



# COMMUNITY PROFILE REPORT

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## **Executive Summary**

### **Introduction**

The Columbus Affiliate of Susan G. Komen for the Cure is a non-profit, volunteer driven organization serving 30 counties in Central and Southeastern Ohio. Since our first Race for the Cure in 1993, we have been raising funds through our yearly Race and other annual campaigns and activities. In addition to fundraising, our staff and volunteers work diligently to spread the message of early detection and breast health awareness through a variety of mediums and initiatives and to advocate for increased access to care for women in Ohio throughout each year.

More than 75% of the funds we raise are given back to local organizations and hospitals to support breast health screening and education. Over the past eighteen years, the Columbus affiliate has funded more than \$18million in community health grants to provide education, screening and treatment assistance programming to underserved women in need. Several of our grant programs assist minority or special populations that face unique circumstances or barriers, including African American, Asian, Somali, Latina and Appalachian women.

The Community Profile report will serve as a foundation for affiliate priorities and action items in the coming years. The Columbus Affiliate conducted quantitative and qualitative research to identify the needs, resources and issues related to the breast cancer continuum of care in our service area. The findings from this research provide a basis for the affiliate to make strategic decisions about grant funding, partnership-building, fundraising efforts and volunteer engagement. While the Community Profile process and report are not exhaustive and therefore limited, we believe our efforts to identify community needs were comprehensive and provide sound justification for our future plans.

### **Statistics and Demographic Review**

Breast cancer incidence and mortality statistics from the American Cancer Society's 2009 and 2010 Facts and Figures Reports, as well as stage at diagnosis data from the Ohio Cancer Incidence and Surveillance System, were analyzed for trends in breast health throughout the 30-county service area. Mammography data from the Ohio Department of Health's Behavior Risk Factor Surveillance System was also reviewed to learn more about screening behaviors of women in the service area. To learn more about population demographics and socioeconomic variables, data provided by Komen Headquarters and Thomson Reuters was referenced, and supplemented by data from the United States 2000 Census Report.

The state of Ohio ranks below average for breast cancer incidence (121.9 /100,000 women in Ohio compared to 123.6 /100,000 in U.S.), but fourth in the country for breast cancer mortality (27.6 /100,000 women in Ohio compared to 25 /100,000 in U.S.). This disparity can also be seen at the county level within the Affiliate service area, with many

counties reporting a higher burden of breast cancer deaths compared to state and national averages. Lawrence County ranks first in the state for breast cancer mortality with 35.1/100,000 women dying from breast cancer (American Cancer Society, 2010). Several other counties report high mortality rates and more late-stage diagnoses than the state and national averages, including Licking, Fayette, Franklin, Clark, Delaware, Fairfield, Muskingum, Union, and Washington.

Understanding the socioeconomic and demographic statistics of the affiliate service area is critical to appreciating the general and breast health needs. The affiliate service area is made up of a generally homogenous and low-income population. In the thirty county service area, twenty-six counties have populations that are least 90% Caucasian, only four have more than an 8% black population and none have more than a 5% Hispanic population. Three-quarters of our entire service area population lives within ten counties: Clark, Delaware, Fairfield, Franklin, Licking, Marion, Muskingum, Ross, Scioto, and Washington.

Despite the apparent homogeneity of the service area, it is important to note that areas of diversity and cultural differences do exist and may influence health behaviors and barriers to care. Franklin County is home to an urban population of multiple ethnic, racial and social subgroups including the third largest population of Somalis in the world, several additional populations that encounter discrimination and language barriers, and an established homosexual community that does not frequently require gynecologic and family planning services and therefore do not receive provider recommendations for early detection and screening services. Seventeen of our counties are classified by the government as Appalachian; a geographic region characterized by isolation, poverty, lower educational attainment and social characteristics that affect health behaviors such as modesty and privacy.

Fourteen of our counties have more people below the poverty level than both the state and national average. Comparing rates of insurance, both private and Medicaid/Medicare, the affiliate service area has a higher proportion of uninsured females than the state average; thirteen of the affiliate counties have more uninsured females than the national average. More than half of the Affiliate's counties have higher rates of adults who did not complete high-school than both the state and national average, making health literacy and knowledge of health issues and behaviors a concern.

For the Community Profile exploratory data collection process, the Affiliate identified four counties to target that report breast health statistics which may indicate problems within the continuum of care. The four target counties also represent four distinct regions of the service area, each characterized by differences in population size, diversity and socioeconomic status: urban (Franklin County), contiguous (Licking County), non-contiguous and non-Appalachian (Fayette County), and Appalachian (Lawrence County).

## **Health Systems Analysis**

Assets such as mammography locations, diagnostic and treatment providers including surgery, chemotherapy, radiation, reconstruction and follow-up care, as well as public health departments, federally qualified health centers and organizations offering cancer support services were identified and mapped to identify local resources as well as gaps throughout the service area. Key informant interviews with medical providers, clinicians and grantees were conducted within the target communities and other counties of concern. Key informant responses were analyzed for common themes and gaps identified for specific populations or communities along the continuum of care.

Beyond Central Ohio, most counties do not offer a comprehensive continuum of care, but are able to provide digital screening mammography services and follow-up care. However, seven counties within the service area do not have a hospital and five do not have screening mammography within county lines. Lawrence County, which ranks highest in mortality, does not have any breast health services beyond medical providers who can provide clinical breast exams to women with insurance and a local health department that can refer women to services when accessed. The state and federally-funded Ohio Breast and Cervical Cancer Program (BCCP) offers early detection services through contracted providers to low-income uninsured women; however with limited funding available, a significant number of eligible women are not screened through Ohio BCCP.

Until the new Ohio biennial budget is finalized by the legislature, the Affiliate is unsure of how the Ohio BCCP will be impacted by potential budget cuts. Regardless of the amount of state general revenue funds appropriated for this vital screening and early detection program, the need to create additional revenue streams and increase sustainability of the program must remain an advocacy priority. Without the Ohio BCCP, the number of women facing barriers to screening and diagnostic services, as well as the BCCP Medicaid Treatment option, will increase drastically.

While screening, diagnostic and treatment facilities are abundant in Franklin County and the Central Ohio region, many populations including immigrants, the working poor, and uninsured women have trouble accessing them due to common barriers. Provider key informants validated several issues as potential barriers hindering timely entrance to all areas of the continuum of care: insurance status, poverty status, transportation, inconvenience, fear, and other health priorities including co-morbidities or chronic health conditions. Key informants also highlighted the importance of provider and patient education, as it relates to screening recommendations, treatment options and knowledge of available resources.

### **Qualitative Data Overview**

To learn more about the barriers and gaps faced by women in the target communities, nine focus groups were conducted:

- Fayette County women, ages 35-65
- Franklin County

- African American women including survivors
- Latina women, documented
- Latina women, undocumented
- Low-income Caucasian women
- Recently diagnosed survivors (<5years)
- Long-term survivors (>5years)
- Lawrence County women, ages 18-65
- Licking County women, ages 35-65 including survivors

Each focus group session lasted between 45 and 90 minutes duration, depending on the number of participants and the level of participation in the discussion. Each discussion was transcribed by a note taker and recorded so that they could be further analyzed for participant quotations and themes.

Most of the focus group discussions corroborated the general themes and barriers identified by key informants and the asset mapping process: insurance status or poverty, transportation barriers, lack of knowledge about screening recommendations and resources, and lack of education about follow-up/survivorship care

The consensus among focus group participants concluded that screening was the highest priority and that Komen should focus its efforts on specifically reaching the under/uninsured populations that have limited assistance available for early detection and preventative health services. Specifically, mobile units were recommended to target populations with isolation or transportation concerns. Low literacy populations were mentioned in several focus groups, highlighting the need for culturally appropriate outreach and educational materials.

Services along the continuum of care, as suggested in the key informant interview findings, are available to most insured women in the target areas. Focus group participants highlighted the disparity in access to services for women who could not afford to pay. Many participants did not know about reconstruction and follow-up care, and they were surprised that cancer patients should expect much beyond treatment. Participants also highlighted the distance a woman might have to travel to reach a mammography service or hospital, especially in northern Lawrence County and parts of Fayette County.

Lack of survivorship care was noted and most participants were not educated about breast cancer survivorship and what long-term follow-up might include and could therefore not speak to the lack of services in their community. Overall, survivorship education and services were deficient throughout the service area.

## **Conclusions**

Depending on the community of interest, barriers and gaps exist throughout the breast health continuum of care that prevent many women from accessing affordable and quality care in a timely manner.

The Affiliate can address several of the education, screening and treatment concerns through the Community Health Grants program as well as Affiliate initiatives with the assistance of our volunteer committees, Medical Advisory Council, Survivorship Advisory Council and Public Policy efforts.

The findings and conclusions of each module of the Community Profile assessment were analyzed and lists of priorities for each were constructed; recurrent priorities were considered and a final set of affiliate priorities was formed.

### **Affiliate Priorities and Action Plan**

While the Affiliate does not want to establish priorities that may limit our ability to serve women and men throughout the service area, additional consideration and preference will be given to high-risk populations and those target communities identified in this report.

The following measurable objectives will enable the Affiliate to monitor its progress and upon completion of the action plan, the Affiliate will be able to re-evaluate the state of breast health in the service area and adjust the outreach and mission activities accordingly.

- By August, 2011 the Affiliate's Community Health Grants Program will be revised to offer two separate Requests For Proposals (RFP); the majority of Affiliate funding (70%) will support programs focusing on early detection and patient navigation services, while programs focusing on survivorship care, long-term wellness services and medical provider education will be considered for Affiliate funding as well (30%).
- During 2011 and 2012, the Affiliate will consider and investigate the potential to offer multi-year grants that would provide additional opportunities for grantee's to increase sustainability and increase impact.

#### **Priority 1:**

**Increase and improve delivery of early detection services, including (re)screening and diagnostics that will improve mortality rates.**

- Objective 1: Following the release of the 2012 Ohio state budget, the Affiliate will engage with elected officials and Ohio BCCP constituents to advocate for funding of the state screening program.

- Objective 2: By August, 2011, refine the 2012-2013 RFP to focus on programs that incorporate culturally competent outreach, patient navigation, financial and transportation assistance.
- Objective 3: By March 31, 2012 the Komen Columbus Medical Advisory Council will create a medical provider campaign to educate Primary Care Physicians and OB/GYNs in the 30-county service area about recommended screening recommendations and available resources.

**Priority 2:**

**Improve survivorship support that is evidence-based and/or represents an innovative approach.**

- Objective 1: By July, 2011, the Komen Columbus Survivorship Advisory Council, Medical Advisory Council and survivor advocates will establish a definition of expected survivorship care that can be used for ongoing education initiatives, as well as the Community Health Grants RFP.
- Objective 2: By August, 2011 the 2012-2013 Community Health Grants RFP will solicit programs that support and advocate for systemic approaches that transform delivery of care to breast cancer patients.
- Objective 3: By August, 2011 the 2012-2013 Community Health Grants RFP will solicit wellness programs that improve health outcomes through quality of life and/or psychosocial focus, especially in underserved populations.
- Objective 4: By March 31, 2012 the Affiliate will create a survivor advocate training program to engage a total of 30 survivors, one from each county in the service area, to be educated on survivorship concerns, long-term follow-up expectations, and available resources.

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