



Pacific Islander Cancer Survivorship Educational Forum – Pilot Project Focus Group Summary

Project Partners

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



This report was made possible by the
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This Pacific Islander Cancer Survivorship Educational Forum - Pilot Project Focus Group Summary 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, Nicole Kang, Leafa Taumoepeau, Sala Mataalii, Lola Sablan-Santos, and Amy Wong.

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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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Introduction

According to the Census 2000, 58% of Pacific Islander (PI) populations lived in two states outside of the Pacific Island Jurisdictions, Hawaii and California. Large clusters of PI communities are concentrated in the Northern and Southern Californian cities — most notably in Los Angeles, San Diego, San Francisco Bay Area, Long Beach, Sacramento, and Hayward.

While there is limited data available on cancer prevalence, incidence, and general socio-survivorship, anecdotal evidence has shown that Pacific Islanders have disproportionate rates of cancer compared to other racial/ethnic populations. For example, American Samoan men living in Hawaii and California were ten times more likely to have nasopharyngeal cancer, seven times more likely to have liver cancer, and three times more likely to have stomach cancer as compared to white American males.¹ Cancer is the second leading cause of death on Guam. From 1989-1991, 61% of cancer deaths occurred in the Chamorro and Pacific Islander populations of Guam. Among Chamorros, the leading cancer site was lung (37%) followed by oral cavity, breast, cervix, and colorectal.² The number of Chamorro and Carolinian women who have been diagnosed with cancer is three times higher than U.S. rate according to the Commonwealth of North Marianas Islands Department of Public Health.³ In Tonga, liver cancer prevalence rates in the adult population are hyperendemic at 10%-14%. Lung cancer now ranks among the three most common

cancers, as a result of smoking, and it is expected that the incidence will continue to increase.⁴

During the first year of the pilot project funded by the Lance Armstrong Foundation, the Asian & Pacific Islander American Health Forum (APIAHF) worked with Guam Communications Network (GCN), Samoan National Nurses Association (SNNA), and Taulama for Tongans to conduct in-language focus groups with Chamorro, Samoan, and Tongan cancer survivors and/or patients. Through the focus groups, qualitative information about cancer survivorship, availability of cancer resources, and cancer support needs that impact the community has been compiled and is presented in the Summary.

(Footnotes)

¹ 1996 Mishra SI, Luce-Aoelua P, Wilkens LR, and Berstein L. Cancer among American Samoans: Site-specific incidence in California and Hawaii. *Intl J Epidemiol*.

² Guam Department of Public Health and Social Services. Annual Statistics Report. Office of Vital Statistics. Agana, Guam. 1993.

³ Pacific Magazine, January 31, 2006, <http://www.pacificislands.cc/pina/pinadefault2.php?urlpinaid=19524>

⁴ World Health Organization- Regional Office for Western Pacific, 2005, www.wpro.who.int/countries/05ton/health_situation.htm



APIAHF Pacific Islander Cancer Survivorship Educational Forum – Pilot Project Focus Group Summary

Between March and June 2005, a total of five focus groups were conducted in Southern and Northern California. The focus groups were conducted with Chamorro, Samoan, and Tongan cancer survivors and/or patients. To obtain qualitative information about cancer survivorship specific to the communities, the partner agencies worked with APIAHF to develop a focus group protocol that was culturally appropriate and relevant to PI cancer survivors. The focus group protocol consists of six questions which center around three categories – support services available, challenges and barriers, and cancer survivorship recommendations.

Chamorro Focus Groups

Two focus groups were conducted for the Chamorro community in Southern California. The first focus group was held in San Diego, California on April 30, 2005, and the second was held in Los Angeles, California on May 9, 2005. In total, there were ten Chamorro cancer survivors that attended either of the focus groups. Seven participants were breast cancer survivors, one was a Hodgkin's Lymphoma survivor, one was a thyroid cancer survivor, and one was a uterine cancer survivor.

When asked about where and from whom the participants turn to for cancer information, the participants from both focus groups indicated that they received information through physicians, the American Cancer Society (ACS), pamphlets/brochures, and other community based organizations. Participants from the San Diego focus group indicated that they turn to information found online/Internet, in books, through group therapy, supports groups, and medical journals.

In both focus groups, the participants all agreed that there were no programs and resources specific to Pacific Islander communities in their local regions. However, the participants mentioned some activities and services that they felt were helpful for either the patient or the family members. Activities included cancer research in the local

neighborhood, being a panel speaker, joining a Chamorro club or organization, getting together with other breast cancer survivors and women, attending breast cancer luncheons, picnics, and gatherings. Participants from the Los Angeles focus group were asked what would motivate them to participate in cancer survivorship related activities if they do not currently attend one. Activities including playing cards, singing Karaoke, social chatting, and cooking were suggested in order to motivate others to participate.

When asked about the types of challenges and barriers faced by the cancer survivors and their family members, most responses fell into the categories of information and support. For example, providing information to spouses and their children in order to better understand cancer as a disease, what to expect, how to deal with fear and denial, and dispelling the myth that cancer is contagious. By becoming better informed, family members can provide better support to the cancer patient. In addition, there is a lack of knowledge of available resources that provide information and support for the family, financial assistance, what to do in case of recurrences, and other complications due to multiple chronic disease occurrences.

Samoan Focus Groups

Two focus groups were held for Samoan cancer survivors in Carson, California (located in the greater Los Angeles area). The first focus group was held on May 12, 2005 and the second was held on May 26, 2005. In total, ten cancer survivors (seven female and three male) attended either of the focus groups. Six of the participants were breast cancer survivors and the rest were bone cancer, prostate cancer, liver cancer, and adrenal cancer survivors. Both focus groups were conducted in Samoan and English.

While most of the participants received cancer information from their physicians and nurses, one breast cancer



survivor noted that after her operation most of the cancer information was obtained from the Samoan National Nurses Association (SNNA). In addition, participants mentioned how they received information from support groups, other survivors, family and friends, television, and conferences they had attended.

All participants agreed that there were no Pacific Islander focused cancer programs and/or services available in the community besides the SNNA cancer support group. Several participants noted that the only cancer screening programs offered in the community were sponsored by SNNA. One participant mentioned how she had attended a wellness community program in Redondo Beach but left that program when she found out about the SNNA programs.

Participants indicated that they “wished there [were] particular services available” for Samoan cancer survivors when asked about activities and services that were helpful. For the breast cancer survivors, they participate in the SNNA support group; however for the other participants, they were not aware of any existing activities at all. While a participant mentioned other cancer programs like the Revlon walk and the Relay for Life walk, those programs are not specifically catered for the Samoan community. Those survivors who were not aware of the SNNA support group program, mentioned how hearing survivor’s testimonies, seeing other survivors attend the program, and having refreshments are good ways to motivate them to participate in the activities. For those survivors already attending the support group, their motivation to participate was due to the group offering them a source of hope and encouragement.

The Samoan focus group participants mentioned many challenges and barriers faced due to cancer. Responses included financial issues, fear of letting other know that they have cancer, not being able to work and provide for their family, recurrence of cancer, lack of support from family and others, living paycheck to paycheck, concerns

about the future of their family and children, and the scarcity of needed programs and services for cancer survivors in their own community.

Tongan Focus Group

The Tongan Focus Group was held in the greater San Francisco Bay Area on May 17, 2006. While the focus group was originally scheduled for March, it was rescheduled twice due to the low attendance and cancellation of the participants. Only three participants were able to attend; two were breast cancer survivors and one was an osteogenic sarcoma survivor.

At the time of cancer diagnosis, participants mentioned that their oncologists provided information about cancer. In addition, a family doctor, the African American Health Advisory, and Taulama for Tongans were the only types of support available.

The participants made no mention of programs and/or services that were specific to the Tongan community besides health fairs that Taulama for Tongans attended. Programs and activities mentioned included Relay for Life, recruitment of women for breast cancer screenings, raising money for cancer research, and meeting other cancer survivors. The participants commented on the lack of knowledge about programs that were culturally relevant and appropriate and the desire to meet people in the same age group that have gone through similar cancer experiences.

There were many challenges and barriers faced by the participants. For the cancer survivors, it was difficult to come to terms with the disease especially when faced with having to have an amputation and/or mastectomy. In addition, it was mentioned about the difficulty of living life normally as compared to pre-cancer diagnosis and how cancer affects the family and other loved ones traumatically.



Recommendations

Based on the information provided by the focus group participants, the detailed recommendations are separated into three categories. The three categories include, 1) ideas for Pacific Islander cancer support groups, 2) recommendations for healthcare providers around the issues of cancer, and 3) types of support groups recommended for each PI community.

Ideas for Pacific Islander Cancer Support Groups

While there are limited numbers of cancer support groups available for Chamorro, Samoan, and Tongan communities, there are activities that can be conducted to provide support to cancer survivors that are appropriate for these communities.

- Work with Pacific Islander community, cancer advocates, and/or healthcare providers to outreach and identify cancer survivors in the community.
- Create materials to assist in outreaching, providing information, and connecting to cancer survivors. Possible materials can include newsletters and/or survivors' website.
- Provide incentives for survivors to attract and encourage their involvement in cancer survivorship related activities.
- Provide opportunities and informal events, such as potlucks, picnics, special events, and monthly trips that outreach to Pacific Islander cancer survivors and bring them together to provide informal support in the community.
- Collaborate with other Asian American and/or Pacific Islander cancer survivors to form culturally and linguistically appropriate support groups. In addition, separate support groups should be formed to provide support to caregivers and family members.

- Create tools and materials to assist in development of support groups and the structure of the group. Support groups should address topics on cancer screening, how to deal with cultural stigma, how to seek counseling, resources in the community, and involve guest speakers with different experiences and levels of expertise, such as other survivors and physicians that serve the community.

Recommendations for Health Care Providers around the Issues of Cancer

In order to increase the community's knowledge around the issues of cancer and survivorship, health care providers are a critical component in the continuum of care.

- Create culturally and linguistically appropriate brochures and information materials (cancer information, survivorship, resources, support, etc.) that are available for Pacific Islander cancer patients and survivors during office visits. In addition, it is recommended that providers should take the time to explain detailed cancer information to patients, caregivers, and family members.
- Provide bilingual staff and translated materials, such as forms and paperwork, in the clinical setting.
- Support alternative care and services, such as acupuncture and massage therapies that are available to complement medical treatments for cancer patients.
- Develop training to increase the number of Pacific Islander health care providers in the community.
- Make available a hotline for patients to ask questions from health care providers, such as nurses.
- Invite healthcare providers to speak to women.



Specific Types of Support Groups that Would Work for the Community

For the Chamorro community, it is suggested that support groups should involve youth groups and include activities like picnics, social gatherings, novenas/rosaries, tea parties/Tupperware parties, and barbecues that can help to outreach and attract cancer survivors to participate. It is important to keep in mind that financial assistance is need for supporting the work of cancer survivors especially due to the additional expenses incurred from cancer treatment.

For the Samoan community, it was suggested that there should be support groups that are specifically developed for Samoan cancer survivors. In addition, there is a need to increase support groups that are separate for male cancer survivors.

For the Tongan community, it is important to recognize the need for culturally competent cancer support services.

Additional Cancer Needs

During the focus groups, each community provided additional feedback around cancer needs that are faced by cancer survivors in the Chamorro, Samoan, and Tongan community.

- Low cost medicine
- Family leave
- Financial help
- Support
- Life insurance
- Information on how to ease family's burden
- Write letters to government officials regarding Medical Referral Patients sent off island for further treatment and then end up having to return home before completion of treatment due to financial hardship
- Have a central place to get cancer information or brochures
- Have a central place to gather as cancer survivors

- Encourage other survivors to participate and get involved
- Encourage the importance of education in the community — learn about the effects of different types of cancer
- Important to bring survivors together and offer support for each other and their families
- Share the message of survivorship
- Make resources more readily available





Organizational Resources

For additional information about the organizations that participated in the focus groups, 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, CA 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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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 grassroots 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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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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Pacific Islanders (PI) Cancer Survivors Educational Forum Project

Focus Group Guide – Cancer Survivors/Caregivers

I. Introduction

- Good evening and thank you for coming. My name is _____. Thank you for agreeing to take part in this discussion. We hope to learn about better ways to coordinate cancer support resources between cancer programs and PI community based organizations. We are interested in better understanding the availability of cancer support resources, challenges and barriers, and recommendations to improve access to culturally and linguistically appropriate cancer survivorship/support services and programs.
- The Pacific Islanders (PI) Cancer Survivors Educational Forum Project is a program of the Asian & Pacific Islander American Health Forum (APIAHF) and is currently being funded by the Lance Armstrong Foundation (LAF). The project aims to improve cancer prevention, early detection, and survivorship among PI communities. The PI Cancer Survivors Educational Forum project serves develop educational forums for 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.
- Your participation is very important because you will help to provide recommendations for the development of PI cancer survivorship programs and resources. There are no right or wrong answers to any of the questions – please respect other’s points of view if different from your own. Feel free to express your ideas, opinions, or experiences. Many important things need to be discussed during our hour together, so at times we may change the subject or move ahead. We’ll try to come back to earlier points at the end of our conversation if time permits.
- As you may have noticed, there is a tape recorder in the room. We hope that having a tape recorder will not make you feel uncomfortable. We want to make sure we capture all of your ideas and that we don’t miss any valuable information the group may offer. The tape recorder ensures this. There will be a couple of notetakers who will be recording your response to ensure that we capture what you are saying accurately.
- Please be assured that your individual comments here today are confidential in the sense that we will not identify anyone’s statements by name. If you have not done so, we would like you to sign a consent form to ensure your confidentiality and to affirm your voluntary participation in this discussion.
- Before beginning, are there any questions or comments?
- Let’s start our discussion.....

II. Support Services Available

1. Where/whom do you turn to for your cancer information?
2. What types of PI cancer programs and/or resources are available in your community or region? (e.g. cancer support groups, screening, etc) Please briefly describe those programs and/or resources.
3. What activities or services have been particularly helpful for you and/or your family member?
 - Are there particular services? Please briefly describe the services.
 - Are there existing activities that you now participate in?
 - If you do not participate in any activities, what would motivate you to do so?

III. Challenges and Barriers

4. What are issues faced by you and/or your family member?

IV. Recommendations

5. Do you have any recommendations for working with PI cancer support groups and/or support services?
6. Do you have any recommendations for:
 - healthcare providers around the issues of cancer?
 - specific types of support groups that would work for your community?
 - other needs for your community around cancer?

V. Closing and Evaluation

- We are now finished with the discussion. Before we leave, do you have other responses or comments about the information discussed today?
- As part of our evaluation of the focus group session, were there components of the process that you liked or thought needed to be changed for future focus groups? (pluses and delta evaluation)

record comments made by the focus group participants

- Once again, we would like to reassure you that everything you said here today is strictly confidential and anonymous. Your name will not be connected to the information given today.
- Thank you for coming. The information that you have provided is very important and we appreciate you spending the time with us.

Asian & Pacific Islander American Health Forum (APIAHF) Pacific Islander Cancer Focus Group Consent Form

_____ (insert date)

Thank you for your interest and willingness to help us. You are being asked to participate in a discussion group. We hope to learn more about better ways to coordinate cancer support resources between cancer programs and Pacific Islander community based organizations. We want to do this by better understanding available cancer support resources, challenges and barriers, and recommendations to improve access to culturally and linguistically appropriate cancer survivorship/support services and programs for Pacific Islanders. We do not expect these discussion questions to cause you any discomfort.

You will be asked to participate in a discussion group that should require one (1) hour.

Participant's Initials: _____

This community assessment may have implications for the development of culturally and linguistically appropriate cancer support programs to improve the quality of life and health of the Pacific Islander communities.

The discussion will be recorded to capture your comments and recommendations so that we will not miss your valuable information. Any identifying information will not be included in our written summary.

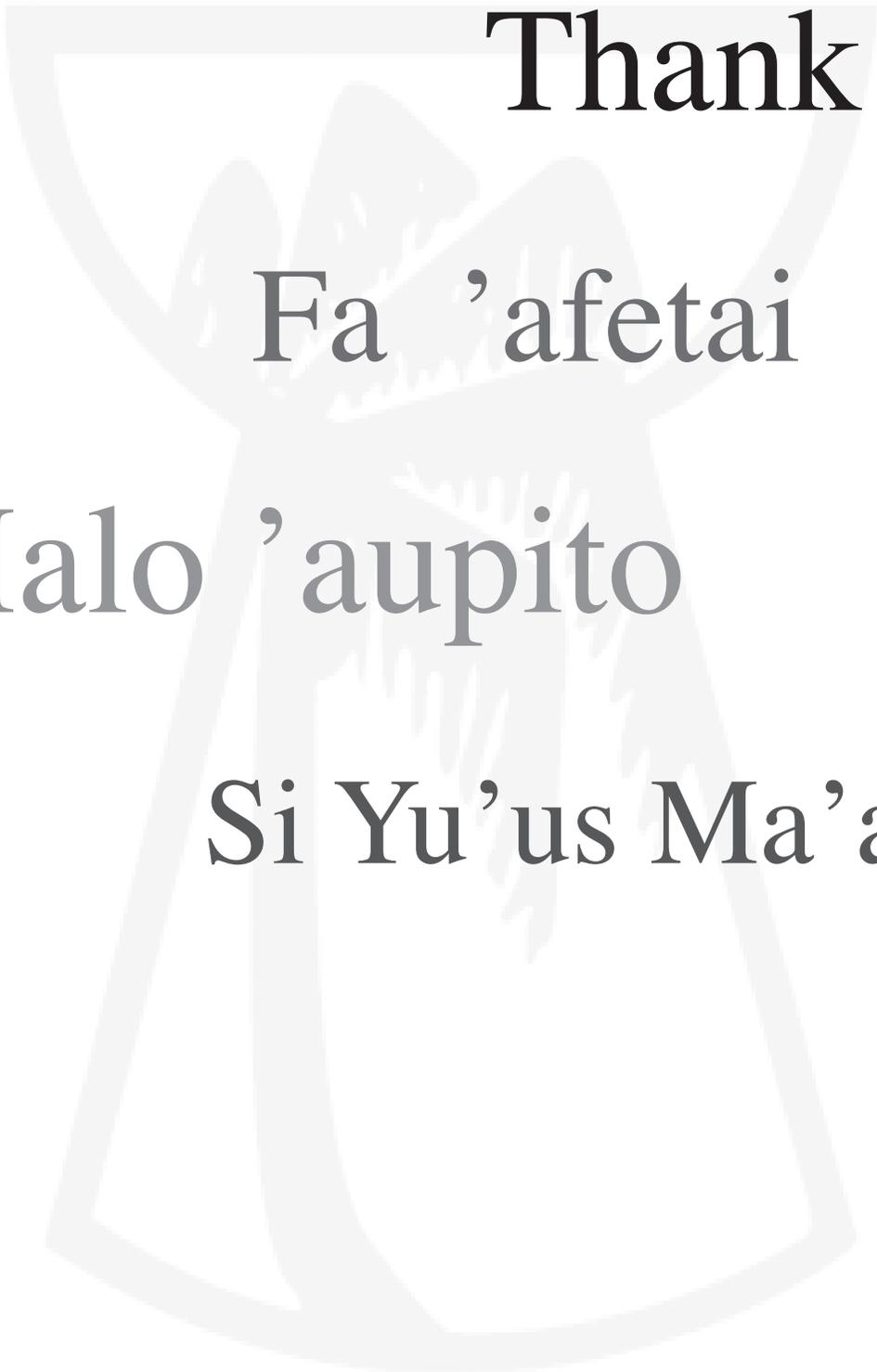
If you feel uncomfortable at any time, you should feel free to leave the discussion.

Participant's Initials: _____

Permission: Your signature, below, will indicate that you have decided to volunteer as a discussion participant and that you have read and understood the information provided above.

Signature of Participant: _____ **Date:** _____

Signature of Coordinator: _____ **Date:** _____



Thank you

Fa 'afetai

Malo 'aupito

Si Yu'us Ma'ase



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