## Tautai Lavea'i Updates Stipend Applicant Data

Luana Scanlan



The American Samoa Community Cancer Coalition distributed its first financial (684)699-0110 stipend to a local cancer patient in September of 2006. Since then, by implementing several successful fundraisers over the years from Vegas Nites to Golf Tournaments, in addition to partnering with and receiving donations from many generous businesses and individuals, the Coalition has distributed 243 stipends through November 5, 2017.

To improve our financial stipend program, the Coalition received funding from the Department of the Interior in 2017 to establish a community based 'patient navigation program'. **Patient navigation** is a process developed by Dr. Harold Freemen in 1990 in response to the American Cancer Society's "Report to the Nation on Cancer in the Poor" (1989). The report found that the most critical issues related to cancer and the poor involve barriers to accessing cancer diagnostic and treatment services. These issues stem from poverty and geographic isolation, as well as language and immigration status. These are issues which the American Samoa Community Cancer Coalition's cancer stipend recipients experience as well.

To help these patients, the Coalition, in partnership with **LBJ Hospital**, is in the process of designing a community-based navigation program – **Tautai Lavea'i**, which will enhance the Coalition's existing stipend program by providing assistance to patients preparing for off-island care, follow-up on patient outcomes, collection and analysis of cancer patient data. Tautai Lavea'i will operate out of the Cancer Coalition office, manned by existing staff who have over 10 years of experience working with the local healthcare system and cancer patients. Their time and expertise are voluntarily invested in helping these patients.

Tautai Lavea'i has begun the task of reviewing, cleaning and analyzing the data from stipend recipients dating back to 2006. Information about cancer in American Samoa is scarce because once patients leave the Territory for care they rarely return their off-island medical records to LBJ Hospital for record keeping. Additionally, if they are not diagnosed locally, their cancer status is not included in the local Cancer Registry data. Data driven decisions produce relevant, effective, and sustainable outcomes. For this reason, the data component of Tautai Lavea'i is the first task to be addressed in the project. By understanding who we have helped in the past, we can make better decisions on how to help them more effectively moving forward.

The following is a descriptive synopsis of the cancer patient stipend recipients helped by you, our community donors and volunteers, since 2006.

Who received stipends? 71 men and 149 women (23 individuals received additional stipends in subsequent years) 143 were married, 188 were Samoan, and 74 were unemployed while 67 were retired

The profile of a typical stipend recipient is a female between the ages of 45 and 50 who is married and unemployed. Almost half of these females (47% or 70) were diagnosed with breast cancer. The most common cancers amongst men are lung (n=20) and prostate (n=13). Thirty-six different types of cancer were reported by recipients, including rare types of lymphoma.

A major improvement in cancer related health behavior over the last 10 years is that more stipend applicants state they are seeking and receiving cancer treatment, however most patients continue to be diagnosed after the cancer has already spread and the prognosis for treatment and survival is poor. To date, the average age of our recipients is 52.70 compared to the U.S. national median of 66 years (CDC, 2017). While our stipend recipient group is small, the sample reflects that more of our people are being diagnosed with cancer and at younger ages than the average American.

Over 100 recipients were in Stage III or IV of their disease. Sixty-three of the 220 patients – 29% of all applicants – were diagnosed and immediately placed in palliative (end of life) care. Late-stage cancers progress quickly so an immediate response to a diagnosis is critical. Less than half of our recipients were born in American Samoa; obtaining proper travel documents to access timely, effective cancer care off-island continues to be a significant barrier to survival for the majority of patients who live here using visas. The astronomical cost of airfare is also prohibitive. These are significant 'health disparities' or inequities.

As the Coalition continues to strive towards achieving its mission, "to help the people of American Samoa fight cancer", its diverse outreach and research activities have ignited a momentum of partnerships locally and abroad, thereby strengthening the Territory's capacity to build a healthier community. While the statistics described above reflect a continuing healthcare access issue, the fact that patients are seeking help rather than hiding or ignoring their disease, demonstrates an improvement in cancer awareness and understanding. Cancer is no longer spoken of in hushed, fearful tones or considered incurable. With healthy living – physically, mentally and spiritually – that includes early cancer screening and timely treatment, cancer patients today have a better chance of survival than 10 years ago.

During this week of Thanksgiving, we extend our sincere appreciation to the many businesses and individuals who generously gave of their time and finances to help local cancer patients over the years. We encourage you to 'Buy Local' to support our economy and keep our money here to help our own community members help each other.

To apply for a financial stipend of \$500, which is available to a patient once per year at reapplication and approval, please visit the Coalition office on the 2<sup>nd</sup> floor of the Iosia Jr. Building in Nu'uuli (next to Milovale's). You can also complete the application available on our website at <a href="www.asccancercoalition.org">www.asccancercoalition.org</a> and email it to us at <a href="mailto:info@cancercoalition.as">info@cancercoalition.as</a>. Please follow us on Facebook American Samoa Community Cancer Coalition for updates on our work with our community!