

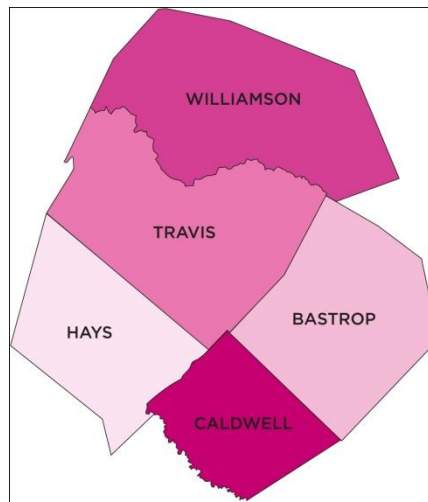
2011 Community Profile-Austin Affiliate of Susan G. Komen for the Cure

Executive Summary

Introduction

The Susan G. Komen for the Cure, Austin Affiliate ® was established in late 1999 to spread the life-saving message of early detection and to support breast cancer screening and education programs in Central Texas. The Austin Affiliate covers five counties including Bastrop, Caldwell, Hays, Travis, and Williamson, as shown in Figure 1. These five counties make up an area of 4,284 square miles and encompass a population of slightly more than 1.67 million residents.

Figure 1. Service area County Map



The Race for the Cure, held in November, is the signature fund raising event of the Affiliate. It has grown to an attendance of approximately 21,000 participants, recorded during the 2010 Race. The Affiliate has granted out over 10 million in the twelve years of its existence to help women in the service area, and in 2011 we will grant out over \$1.1 million alone. The services funded include screening, diagnostic services, treatment, patient navigation services, breast health education and outreach, emergency funds needed for everyday expenses and support services for women undergoing breast cancer treatment.

Every two years each of the Susan G. Komen for the Cure ® affiliates conducts a Community Profile to gather and organize information for the purpose of creating a snapshot of the state of breast health and breast health services in the Affiliate service area. This report is intended to serve as a roadmap to the services currently funded and to identify any existing gaps in those services for the five county service area. It is also intended to outline program plans on how the Affiliate will seek to meet the needs of the identified groups which will potentially lead to

change in behavior in an effort to reduce breast cancer mortality. A plan was outlined by the Executive Director, the Director of Mission Services and the Director of Grants to determine community participation in the Community Profile.

Statistics and Demographic Review:

In examining demographic and breast cancer data and statistics in the Affiliate's five county service area, a number of sources were researched and utilized. The sources used for the Profile, include but were not limited to, Texas Cancer Registry, Thomson Reuters ©2010, NCI, and Cancer Control P.L.A.N.E.T. In the process of researching and obtaining breast health statistics, both the Texas Cancer Registry and the Behavioral Risk Factor Surveillance System (BRFSS) provided vital information for the profile.

After careful review of both national and local breast health statistics, the following emerged: the disproportionate incidence and/or mortality rate in African American and Hispanic women, the exponential growth in the Hispanic population, and the high poverty rates, and lack of breast health services in Bastrop and Caldwell counties. The American Cancer Society shows that the higher mortality rate in African-American women (35.1 vs. 22.5 in non Hispanic Whites) in Texas may be related to differences in access to and utilization of early detection and treatment and differences in tumor characteristics.

Additionally, American Cancer Society U.S. data shows that even though Hispanic women have lower breast cancer rates (90.2 per 100,000) they are more likely to die from the disease (17.2 per 100,000). This contradiction is due to the fact that Hispanic/Latina women are less likely to participate in mammography screening and more likely to be diagnosed at later stages of breast cancer.

Therefore, we will focus our outreach efforts on both the African American and Hispanic populations, to inform them about their increased risk, the importance of breast cancer early detection, and to motivate them to get screened. Additionally, a continued emphasis will be kept on both Bastrop and Caldwell Counties since the data continues to demonstrate they have the highest poverty rates and least amount of breast health service providers in their counties.

Health Systems Analysis

The health systems analysis of the community profile included interviews with individuals in each of the five counties in the service area representing medical professionals, oncologists, breast cancer survivors, indigent care clinics and current Affiliate grantees. A complete list of breast health service providers spanning the continuum of care were documented in tables by County. These providers were contacted by phone to verify the service offerings or were provided as a known resource by key informants during the interview process.

The outreach and breast health education component to all women in the rural counties can be strengthened as verified by the number of women who are fearful, lack information, and do not seek preventive health services. Gaps in diagnostic and treatment services continue in Bastrop

and Caldwell Counties. Barriers to care remain consistent over time: lack of insurance; fear of costs, outcomes, family reactions; lack of transportation or high cost of gasoline; time off work for medical appointments and treatment; loss of income during treatment; financial obligations during diagnosis and treatment; numerous and costly co-payments for insured women.

Medical services have increased significantly in Hays, Travis and Williamson Counties. Large hospital networks are expanding into Bastrop and Williamson Counties during the next two years. While there are medical services, not all facilities offer a complete continuum of care. Thus, patient navigators play critical support roles in helping clients negotiate the overwhelming healthcare systems and linking clients to necessary resource supports.

Komen grantees have strong collaborative networks and provide a critical safety-net throughout the five county service area for clients who reach their doors. Challenges remain in increasing awareness about grantee services and securing grantees to address gaps in transportation, psycho-social support, emergency financial support, targeted breast health education and outreach. Financial support for treatment is critical and must remain a focus for the Affiliate.

The Affiliate has a strong screening mammography program and has increased partnerships with medical centers, hospitals, and radiology associations to ensure that screening sites remain available at no cost to our target population throughout all counties. These partnerships will continue in 2011-2012. We will support Seton Family of Hospitals in their quest to obtain funding for new digital mobile mammography equipment.

The Affiliate will continue to maintain a visible presence with the legislature to support funding for the state health department's Breast and Cervical Cancer Screening (BCCS) program and Cancer Prevention and Research Institute of Texas (C.P.R.I.T.).

Qualitative Data Overview

The qualitative component of the community profile included a total of seven focus groups and five community leader/breast cancer survivor interviews with women from varying ethnicities and locations within the service area. The participants represented the wide diversity in our five county service area including breast cancer survivors, uninsured and/or underinsured women, women who had little or no connection to breast cancer, and women who had accessed the services provided by the Affiliate grantees.

As anticipated, the focus groups demonstrated that the breast cancer survivors in the groups had a higher level of knowledge around the issues of breast health, particularly around the topics of breast health, resources, and access to care and treatment. However many of the survivors stated that the prior to diagnosis, this was not the case, and many described their breast health knowledge as limited. In comparison, the participants, who were not breast cancer survivors have limited knowledge regarding breast cancer and breast cancer screening, but almost no knowledge about breast cancer resources in the community. Their breast health knowledge gave us great insight into the myths and barriers that still exist in the Affiliate service area.

Additionally, many of the women were not aware of the services provided by the Susan G Komen for the Cure grantees; much of their knowledge was limited to the annual race event.

The community leader/breast cancer interviews provided information related to the needs of the breast cancer survivor community which highlighted the need for psycho-social support, and the lack of treatment options for the uninsured.

After data collection, both the focus group and the key informant interview responses were analyzed to identify emerging theme. Response data was then compared to data sources provided by Komen Headquarters and other sources. These include but were not limited to C.A.N.C.E.R Control Planet, The Texas Cancer Registry, Thomson-Reuters © 2010, The Behavioral Risk Factor Surveillance Center of the CDC and the National Cancer Institute.

Key Findings and Themes

Focus groups, questionnaires, and key informant interviews with current Affiliate grantees, health care providers, breast cancer survivors, and community leaders, revealed a number of key findings with regards to breast health in the five county service areas. Three dominant themes emerges from the focus groups and key informants as to why women do not get screened: fear related to breast health issues; lack of education about breast health and breast health services; cultural beliefs. However, many women expressed the importance of communicating breast health care to different populations, not just those over 40, in order to help subside some of these fears. Many women felt strongly about the importance of communicating the availability of services for the uninsured and underinsured, whether it be through education events in their counties, mass marketing via radio, or distributing resource sheets in various doctors' offices, stores, pharmacies, and even social media sites for the younger demographic. Currently, they do not feel they have adequate access to breast health information, and only a few women knew where to access it. Some of the sources they mentioned included: their doctors, friends, church, the Susan G. Komen for the Cure ® website, American Cancer Society, Lance Armstrong Foundation, or miscellaneous internet sites.

In addition to fear, other barriers to screening include: lack of knowledge about screening, cost of screening, not knowing where to go for free or low cost screening, transportation, embarrassment, "it won't happen to me", cultural barriers related to privacy of body, low priority, and language barriers.

When providers and key informants were asked the question related to why they believe women don't get screened, many of the responses were similar to those from the focus group participants. This can only lead us to believe that both providers and community leaders understand the barriers to screening, and therefore we must find a way to bridge the gap between the community and the providers so that women can have access to these life saving exams.

Conclusions and Affiliate Priorities

Based on the findings of the Community Profile from data gathered from interviews and research, the Affiliate developed priorities which align with their strategic plan. The Strategic Plan will be used to improve and guide the grant process and education programs for the Affiliate in the next two years. These priorities include:

1. Increase the breast health education and outreach to uninsured and underinsured Hispanic women across all 5 counties,
2. Engage volunteers in the African American community to provide breast health education and serve in an advisory role to the Affiliate with issues related to the African American population and breast health,
3. Establish a speakers bureau comprised of community members, providers, and key leaders that will allow us to increase the number of educational events and speaking engagements in the 5 county service area,
4. And collaborate with community and health care leaders to explore lowering the cost of breast health services in Bastrop and Caldwell Counties.

A full copy of the 2011 Community Profile, can be found on our website at www.komenaustin.org or contact Monica Saavedra, Director of Mission Services, directly at 512.683.3884 or msaavedra@komenaustin.org, for more information.