bit. Ms. Latu is 28 years old and currently working as an administrative assistant at a recruiting firm in South San Francisco. She resides in San Mateo with her parents and younger sister. She cannot say that she has any hobbies, but she enjoys life and the experiences to be had living it.



Leonatasi Saiti
Tongan Prostate Cancer Survivor



On second Sunday of August 2004, I was preaching. Afterwards, I went outside and felt someone was chopping me up into pieces and they took me to UCLA. I had a biopsy and was I diagnosed with prostate cancer. I had chemotherapy and radiation, but my hair did not fall off. I feel that's a good sign. I took everything they gave me because I know that our Savior will not let you down if you believe in Him. I hope everyone who has cancer will always remember our Savior.

Biography

Leonatasi Saiti is a male Tongan cancer survivor who lives with his family in Long Beach. He is very happy to share his story with the community. He has recently gone thru 3 weeks of radiation and is undergoing chemotherapy. Mr. Saiti is the father-in-law of Nelly Skeen, who is involved with the Tongan Community Service Center. He is a retired architect from Tonga.



Afternoon Breakout Sessions

Breakout Session—Clinical Trials

Zul Surani, National Cancer Institute Cancer Information Services

Laurel Eu, Food and Drug Administration



Mr. Zul Surani, Partnership Cancer Control Coordinator of the NCI's Cancer Information Service of California, facilitated a discussion about clinical trials and how Pacific Islander communities can become involved. The presentation included discussions about the history of clinical trials, current clinical trials for cancer patients, eligibility requirements, and resources to which patients can refer for further information. Laurel Eu talked about her experience in participating in clinical trials.

To request a copy of this presentation, please contact the Asian & Pacific Islander American Health Forum.

Biographies

Zul Surani is a Coordinator in the Cancer Information Service (CIS)-California Region's Southern California Partnership Program Office, located at USC Norris Comprehensive Cancer Center. Mr. Surani studied Health Services Administration and Public Health at USC and has over 10 years of experience in developing cancer prevention and control programs for diverse and medically underserved communities. Through his work at the CIS, he has developed partnerships in cancer education and research in Asian, Pacific Islander, African-American, Hispanic, Middle Eastern and American Indian communities, many of which have been profiled in publications and presentations at numerous conferences. Prior to coming to the CIS, Mr. Surani developed and managed UCLA's Mobile Mammography Program and has most recently contributed to the development of UCSF's Digital Mobile Mammography Program. He is also active in the community, serving on the boards and advisory committees of several local, state, and national organizations. In 2001, he was nominated for the Ford Foundation's Community Leadership Award. He is also a recipient of the Susan G. Komen Foundation's Community Hero Award.

Laurel Eu has a Master of Arts in Educational Psychology from Stanford University and a Bachelor of Arts in Psychology and Elementary Education from the University of Hawaii. As a Public Affairs Specialist, Ms. Eu implements public health campaigns and educates community groups, health professionals, consumers and media about the U.S. Food and Drug Administration (U.S. FDA). Major projects include coordinating translations of food labeling material, diabetes awareness, and developing and translating brochures on cancer screening



and medication safety into various Asian and Pacific Islander languages. She has worked extensively on medication safety, nutrition, and breast and cervical cancer screening programs for Southern California's diverse population. Ms. Eu has made numerous presentations about the different products the FDA regulates including medication safety, the drug approval process, nutrition issues including trans fat, allergens, and obesity, food safety issues, medical devices, biologics and cosmetics. She also is the recipient of the Plain English Award for her work developing and translating a clinician recommendation packet for breast and cervical cancer screening.





Breakout Session 2—Pacific Islander Support Groups

Lola Sablan-Santos, Guam Communications Network
Sala Mataalii, Samoan National Nurses Association

This session was designed for Guam Communications Network and Samoan National Nurses Association, two Southern California CBOs with support groups that serve the Chamorro and Samoan communities, respectively, to highlight their experiences with developing and implementing programming to cater to the needs of Pacific Islander cancer patients and survivors and to invite community feedback into determining improvements that can be made to existing support group models. Sala Mataalii of the Samoan National Nurses Association and Lola Sablan-Santos of Guam Communications Network specifically highlighted the history of their support groups, the successes and challenges they encountered in creating and launching their support groups, and their recommendations for

prospective support group facilitators who wish to serve Pacific Islander communities.

The crux of the discussion rests in the groups’ discussion of the triumphs and difficulties that they have experienced with their support groups. In terms of successes, both groups have garnered continued interest since their inception and attribute this to their shared underlying mission, which is “Food, Fun, and Fellowship”. Ms. Sablan-Santos mentioned that it is important to integrate such an approach for the dual purpose of creating a safe, comfortable space for patients and survivors to share private issues about themselves and to foster camaraderie among participants, who would otherwise choose to





remain isolated with their conditions. Another key success defining the support groups include the empowerment that the attendees gain by participating in the support group; in addition to becoming more proactive in supporting and advising other group members, many participants become involved in outreach and advocacy activities to promote cancer awareness in their communities.

Coupled with the successes that both groups have encountered are also longstanding challenges. Although interest in the support groups has been high in the community, it has been difficult to for the groups to effectively promote the concept of “survivorship in the communities. Because cancer continues to be considered as taboo or synonymous with death, the role and importance of support groups are often met with skepticism. In addition, it was difficult at one point for both groups to secure the commitment of participants; many community members had expressed interest in attending, but were “no shows” because of community-wide awkwardness with the concept of survivorship or other factors.

Biographies

Lola Sablan-Santos is the Executive Director of Guam Communications Network (GCN), a community-based and multi-service agency headquartered in Long Beach. She has been involved in cancer education, outreach and advocacy for over 10 years. In 2001, she served as Co-Principal Investigator, along with Dr. Tanjasiri, in the 3-year California Breast Cancer Research Program (CBCRP) funded project entitled, “A Network-Based Intervention for Chamorros in Southern California and is currently and is currently involved as one of the Chamorro partners in the WINCART (Weaving an Islander Network in Cancer Research and Training) project. Ms. Sablan-Santos has served as a member of the CARE Program

Advisory Committee with the Association of Asian Pacific Community Health Organizations (AAPCHO), Asian & Pacific Islander National Cancer Survivors Network (APINCSN) Steering Committee Member, Orange County Breast Cancer Partnership, Executive Council and API Task Force, the Partnered for Progress, API Task Force, the State of California Breast Cancer Early Detection Program’s API Committee and Media Ad Hoc Committee. She currently serves as the Chairperson for the State of California’s Office of Multicultural Health Community Council. Ms. Sablan-Santos is one of the co-founders of the Pacific Islander Health Care Collaborative and the Media Alliance for Pacific Islanders.

Sala Mataalii, RN, MSN, MBA/HCA, MA is a founding member and president of the board of Samoan National Nurses Association (SNNA). She constantly works to improve the lives of those around her and the life of the community she resides in, and is a recognized leader in Pacific Islander communities. Through Ms. Mataalii’s leadership, SNNA has gained a respected reputation for delivery of services, commitment of its staff, and a dynamic dedication to improving the quality of life for Pacific Islander families and their communities. Ms. Mataalii has served as an Asian & Pacific Islander National Cancer Survivors Network (APINCSN) Steering Committee Member. As a community organizer, she has supported community health initiatives, and joined the struggle to reverse the trends of disparity in breast/cervical/ prostate cancer, diabetes, obesity, cardiovascular, and disability in our people. As a cultural leader she brings recognition as a positive role model through her presence at and development work for cultural celebrations in our community.



Breakout Session 3—Cancer Survivorship Issues Asian & Pacific Islander American Health Forum

This session was designed to provide participants with an overview of APIAHF’s report on cancer survivorship issues in Pacific Islander communities; the report, which was a compilation of community feedback in regards to cancer service accessibility and quality, was presented at full length and opportunities were given to participants to discuss and contribute to the report.

The main topics of the discussion primarily centered around the issue of insurance. Participants shared that community members continue to underutilize prevention and treatment services because of the lack of insurance coverage. The rates of insurance premiums and/or the lack of understanding surrounding insurance policy has deterred patients from seeking timely, appropriate care. In addition, participants discussed the nature of patient-provider relationships; community members

continue to express concern that mainstream hospitals, health care organizations, and doctors do not a) provide translation services that can alleviate the communication gap between patients and healthcare staff; b) understand and uphold the cultural factors that patients abide by in their approach of health care; and c) encourage the trust of patients, which prevents them from sharing the details of their medical history and feeling that they may have about their prognosis and treatment. Finally, participants discussed the issue of prevention. Many community members still do not grasp the importance of early detection and attribute their lack of understanding to the dearth of culturally and linguistically specifically outreach educational programs that inform communities about cancer.



Fa 'afetai



Malo 'aupito



Si Yu'us Ma'ase



Thank you



Organizational Resources

For additional information about the organizations that participated in the planning, coordination, and implementation of the Pacific Islander Cancer Survivorship Educational Forums, the description of the services and contact information are included in this section.

Guam Communications Network (Inetnon Kuminikasion Guahan)

The Guam Communications Network (GCN), headquartered in Long Beach, California was established in 1993, as a nonprofit community-based organization. It is the sole Chamorro community-based multi-service agency in the State of California with a mission to facilitate increased public awareness of the issues facing the Chamorro (group indigenous to the Island of Guam and the Commonwealth of the Northern Mariana Islands) people through education, coalition building and advocacy. The agency operates over 12 cultural enrichment and social service programs including breast cancer education and community participatory research in cancer.



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Executive Director- Lola Sablan-Santos

Samoan National Nurses Association (Sulu O Le Tautua)

Established in 1996, Samoan National Nurses Association (SNNA) is a committed group of professionals serving the Samoan community. SNNA works to improve and expand the community's opportunities through service, education, advocacy, organizing, and research. SNNA services to Pacific Islander community include: Health Education—Diabetes, Breast, Cervical, and Prostate Health, Cardiovascular, Hypertension, Gout, Obesity, and Nutrition; Immunization; Patient Navigation; Translation Services; Health Policy Education; Provider Trainings; Culturally Sensitive Health Literature; Monthly Pacific Islander Breast Cancer Support Group; Adult Immunization and Screenings; Care Management Services for Seniors; Older Adults Care Giver Support; and Medi-Cal/Medicare Application Assistance. SNNA has been instrumental in providing a community-based network of nurses and other health professionals to identify relevant health issues within the Samoan and other Pacific Islander communities. SNNA has successfully organized numerous grass-roots campaigns geared at raising awareness and education for issues that include: heart disease, diabetes, breast health, hypertension, cancer, and tuberculosis to both mainstream and ethnic communities and groups.



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Executive Director- Marion Hannemann



Taulama for Tongans (Taulama Ma’Ae Tonga)

Taulama for Tongans is a non-profit community based organization dedicated to improving the health of all Tongans through education, advocacy, research, and service. It was formed to address the health needs of the Tongan population, as well as other Pacific Islanders living in the San Francisco Peninsula Area. The word “Taulama” means to “guide” or “guidance”. Our main goal is to provide guidance to our population by increasing awareness among Tongans of the health programs, resources, material and services that are available to them. We have been in operation since 2001. During this short period of time we have successfully networked with local and state agencies to increase the health awareness and support for Tongans in this area. Yet, as an underserved migrant population, much work still needs to be done to both maintain our current efforts and forge more collaborations that will improve the health and well-being of Tongans, and encourage more Tongans to enter the health professions.



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Cancer Information Service

The Cancer Information Service (CIS) is a program of the National Cancer Institute (NCI). The California Region CIS headquarter office is located at Northern California Cancer Center, with Partnership Program offices at UCSF Comprehensive Cancer Center, Stanford Comprehensive Cancer Center and USC/Norris Comprehensive Cancer Center. The CIS Partnership Program builds capacity to bring cancer information to people who may have difficulties seeking health information because of educational, financial, language, or other barriers. It also strives to increase partners’ awareness and abilities to communicate that cancer health disparities are a major public health problem, where the burden of cancer falls disproportionately on certain racial, ethnic, and socioeconomic groups.

For more information about the California Region CIS, please visit www.nccc.org/cis.htm.



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Asian & Pacific Islander American Health Forum

The Asian & Pacific Islander American Health Forum (APIAHF) is a national advocacy organization dedicated to promoting policy, program, and research efforts to improve the health and well-being of Asian American and Pacific Islander (AAPI) communities. Founded in 1986, APIAHF approaches activities with the philosophy of coalition-building and developing capacity within local AAPI communities. APIAHF advocates on health issues of significance to AAPI communities, conduct community-based technical assistance and training, provide health and U.S. Census data analysis and information dissemination, and convene regional and national conferences on Asian Americans and Pacific Islanders.



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