



COMMUNITY PROFILE REPORT

Puget Sound Affiliate Susan G. Komen for the Cure®

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Executive Summary

Introduction

The Susan G. Komen Foundation began as a promise between two sisters to end breast cancer forever. Susan Goodman Komen was diagnosed with breast cancer at the age of 33 and died three years later. Ms. Komen's younger sister, Nancy Goodman Brinker, founded the foundation in 1982. The Komen Puget Sound Affiliate was founded in 1993 to forward the mission of our national organization – to save lives and end breast cancer forever by empowering people, ensuring quality of care for all and energizing science to find the cures. Since its inception, the Komen Puget Sound Affiliate has invested nearly \$23 million in local nonprofit, tribal and government agencies that provide breast health and breast cancer services to medically underserved residents of our 16-county service area (Service Area).

The purpose of the community profile is to take a timely assessment of the state of breast cancer in the Affiliate's Service Area. This report examines statistics, services and community perspectives to identify disparities, gaps in service and barriers to care that prevent women who live in our community from accessing, early detecting and surviving breast cancer. This report will be used to set the Affiliate's priorities, goals and objectives in its strategic planning, grant making and educational efforts to ensure that we are meeting our promise to save lives.

Statistics and Demographic Review

The majority of data used in the demographic section of the community profile was obtained through Thomson Reuters © 2009, a National Komen commissioned custom module of estimated demographic data for the Affiliate's Service Area. Statistical data on breast cancer incidence and mortality was obtained from the Washington State Cancer Registry and the Cancer Surveillance System, the Surveillance Epidemiology and End Results (SEER) Program cancer registry serving 13 of the 16 counties in our service area that is funded by the National Cancer Institute.

The Service Area as a whole, with 69 percent (or 4,607,327) of the total state population, is the densest and most racially/ethnically diverse area in the state. Within the Service Area, the Greater Metropolitan areas of King, Snohomish, Pierce and Kitsap counties had the greatest number of residents (78.6 percent or 3,623,557) and the greatest diversity (25 percent minorities). While King, Snohomish and Pierce counties have the greatest numbers of uninsured residents and families living below the poverty level, the counties in the southwest region of the state have the highest percentages of families below the poverty line and individuals who are uninsured.

Breast cancer is the most frequently diagnosed cancer among Washington State women and the second leading cause of cancer death. Washington ranks 12th highest in incidence and 35th highest in mortality in the country.

Higher proportions of cases diagnosed at advanced stage and/or lower proportions diagnosed at the in situ stage are likely indicators of insufficient rates of mammogram screening. African American, Hispanic, American Indian/Alaskan Native (AI/AN), and Vietnamese, Pacific

Islander and Asian Indian/Pakistani women had the highest proportions of breast cancers that were advanced stage at diagnosis. African American, AI/AN, Asian Indian/Pakistani and Pacific Islander women have the lowest five year rates of survival among all the ethnic and racial groups in the Service Area, with the majority of these women living in King, Pierce and Snohomish counties.

Lewis and Pacific counties had the highest proportion (both at 32 percent) of breast cancer cases diagnosed with advanced stage in the Service Area. Compared to the statewide average (20 percent), several counties had considerably lower proportions of cases with an in situ diagnosis – Pacific (12.4 percent), Clallam (13.7 percent), Grays Harbor (15.6 percent) and Thurston (17.2 percent).

Seven counties (of the 13 with breast cancer survival data) had lower than average five year survival rates: Mason, Grays Harbor, Jefferson, Clallam, Skagit, Whatcom and Pierce.

It is important to note that the three most densely populated counties (King, Pierce and Snohomish), although not the worst performers in terms of proportions of cases with advanced stage at diagnosis and survival, carry some of the heaviest burdens in our service area because of the sheer large numbers of women diagnosed with advanced stage or dying from breast cancer.

With respect to utilization of breast cancer screening, 76 percent of Washington women over age 40 who were surveyed reported having a mammogram in the past two years, which mirrors the national average. Of the 16 counties in the Service Area, the five counties with the lowest screening rates were Wahkiakum (48.4 percent screened), Lewis (64.7 percent), Grays Harbor (70.1 percent), San Juan (71.9 percent) and Clallam (72.3 percent). American Indian/Alaskan Native women had the lowest screening rate at 54 percent reporting having a mammogram within the past two years.

Health Systems Analysis

Identification and updating of breast cancer resources were focused more on the “new” counties and populations not previously identified as areas of interest in the 2009 Community Profile. These are Clallam, Whatcom, Skagit and Thurston counties and Pacific Islander and Asian Indian/Pakistani women. For these “new” counties identified for further exploration, snapshots from the 2007 report were sent to key informants in those counties to confirm accuracy and for any additions or changes. These snapshots include information on breast health resources and gaps in services in their community.

For the previously identified counties of interest in the 2009 report – Greater Metropolitan counties of King, Pierce and Snohomish and Southwestern counties (Grays Harbor, Lewis, Pacific and Mason) – key informants from those communities were asked to verify/update statements from the last report.

Western Washington is home to many state-of-the-art medical facilities, mammography centers, and cancer treatment centers; however, the majority of services are clustered in the Greater Metropolitan (Seattle/Tacoma) area. The challenge in this region is not so much the lack of facilities and resources, but rather disparities in utilization or access. The focus must be on

ensuring that women are knowledgeable about and can access existing resources, and that providers and programs have the capacity to meet the demands for breast cancer screening and treatment of low-income residents who require no-cost care.

Many women living in the Southwest Washington region struggle with lack of information about breast health resources, transportation and poverty. Women's health care is very fragmented and typically involves sending a woman to several providers when she is diagnosed with breast cancer. Communication can be difficult and women may get lost in the system.

Qualitative Data Review

The Affiliate gathered input from key stakeholders whose connection to residents of targeted geographic areas and to racial and ethnic communities and their issues would be helpful to the community profile process. Key informant interviews and/or focus groups were conducted to get perspectives from those living and working in the target areas and populations. Participants included community leaders, employees of county health departments, representatives from local hospitals, WBCCHP Prime Contractors and subcontractors, breast cancer survivors and health care providers.

Financial barriers and lack of health care insurance are the most commonly reported reasons why women of color don't get screened. This is followed by the lack of awareness or prioritization of breast health or preventive health care practices in general. Myths about breast cancer and mammograms, as well as cultural taboos, fears and modesty issues were all commonly cited as barriers to screening among women of color.

There are many concerns among racial and ethnic minorities about trust, and the intentions of the healthcare system. Based on their past history, this is especially true for African American and Native American women who may fear experimentation or doubt the intention of healthcare providers to care for people of color. Undocumented Hispanic women often fear the consequences of entering a government-supported program, doubt the actual anonymity of care and may find questions from providers to be intrusive and alarming.

Conclusions

Based on detailed analyses of the breast cancer statistics, demographic information, health system resources and qualitative data, we identified areas of need:

- African American, Hispanic, American Indian/Alaska Native, Vietnamese, Pacific Islander and Asian Indian women need early detection services and support during treatment.
- Lewis, Pacific, Grays Harbor and Mason counties in Southwest Washington continue to need increased access to quality and convenient breast cancer treatment as well as early detection services.
- King, Pierce and Snohomish counties have the greatest burden of women in need of service, particularly women of color; women living in these counties need more information about available resources, as well as increased capacity for screening, patient navigation and treatment support.

- A common theme heard among all counties and populations was the need to increase awareness about breast health and about available resources and the need to address gaps in transportation, particularly in rural areas, and interpretation services to address language barriers of racial and ethnic minority women.

However, the current economic climate has resulted in tremendous increase in demand for free or low cost breast health services. The Affiliate does not have adequate resources to meet this demand, but is committed to working with our partners to preserve and protect current services and will continue our commitment to increase funding to invest in proven effective life-saving strategies.

Action Plan

Goal: Increase breast cancer screening, patient navigation and treatment support services offered in Grays Harbor, Lewis, Pacific and Mason counties, particularly for low-income, Hispanic and American Indian/Alaska Native women.

Objective 1 – By March 2014, increase investments in effective screening, patient navigation and treatment support services and cultivate new applicants to the Affiliate’s grant programs that meet our target communities and priority service areas.

Objective 2 – Each grant period, increase by 5% the number of women enrolled and screened through WBCCHP and other partners providing low/no-cost screening, especially among Hispanic and American Indian/Alaska Native women.

Objective 3 – By March 2014, work with local partners to develop new and expand current awareness campaigns (using traditional and social media, Worship in Pink, Hispanic Initiative, etc.) that target low-income, Hispanic and American Indian/Alaska Native women in these counties.

Goal: Increase breast cancer awareness, screening and patient navigation in King, Snohomish and Pierce counties for low-income, African American, Hispanic, American Indian/Alaska Native, Vietnamese, Pacific Islander and Asian Indian women.

Objective 1 – By March 2014, increase investments in effective education, screening and patient navigation services and cultivate new applicants to the Affiliate’s grant programs that meet our target (current and new) communities and priority services.

Objective 2 – By March 2014, expand Worship in Pink campaign to include faith-based organizations beyond the African American community.

Objective 3 – By March 2014, increase the number of African American, Hispanic, American Indian/Alaska Native, Vietnamese, Pacific Islander and Asian Indian women who are enrolled in WBCCHP by 5% each grant period.

Objective 4 – By March 2014, work with local partners to develop new and expand current awareness campaigns (using traditional and social media, Worship in Pink, Hispanic Initiative, etc.) that target low-income, African American, Hispanic, American Indian/Alaska Native, Vietnamese, Pacific Islander and Asian Indian women in these counties.

Goal: Improve access to breast health and treatment services throughout our Service area through strategic alliances and change in public policy.

Objective 1 – By March 2014, work with National Komen, regional and local partners to advocate for increased federal and state funding for WBCCHP.

Objective 2 – By March 2014, work with Affiliate lobbyist to advocate for and prevent cuts to existing transportation programs and collaborate with American Cancer Society to expand its volunteer transportation program.

Objective 3 – By March 2014, work with Affiliate lobbyist and other partners to preserve and/or increase funding for medical interpretation services.

Objective 4 – By March 2014, develop strong alliances with existing and new partners that can help to move the Komen mission forward through Health Reform implementation.