

Executive Summary

Affiliate History

Susan G. Komen for the Cure® North Jersey Affiliate was founded in 1997 on a promise to a ten-year-old girl who lost her mother to breast cancer. Its mission is to save lives and end breast cancer by empowering people, ensuring quality of care for all and energizing science to find the cures. Since its inception, the Affiliate has invested \$17.7 million in mission services: \$12.2 million has been dedicated to Community Grants in the service Area and \$5.5 million has been directed to Susan G. Komen for the Cure® Grants Program at a national level. From 1998 through 2007, the primary source of revenue for the Affiliate was the annual Pink Tie Ball. The Affiliate held its first Race for the Cure in 2008. The Komen North Jersey Affiliate service area is defined as the nine counties of Bergen, Essex, Hudson, Morris, Passaic, Somerset, Sussex, Union and Warren.

Community Profile Objectives

The objectives of the Community Profile are to complete a statistical profile of breast cancer incidence and mortality, population demographics and behavioral breast health factors for the service area; to evaluate the range and effectiveness of available services for women with breast cancer, their families, friends and associates including programs involving the Affiliate; to evaluate community prevention and education needs for targeted populations; and, to formulate conclusions and recommendations for targeted initiatives as well as to position the organization for maximum effectiveness.

Breast Cancer Impact in Affiliate Service Area: Methodology

Data was collected for the Affiliate's service area regarding demographics, screening rates, incidence and mortality rates, stage of diagnosis and five-year survival rates. To determine target communities, 'red flags' were assigned to counties with demographic or breast cancer statistics that reflected a need in the community. The counties with the most 'red flags' were designated as target communities.

Essex County, Hudson County, Passaic County, and Sussex County were recognized as target communities based on the outstanding demographic and breast cancer statistics in these areas. Black females were also designated as a target group because of concerning breast cancer statistics among this population. Essex County, Hudson County, and Passaic County are characterized by lower than state average median income, higher than state average percentage of people living under the poverty level, higher than state average percentage of uninsured females, and higher than state average percentage of unemployed people. Essex County, Hudson County, and Passaic County also stand out as areas that have low education attainment levels. Specifically, these communities have higher than state average percentages of people that have

not completed lower levels of education and lower than state average percentages of people that have not completed higher levels of education.

With regard to breast cancer statistics, Hudson County has the highest percentage of women over the age of 40 that have not received a mammogram within the last 12 months. Among all races of females, Essex County, Passaic County, and Sussex County have high five year average mortality rates compared to the state five year average mortality rate. Among White populations of females, Passaic County and Sussex County have high five year average mortality rates compared to the state five year average mortality rate. Among Black populations of females, Passaic County has a high five year average mortality rate compared to the state five year average mortality rate. In general, Black female populations have higher mortality rates than White female populations. Black female populations are also characterized by higher percentages of late stage diagnoses compared to White and Asian Pacific Islander female populations. Black female populations also have lower five year survival rates compared to White and Asian Pacific Islander female populations.

Identification of the Target Communities

There are four communities of interest designated by the Affiliate as target communities due to outstanding statistics and trends with regard to socioeconomic factors, education attainment, screening, mortality, stage of diagnosis, and survival. These target communities include Essex, Hudson, Passaic, and Sussex Counties. Specifically, densely populated urban centers within these communities strongly influence the data and become targets within the targets. These cities include Newark and East Orange (in Essex County), Jersey City (in Hudson County), and Passaic and Paterson (in Passaic County) (American Community Survey Five-Year Estimates, 2005-2009). In addition, the Affiliate defined Black females as a target group because of high mortality, high percentage of late-stage diagnoses, and low survival among this population of women.

Health Systems Analysis of Target Communities: Methodology

Once the target communities were identified, medical and community resources in each of these areas were pinpointed. These resources were recognized as the community assets and were defined as sites where insured and uninsured women receive breast health screenings and can proceed through the continuum of care, whether or not a breast cancer diagnosis is made. Community assets also included Affiliate Grantees. An asset mapping specialist plotted the community assets in order to best visualize the breast health services available in each of these areas. Community assets were organized into the following categories: hospital, free standing mammography site, NJCEED site, mobile mammography site, and Grantee.

Health Systems Analysis of Target Communities: Gaps and Barriers

NJCEED provides screening and treatment to those without insurance in the target communities – providing over 6,200 mammograms in the four target communities in 2010. While NJCEED only screened an average of 7.1 percent of eligible women in 2010, the opportunity for more screenings exists. It is critical that funding for this program continue on a federal and state level,

and the Affiliate has recognized the role it has now and can have in the near future to advocate for this program.

From surveys and interviews completed by many medical providers, community leaders, and breast cancer survivors, five major themes emerged. These themes outline major gaps and barriers to the continuum of care in the service area, especially in the target communities. These five themes include 1) underserved groups, 2) lack of financial resources or insurance, 3) lack of education in the community, 4) lack of education among doctors, and 5) importance of community and faith-based organizations. The underserved continue to struggle in accessing breast health care. Specifically, ethnic minority groups, uninsured women, low income women, less educated women, unemployed women and undocumented women are at risk of not receiving proper breast health care. These results are consistent with those obtained from quantitative data analysis. Lack of financial resources or insurance is a huge barrier for women and largely prevents them from seeking breast health services. However, even before the issue of finances is raised, women do not understand the importance of maintaining proper breast health and following up with a breast cancer diagnosis. This is the result of a lack of education regarding breast health among women.

For many of the underserved groups of women seeking breast health services in the target communities, medical doctors play an important role in guiding them to resources such as financial assistance programs and support services. For this reason, doctors need to be knowledgeable about these resources or prepared to direct patients to someone who is knowledgeable. Finally, it is important for the Affiliate to reach out to representatives of community and faith-based organizations in order to better understand the communities of women which it is serving.

From the major themes, it is evident that the Affiliate can develop partnerships with community and faith-based organizations, cancer coalitions, county roundtables, and local medical facilities in order to develop a better understanding of the target communities and how to best serve them. Though there are already some partnerships in existence, including the Hudson County Breast Health Roundtable (See Priority III) and the Sussex County Breast Health Project (See Priority III), the creation of similar groups would benefit Essex County and Passaic County. One of the challenges long faced by the Affiliate has been reaching ethnic minority groups of women, especially Black females. It is the Affiliate's hope that stronger ties with community- and faith-based organizations will facilitate a more open dialogue with this population about breast health education and about gaps and barriers faced in accessing breast health care.

Breast Cancer Perspectives in the Target Communities: Methodology

Qualitative data was collected through online and written surveys and key informant interviews. Online surveys were administered through SurveyMonkey to medical providers and survivors. Fourteen medical providers and 205 survivors completed the online surveys. Written surveys were distributed to medical providers, community leaders, and survivors from the four target communities. Five medical providers, 41 community leaders, and 14 survivors completed the written surveys. The key informant interviews were the centerpiece of the qualitative data collection process with fourteen medical providers and seven community leaders interviewed.

Breast Cancer Perspectives: Overview of Target Communities Findings

The groups of women that continue to be identified as those most in need of breast health programs and services included ethnic minority groups, uninsured women, low income women, less educated women, unemployed women and undocumented women. Lack of financial resources or insurance is a major barrier to healthcare within the target communities. From medical provider, community leader, and survivor responses, it is evident that there is a lack of breast health education in the community. Women are not aware of the importance of maintaining proper breast health and of obtaining regular breast health screenings. Then, if diagnosed with breast cancer, patients do not understand the severity of a breast cancer diagnosis and the need to take action in receiving treatment. There seems to be a gap in the doctor-patient relationship with regard to communication. One consistent theme was the importance of faith-based and community organizations in the target communities and the need to reach women through these vehicles.

Conclusions: What We Learned, What We Will Do

Breast cancer is expensive. From diagnosis to treatment to support services for the uninsured and underserved, the number one barrier is 'lack of financial resources'. The goal is both to provide resources and/or support for services in the community that address this need. Breast cancer information and resources are complicated. Even when services exist they are difficult to learn about. The goal is to increase paid treatment resources for breast cancer patients, with a focus on the target communities, as well as increase the awareness of and access to resources for those that need them the most. Breast cancer is treatable when diagnosed and treated in the early stages. Yet, thousands of women, insured and uninsured, over the age of 40 do not get an annual mammogram. Education about the importance of mammography and good breast health is critical to moving forward. The Affiliate has the opportunity to build capacity in the form of volunteers and collaborations to address the needs identified in the entire Community Profile process.

Affiliate Priorities and Action Plan

Priority I: Increase the capacity of breast cancer resources for those uninsured, underinsured and underserved, both through building capacity and by making information about resources more accessible.

Goal: NJCEED provides low-income, uninsured and underinsured women with free breast cancer screenings. The Affiliate's goal is to advocate for flat and/or increased funding for the NJCEED Program and ensure that women in need of screenings have continued access to and information about the Program.

Goal: The Affiliate's goal is to continue supporting local community partners and resources to help build capacity of programs and services which address the screening and treatment needs of the uninsured, underinsured and underserved.

Priority II: Increase the education of women regarding the importance of mammography and breast self awareness

Goal: The Affiliate's goal is to partner with community-based outreach/health organizations to effectively promote awareness of breast health.

Priority III: To build upon the success of the work done through the 2009 Komen North Jersey Community Profile, specifically addressing the ongoing needs of the target communities of the Affiliate's service area: Sussex, Hudson, Essex and Passaic Counties. African American women continue to be the most at-risk population throughout the North Jersey service area and are identified as an additional target population.

Goal: The Affiliate has had successful outcomes from establishing the Sussex County Breast Health Project in partnership with Grantee, Project Self-Sufficiency of Sussex County, Inc., throughout 2009 and 2010; namely greater awareness and increased screening rates. The model was developed to address the breast health gaps/needs in this target County which was identified through exploratory data in the 2009 Community Profile; e.g. highest mortality rates in the Affiliate's service area. The ultimate goal is to replicate the community breast health model in three additional Target Communities -- Hudson, Essex and Passaic Counties.

**Priority IV: Komen North Jersey Affiliate Capacity Building
In addition to the priorities outlined, the Community Profile process has amplified the needs of the Affiliate to build volunteer capacity and organizational support capacity around several areas.**

Goal: Build the volunteer and organizational capacity to support the 2011 Community Profile needs as well as Mission Initiatives.