



# COMMUNITY PROFILE REPORT

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## **ACKNOWLEDGEMENTS**

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## **EXECUTIVE SUMMARY**

### **Introduction**

Susan G. Komen for the Cure was established in 1982 by Nancy Brinker to honor the memory of her sister, Susan G. Komen<sup>®</sup>. Susan died from breast cancer at the age of 36. Today the Foundation is an international organization with a network of volunteers working through local Affiliates and Komen Race for the Cure<sup>®</sup> events to end breast cancer forever through research, education, screening and treatment. In addition to funding national breast cancer research, the Southwest Michigan Affiliate of Susan G. Komen for the Cure funds community-based breast health education and breast cancer screening and treatment projects to fulfill unmet needs in Southwest Michigan.

The Southwest Michigan Affiliate was incorporated in 1998 and services the counties of Allegan, Berrien, Branch, Calhoun, Cass, Kalamazoo, St. Joseph, and Van Buren. Primary funding for all projects of the Affiliate come from the signature event, "Southwest Michigan Susan G. Komen Race for the Cure<sup>®</sup>" and the Affiliate's October breast cancer awareness event, "Southwest Michigan Komen Dance for the Cure<sup>®</sup>," plus third party events and donations from individuals and organizations. Since the initial Race for the Cure in 1998, the Affiliate has awarded more than \$800,000 in local grants to fill gaps in breast health education and breast cancer screening and treatment programs in Southwest Michigan. In addition, the Affiliate has sponsored many educational exhibits, speakers, and programs (about 25-30/year) and provides at least \$10,000 in educational materials annually to individuals and organizations throughout Southwest Michigan.

The purpose of this report is to share information about the demographics of the eight counties we service through a needs assessment of breast health care and services. The report allows the Affiliate to guide priorities and work more effectively within our service areas. The Community Profile includes an overview of demographic and breast cancer statistics that highlight target areas, groups or issues. To ensure effective and targeted efforts it is vital to understand the needs and barriers as well as current programs and services gaps that exist.

### **Statistics and Demographic Review**

A variety of data sources were used to prepare this Community Profile. During data comparison there was a strong effort to use the same data source whenever possible. We used the Thomson Reuter© 2007 data pack provided by Komen Headquarters as well as US Census Bureau, Surveillance Epidemiology and End Results (SEER) and Michigan Resident Cancer Incidence File. Statistics were reviewed using the most recent available data from 2000-2008. The data was analyzed by the Community Profile team and two counties were chosen as the target communities for further analysis.

Southwest Michigan, consisting of 8 counties, has a total population of approximately 892,556. Women account for about 51% of the population. There are 85.9% Whites, 7.9% African Americans and 3.4% Hispanics in the Southwest Michigan area (U.S. Census Bureau, 2005-2009). Allegan has the highest percentage of Whites (94.0%); Berrien the highest percentage of African Americans (13.9%) and Van Buren has the highest percentage of Hispanics (7.2%) (Thomson Reuter© 2007).

Berrien County has the greatest number of families below the poverty level (9.3%) in Southwest Michigan compared to a state percentage of 15% and national percentage of 14% (US Census Bureau 2005-2009). Kalamazoo County has the highest female population (124,495) as well as the highest percentage of uninsured females of all ages (13.5%). The percentage of uninsured females age 18-64 is the same for Kalamazoo and Berrien counties of 17.6%. (Thomson Reuter© 2007)

SEER states that it is estimated that 207,090 women will be diagnosed with breast cancer in 2010 (SEER, 2003-2007). The highest breast cancer incidence rates occurred in Berrien (148.9 per 100,000 women), Cass (140.9) and Calhoun (111.6) counties (Thomson Reuter© 2007). Berrien and Cass were over the state (119.9) and national (118.7) rates (Thomson Reuter© 2007). These counties also have the highest number of females in the age 45-64 category.

The greatest percentage of stage III and IV diagnosed cases combined were in Berrien (8.1%), Calhoun (8.0%) and Kalamazoo (7.9%) counties (Thomson Reuter© 2007). Allegan, Cass and Van Buren counties have the highest percentage of African American Women with Stage IV diagnosis (8.2%) which is above the state and national percentage of 8.1% ((Thomson Reuter© 2007). The highest number of new cases for invasive breast cancer in 2007 were in Berrien (134), Calhoun (76) and Kalamazoo (149) counties (Thomson Reuter© 2007).

SEER estimates that 39,840 women will die of **cancer of the breast** in 2010 based on patients who died in 2003-2007 in the United States. The age-adjusted death rate was 24.0 per 100,000 women per year (SEER, 2003-2007). Kalamazoo (33), Berrien (23) and Calhoun (23) also have the highest number of breast cancer deaths in 2008 (Michigan Resident Cancer Incidence File, 2009).

The Community Profile team analyzed the demographic and breast cancer statistics for all of the 8 counties in order to target two communities that would have further analysis. Based on the data we chose Berrien and Calhoun counties because they were part of the top three highest with respect to poverty level, uninsured females over 40, incidence rate and mortality rate. Berrien and Calhoun have the highest poverty level (9.3%, 8.4% respectively) but they are both below the state and national levels (14% and 15% respectively). These counties also had the highest uninsured females over 40 in Southwest Michigan. The incident rate in Berrien is 148.9 which is above the state (119.9) and national rate (118.7). Both counties also had the highest mortality rates in the service areas (55.2, 63.7 respectively).

## Health Systems Analysis

Key informant interviews were performed in the two target communities Berrien and Calhoun counties. We also conducted interviews with two insurance companies Blue Cross Blue Shield of Michigan and Priority Health. The key interviews were with Breast and Cervical Cancer Control Program (BCCCP) Women's Health Supervisor, a Registered Nurse (RN) from Lakeside Hospital in Berrien County, a doctor from the Consortium for Economic Development in Benton Harbor, and a RN from Oaklawn Hospital in Marshall. Three of the interviews were performed via the phone while the other was distributed electronically.

The Southwest Michigan Affiliate has created a Breast Cancer Resource Manual listing the services available for all 8 counties. There is at least 1 hospital in each county; Berrien and Kalamazoo have 3 hospitals while Branch and Cass have 1 hospital. All 8 counties are serviced by Southwest Michigan BCCCP.

Based on the key informant interviews and surveying the assets in the target communities there are some similarities on issues/gaps, opportunities, difficult laws and policies. The informants stated the women in need of breast health care and services are below the poverty level, African Americans, uninsured and/or the unemployed.

Issues and gaps that were common between the informant interviews were:

- Women not realizing financial assistance is available or not knowing how to access the services
- Lack of transportation
- Perception of breast care health not being important
- Lack of insurance to get services
- Lack of awareness and education
- Not enough practitioners for the service areas.

Opportunities that would help improve breast care health services in the target communities are:

- Offer screening to women of any age who need it and uninsured women
- Increase Komen's presence in these counties
- Increase Oncology Nurse Navigator services
- Create a seamless system for eligibility and payment across agencies
- Provide transportation services
- Provide early education
- Ensure that information and services are provided in the neighborhoods that need it the most (uninsured, low income).

Laws or policies that make it difficult for women to get breast health services in the target communities are:

- The 50 and over statement
- No policies in place that help people access the system

- No community policies or laws that support healthy living.

### **Qualitative Data Overview**

After the key informant interviews were collected and reviewed, the Community Profile team decided to complete focus groups in the two target communities Berrien and Calhoun counties. One focus group was held in Calhoun County comprised of 8 women with varying degrees of experience with the health care system, age range from 38 – 66. Another focus group was conducted in Berrien County comprised of lesbian and transgendered individuals. There were four participants of age range from 46 -65. Each participant received a Meijer gift card. Each focus group took approximately 45-70 minutes and was facilitated by the Affiliate’s executive director and a note taker gathered the comments. The Community Profile team compared the focus group responses to the key informant interview responses as well as the quantitative data to help determine where the major needs are.

The focus group in Berrien County consisted of four lesbian individuals ages 46 -65. Because of their sexual preference it is difficult for lesbian, gay, bisexual, and transgender (LGBT) persons to trust providers to provide fair and supportive services. The focus group participants feel there are biases among practioners and providers which make receiving fair and supportive services to same sex couples difficult. The other focus group in Calhoun County consisted of 8 women with varying degrees of experience with the health care system, of age range from 38-66.

From the exploratory data, we learned support services and education were important to both focus group and key informants, although they had somewhat different perspectives on these issues. A key point of agreement between the focus group women and interviews includes getting basic breast health information to the women of need (low income, African American women, uninsured, LGBT, other minorities). In terms of support services, the programs and services section shows a wealth of resources in the area, along with some gaps. The concern voiced by the focus group women include understanding insurance policies how they are paid and what the policies cover. One limitation of the focus group data is that we did not reach a large number of African American women. These groups were identified in the interviews and focus groups as lacking targeted support services. Their perspectives on community assets and benefits for women of color would have greatly added to this report. Future affiliate work will seek to reach out to this group in greater numbers and ensure that their voice is regularly heard and can contribute to decision-making.

## **Conclusions**

The priorities were selected by the Community Profile team. The priorities and recommendations will influence the Southwest Michigan Affiliate's strategic plan request for proposals and other mission efforts. Based on the quantitative and qualitative data of the Community Profile the following priorities were proposed as needs and targets for the Berrien and Calhoun counties.

### *Southwest Michigan Affiliate Service Area Priorities*

Priority 1: Increase available information regarding breast health through partnerships with community based-outreach organizations in Calhoun and Berrien Counties.

Priority 2: Increase access to services through targeting funding of programs and services that work to improve transportation options and services in isolated areas.

Priority 3: Decrease the perceived and/or documented concerns regarding social barriers to access the services with a particular emphasis in Berrien County.

## **Action Plan**

Priority 1: Increase available information regarding breast health through partnerships with community based-outreach organizations in Calhoun and Berrien Counties.

Objective 1: Within one year, organize educational activities with the Tribal Council, the Benton Harbor City Council and Recreation Department, and Oaklawn Hospital.

Objective 2: Emphasize the importance of helping community members understand insurance programs and where to get additional information on how their insurance provider functions.

Priority 2: Increase access to services through targeting funding of programs and services that work to improve the transportation options and services in isolated areas.

Objective 1: Hold at least one grant writing workshop in the targeted communities aimed at identifying the transportation needs and encouraging applications that work to address this identified need.

Objective 2: Share this barrier with the community and encourage community solvency through specific partnerships that address transportation concerns.

Priority 3: Decrease the perceived and/or documented concerns regarding social barriers to access the services with a particular emphasis in Berrien County.

Objective 1: Establish relationships with health care providers in Berrien County and within one year will convene 1-3 meetings discussing the need for understanding the cultures of the area, how these various cultures perceive their access to services and treatment and understanding this as a part of the overall continuum of care. A specific focus of the meeting would include creating a culture of inclusiveness within a health care organization, provider and communities.

Objective 2: During the second year, there will be a follow up meeting reviewing support documentation regarding the importance of the creation of an inclusive health care culture. Activities of participating organizations will be tracked.

## INTRODUCTION

### **Affiliate History**

Susan G. Komen for the Cure<sup>®</sup> was established in 1982 by Nancy Brinker to honor the memory of her sister, Susan G. Komen. Susan died from breast cancer at the age of 36. Today Komen for the Cure is an international organization with a network of volunteers working through local Affiliates and Komen Race for the Cure<sup>®</sup> events to end breast cancer forever through research, education, screening and treatment. Komen runs one of the most innovative, responsive grant programs in breast cancer today. In addition to contributing 25% of all funds raised to breast cancer research, the Southwest Michigan Affiliate of Susan G. Komen for the Cure funds community-based breast health education and breast cancer screening and treatment projects to fulfill unmet needs in Southwest Michigan.

The first Southwest Michigan Susan G. Komen Race for the Cure<sup>®</sup> was organized by local founder, Wayne Young, and held in Battle Creek in 1996. This race generated \$10,000 for our first local grant which was awarded to the Calhoun County Health Department to initiate their "First Look" program of screening for breast cancer. Since the initial Race for the Cure, the Affiliate has awarded more than \$800,000 in local grants to fill gaps in breast health education, breast cancer screening and treatment programs in Southwest Michigan. The Race was held in Battle Creek for 8 years but in 2005 the Race venue was changed to Kalamazoo.

In 1998 the Southwest Michigan Affiliate was incorporated and began with two counties, Calhoun and Kalamazoo. Then in 2001 the Affiliate expanded to include six additional counties of Southwest Michigan (Allegan, Berrien, Branch, Cass, St. Joseph, and Van Buren). Since the beginning, the Southwest Michigan Affiliate has been a primarily all-volunteer organization.

Primary funding for all projects of the Affiliate come from the signature event, "Southwest Michigan Susan G. Komen Race for the Cure<sup>®</sup>" and the Affiliate's October breast cancer awareness event, "Southwest Michigan Komen Dance for the Cure<sup>®</sup>," plus third party events and donations from individuals and organizations. There have been some revenues from Community Foundation grants for specific projects and some revenues from National events in which the Affiliate participates.

In addition, the Affiliate has sponsored many educational exhibits, speakers, and programs (about 25-30/year) and provides at least \$10,000 in educational materials annually to individuals and organizations throughout Southwest Michigan.

## Organizational Structure

The Southwest Michigan Affiliate is led by a Board of Directors, consisting of 13 members. The board is a diverse group of men and women of various ages as well as diverse geographical, ethnic, professional, and social backgrounds. The officers serve as the Executive Committee and consist of President, Vice President, Secretary and Treasurer who are elected at an annual meeting of the board. Currently the board consists of the following committees: Education Committee, Grants Committee, Community Profile Committee and a Race for the Cure Committee.

In December 2007 the first Executive Director for the Affiliate was hired as a part-time, 20 hours per week position. In February of 2007, a position of part-time administrative assistant was added. Based on the priorities of the affiliate and the recent growth, the Board of Directors decided to invest in the employment of a full time Executive Director with prior experience in non-profit administration. This position was hired and began with the affiliate in October of 2010.

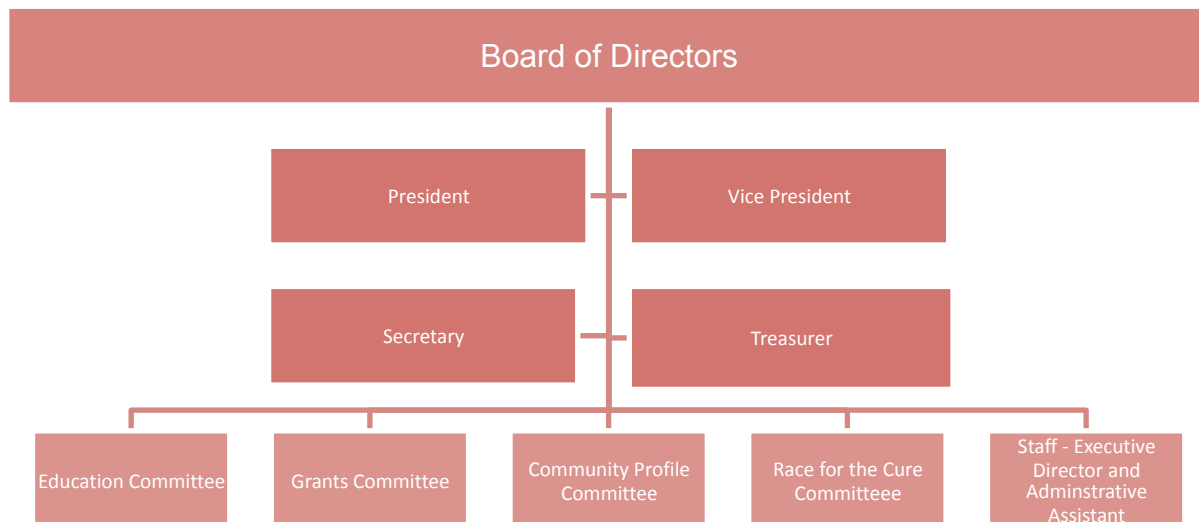


Figure 1. Southwest Michigan Affiliate Organizational Structure.

## Description of Service Area

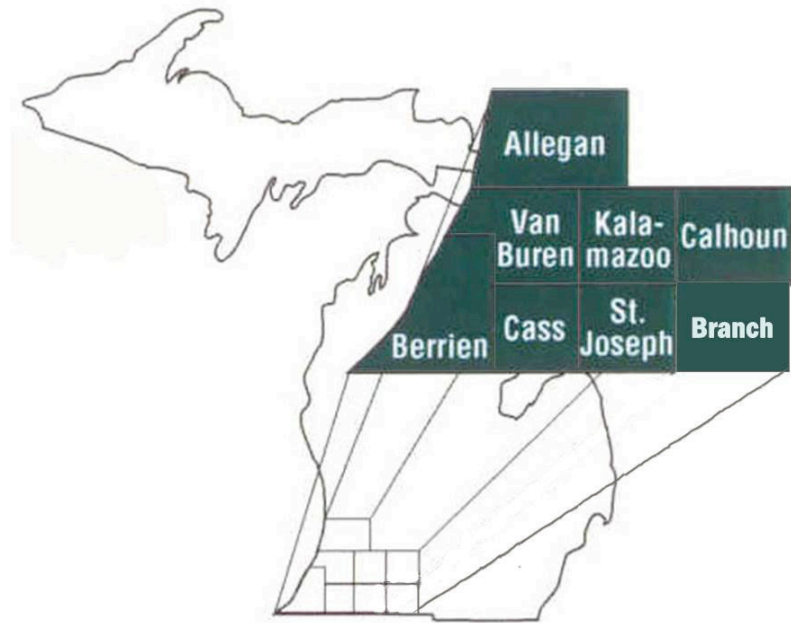
The Michigan population accounts for about 3% of the United States population (U.S. Census Bureau, 2005-2009). The Southwest Michigan Affiliate consists of eight counties: Allegan, Berrien, Branch, Calhoun, Cass, Kalamazoo, St. Joseph, and Van Buren. The eight counties contain approximately 892,556 women which represent about 8.9% of the Michigan population (U.S. Census Bureau, 2005-2009). Women account for about 51% of the population in Southwest Michigan which is the same as the state and national's female population percentage (U.S. Census Bureau, 2005-2009). There are 85.9% Whites, 7.9% African Americans and 3.4% Hispanics in the Southwest Michigan area per the table below.

Table 1.

*Population, Race/Ethnicity, Education and Poverty Demographics of United States, Michigan and Southwest Michigan.*

2005-2009	United States	Michigan	Southwest Michigan
Total Population	301.5 million	10.0 million	892,556
Females	51%	51%	50.5%
White	74%	80%	85.9%*
Black or African American	12%	14%	7.9%*
American Indian	1%	1%	0.3%*
Hispanics	15%	4%	3.4%*
Other Race	6%	2%	1.4%*
People 25 years and over who have at least graduated from high school	85%	87%	81.8%
People who have a bachelor's degree or higher	28%	25%	16.5%
People were in poverty	14%	15%	14.9%

U.S. Census Bureau, 2005-2009 American Community Survey and \*Thomson Reuters© 2007.



*Figure 2. Southwest Michigan Affiliate Service Areas.*

### **Purpose of the Report**

The purpose of this report is to share information about the demographics of the eight counties the Southwest Affiliate services through a needs assessment of breast health care and services. This will help the Affiliate understand the populations to be served, services available, the location and the barriers to services and any other gaps that might be discovered. The report allows the Affiliate to guide priorities and work more effectively within their service areas. The Community Profile includes an overview of demographic and breast cancer statistics that highlight target communities, groups and/or issues. To ensure effective and targeted efforts it is vital to understand the needs and barriers as well as current programs and services gaps that exist. Analysis of the community also includes the voices of those living in target communities and representing target populations.

## BREAST CANCER IMPACT IN AFFILIATE SERVICE AREA

### Methodology

A variety of data sources were used to prepare this Community Profile. During data comparison there was a strong effort to use the same data source whenever possible. We used the Thomson Reuter© 2007 data pack provided by Komen Headquarters as well as US Census Bureau and Michigan Resident Cancer Incidence File. Statistics were reviewed using the most recent available data 2000-2008. The data was analyzed by the Community Profile team and two counties were chosen as the target communities for further analysis.

### Overview of the Affiliate Service Area

The service area for Southwest Michigan includes Allegan, Berrien, Branch, Calhoun, Cass, Kalamazoo, St. Joseph, and Van Buren counties. Southwest Michigan has a total population of approximately 892,556. Women account for about 51% of the population. There are 85.9% Whites, 7.9% African Americans and 3.4% Hispanics in the Southwest Michigan area (U.S. Census Bureau, 2005-2009). Allegan has the highest percentage of Whites (94.0%); Berrien the highest percentage of African Americans (13.9%) and Van Buren has the highest percentage of Hispanics (7.2%) see table below (Thomson Reuter© 2007).

Table 2.  
*Female Population with % of Total Race/Hispanic: 2009 Estimate.*

Female Population	% White	% African American	% American Indian	% All Other	% Hispanic
Allegan	94.0%	0.8%	0.3%	0.6%	3.8%
Berrien	80.8%	13.9%	0.2%	1.2%	2.7%
Branch	93.3%	3.1%	0.2%	0.7%	2.2%
Calhoun	84.2%	9.8%	0.3%	1.7%	2.7%
Cass	89.3%	5.3%	0.6%	1.6%	2.7%
Kalamazoo	83.2%	9.6%	0.3%	2.1%	2.8%
St. Joseph	92.0%	1.9%	0.2%	0.7%	5.0%
Van Buren	87.2%	3.5%	0.5%	1.1%	7.2%
SW Michigan	85.9%	7.9%	0.3%	1.4%	3.4%
Michigan*	80%*	14%*	1%	2%*	4%*
United States*	74%*	12%*	1%	6%*	15%*

\*U.S. Census Bureau, 2005-2009 American Community Survey and Thomson Reuters© 2007.

Table 3 displays that Berrien County has the greatest number of families below the poverty level (9.3%). Calhoun County has the lowest median household income (\$42,192). Kalamazoo County has the highest female population (124,495) as well as the highest percentage of uninsured females of all ages (13.5%). The percentage of uninsured females age 18-64 is the same for Kalamazoo and Berrien counties (17.6%). (Thomson Reuter© 2007)

Table 3.

*Annual Median Household Income and Families below Poverty Level – 2009 est.*

	Total Families	Below Poverty Level		Median HH Income	Fem Pop	Uninsured Females		Uninsured Fem Age 18-64	
		Families	%			Pop	%	Pop	%
Allegan	31,003	1,606	5.2%	\$50,841	49,146	3,890	7.9%	3,140	10.2%
Berrien	43,401	4,044	9.3%	\$42,663	87,092	11,240	12.9%	9,251	17.6%
Branch	11,505	756	6.6%	\$43,455	22,796	1,845	8.1%	1,535	10.9%
Calhoun	35,912	3,030	8.4%	\$42,192	69,795	8,510	12.2%	7,057	16.7%
Cass	14,504	997	6.9%	\$47,941	20,859	2,141	10.3%	1,766	13.6%
Kalamazoo	61,446	4,141	6.7%	\$45,026	124,495	16,785	13.5%	14,121	17.6%
St. Joseph	16,841	1,513	9.0%	\$44,437	31,631	3,260	10.3%	2,650	14.1%
Van Buren	21,457	1,753	8.2%	\$45,131	41,628	3,975	9.5%	3,275	12.8%
SW Michigan	236,069	17,840	7.6%	\$44,994	447,442	51,646	11.5%	42,796	15.4%

Thomson Reuters© 2007.

Figure 3 shows Kalamazoo County has the highest number of women over the age of 40 (56,804) and has the highest percentage of uninsured women (17.6%) which is also equal to the percentage of uninsured women in Berrien County. Berrien County also has the highest breast cancer incidence rate (148.9). Branch County has the highest estimated percentage of women not having mammograms (40.7%). (Thomson Reuters© 2007)

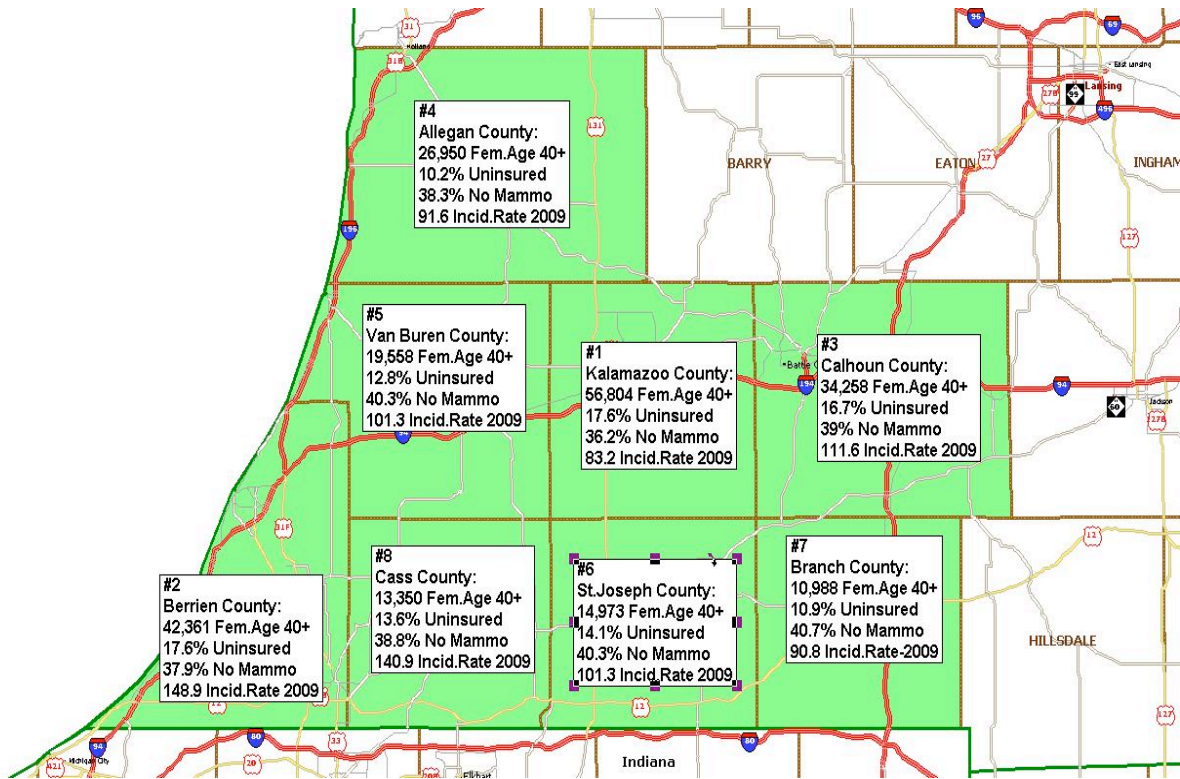


Figure 3. Females Age 40 and over, Uninsured Females Age 40 and over, estimated % with No Screening Mammograms and Breast Cancer Incidence Rates. Thomson Reuters© 2007.

The Surveillance Epidemiology and End Results (SEER) state that it is estimated that 207,090 women will be diagnosed in the US in 2010. Berrien (148.9), Cass (140.9) and Calhoun (111.6) counties had the highest breast cancer incidence rates for Southwest Michigan. Berrien and Cass were over the state (119.9) and national (118.7) rates (Thomson Reuters© 2007). These counties also have the highest number of females in the age 45-64 category per Figure 4 below.

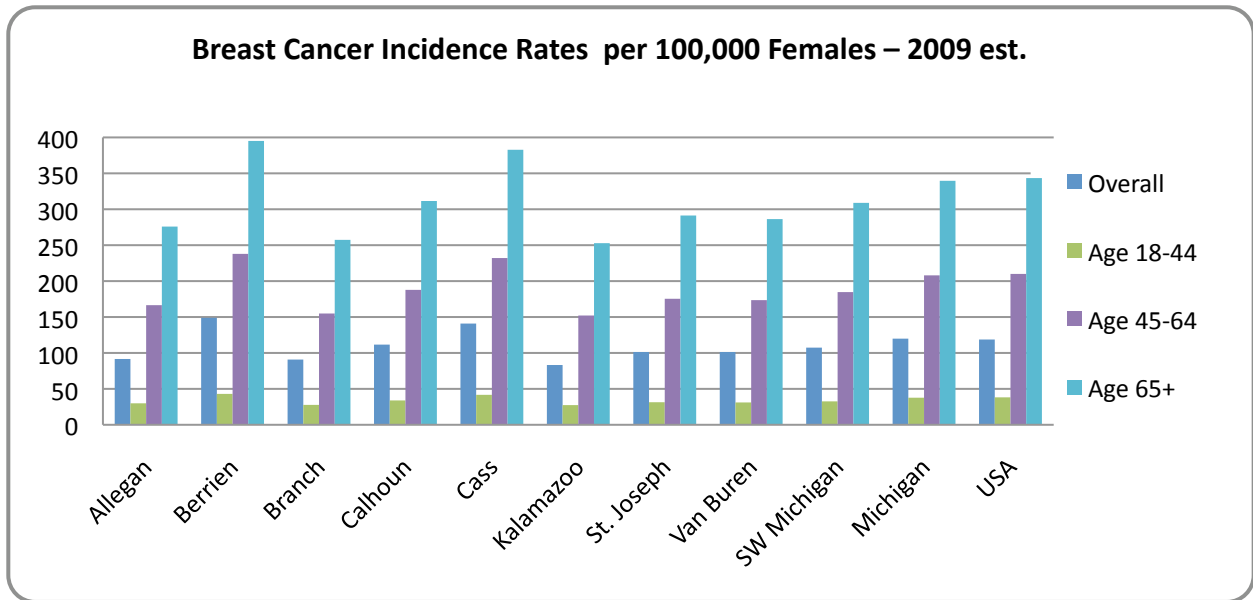


Figure 4. Overview of Breast Cancer Statistics. Thomson Reuters© 2007.

Table 4 shows that Berrien (8.1%), Calhoun (8.0%) and Kalamazoo (7.9%) counties have the highest percentage of stage III and IV diagnosed cases combined. Allegan, Cass and Van Buren counties have the highest percentage of Black Women with Stage IV diagnosis (8.2%) which is above the state and national percentage of 8.1% (Thomson Reuters© 2007).

Table 4.

*Breast Cancer Incidence at Stage of Diagnosis (% of Total).*

	Stage I		Stage II		Stage III %		Stage IV %		Stage III+IV % of Total
	% of Total	Black Women	% of Total	Black Women	% of Total	Black Women	% of Total	Black Women	
Allegan	64.8%	55.6%	27.7%	30.5%	3.3%	5.7%	4.2%	8.2%	7.5%
Berrien	64.8%	54.7%	27.1%	31.4%	3.5%	5.8%	4.6%	8.1%	8.1%
Branch	65.3%	50.1%	27.1%	35.8%	3.3%	6.6%	4.3%	7.5%	7.6%
Calhoun	64.8%	55.0%	27.3%	31.1%	3.5%	5.8%	4.5%	8.1%	8.0%
Cass	64.9%	56.1%	27.4%	30.1%	3.4%	5.6%	4.4%	8.2%	7.8%
Kalamazoo	64.3%	54.1%	27.8%	32.0%	3.5%	5.9%	4.4%	8.0%	7.9%
St. Joseph	65.3%	55.2%	27.2%	31.0%	3.3%	5.8%	4.3%	8.1%	7.6%
Van Buren	64.9%	56.1%	27.5%	30.1%	3.3%	5.6%	4.3%	8.2%	7.6%
SW Region	64.8%	54.7%	27.4%	31.4%	3.4%	5.8%	4.4%	8.1%	7.8%
Michigan	64.0%	54.6%	27.7%	31.5%	3.6%	5.8%	4.7%	8.1%	8.3%
USA	64.2%	54.6%	27.7%	31.5%	3.5%	5.8%	4.6%	8.1%	8.1%

Thomson Reuters© 2007.

Berrien, Calhoun and Kalamazoo counties had the top three highest new cases for invasive breast cancer both in 2000 and 2007 per Michigan Resident Cancer Incidence File, 2009 in Figure 5 below.

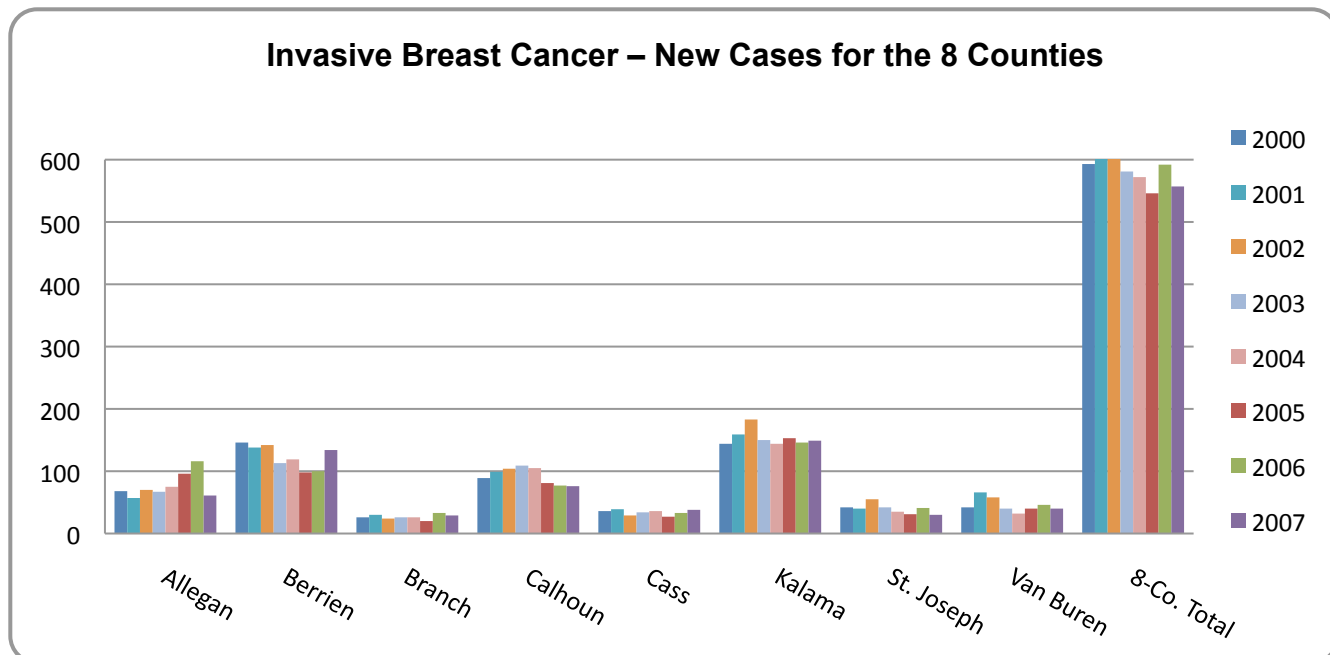


Figure 5. Invasive Breast Cancer – New Cases for the 8 Counties. Michigan Resident Cancer Incidence File, 2009.

SEER estimates that 39,840 women will die of **cancer of the breast** in the US in 2010. The age-adjusted death rate was 24.0 per 100,000 women per year. These rates are based on patients who died in 2003-2007 in the US. Kalamazoo (33), Berrien (23) and Calhoun (23) also have the highest number of breast cancer deaths in 2008 per Table 5.

Table 5.  
Invasive Breast Cancer Deaths

Invasive Breast Cancer Deaths									
Year of Death	Allegan	Berrien	Branch	Calhoun	Cass	Kalamazoo	St. Joseph	Van Buren	8-Co. Total
2000	15	23	7	21	11	20	13	12	122
2001	11	20	5	21	9	30	8	11	115
2002	7	28	3	23	5	39	3	18	126
2003	8	27	6	33	6	27	9	9	125
2004	15	28	5	21	10	31	11	9	130
2005	14	17	10	25	8	35	12	9	130
2006	9	24	7	21	10	35	5	7	118
2007	16	31	10	23	13	43	7	9	152

2008	17	23	9	23	11	33	4	9	129
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Michigan Resident Cancer Incidence File, 2009.

Figure 6 shows that the highest breast cancer deaths were in Kalamazoo, Berrien and Calhoun counties.

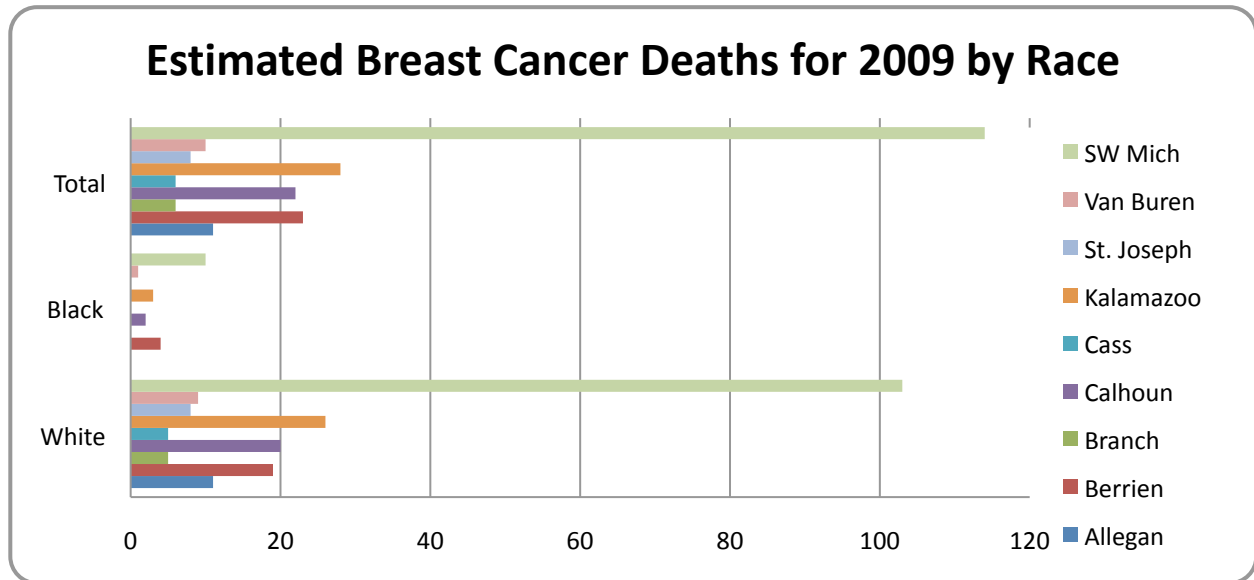


Figure 6. Estimated Breast Cancer Deaths for 2009 by Race. Thomson Reuters© 2007.

Branch (40.7%), St. Joseph (40.3%) and Van Buren (40.3%) counties have the highest percentage of women who have not had a mammogram within the last 12 months as shown in Table 6 below (Thomson Reuters© 2007).

Table 6. Mammogram Screening Survey Results for Women Age 40 and Older: 2009.

County	% No Mammogram Last 12 Months	% Chose Not To	% Didn't Have Time	% Didn't Need	% Have Scheduled	% Other Reasons
Allegan	38.3%	6.3%	10.4%	2.9%	4.0%	14.5%
Berrien	37.9%	6.3%	9.8%	3.3%	3.7%	14.5%
Branch	40.7%	7.3%	10.0%	3.5%	4.0%	15.7%
Calhoun	39.0%	6.5%	10.0%	3.3%	3.8%	15.1%
Cass	38.8%	6.3%	10.0%	3.1%	4.0%	15.2%
Kalamazoo	36.2%	5.9%	9.4%	2.9%	3.3%	14.3%
St. Joseph	40.3%	6.9%	10.0%	3.3%	4.3%	15.5%
Van Buren	40.3%	7.1%	9.9%	3.1%	4.1%	15.9%
SW Michigan	38.2%	6.4%	9.9%	3.1%	3.8%	14.8%

Thomson Reuters© 2007.

## **Communities of Interest/Conclusions**

The Community Profile team analyzed the demographic and breast cancer statistics for all of the 8 counties in order to target two communities that we would further analyze. Based on the data we chose Berrien and Calhoun Counties because they show multiple areas of concern; uninsured females, poverty rates and incidence and mortality rates. Berrien and Calhoun have the highest poverty level (9.3%, 8.4% respectively) but they are both below the state and national levels (14% and 15% respectively). These counties also had the highest number of uninsured females over 40 in Southwest Michigan. The incident rate of Berrien is 148.9 which is above the state (119.9) and national rate (118.7). Both counties also had the highest mortality rates in service area (55.2, 63.7 respectively).

## HEALTH SYSTEMS ANALYSIS OF TARGET COMMUNITIES

### Methodology

Key informant interviews were performed in the two target communities of Berrien and Calhoun counties. We also conducted interviews with two insurance companies Blue Cross Blue Shield of Michigan and Priority Health. The key interviewees were Breast and Cervical Cancer Control Program (BCCCP) Women's Health Supervisor, a Registered Nurse (RN) from Lakeland Hospital in Berrien County, the Director of the Consortium for Economic Development in Benton Harbor, a Native American Women who serves on the Tribal Council and works for the Michigan Housing Authority and a RN from Oaklawn Hospital in Marshall.

### Overview of Community Assets

The Southwest Michigan Affiliate created a Breast Cancer Resource Manual in 2009 listing the services available over the 8 counties. Below is a summary of the services available in each county. All 8 counties are serviced by Southwest Michigan BCCCP.

Table 8.

#### *Health System Analysis of the 8 Counties*

	Hospitals	Community Health Clinics	Holistic Health	Mammography Facilities	Support Groups
Allegan	2	3	0	3	2
Berrien	3	2	3	6	3
Branch	1	2	0	1	0
Calhoun	2	1	2	2	1
Cass	1	2	0	0	0
Kalamazoo	3	4	1	8	1
St. Joseph	2	1	0	3	3
VanBuren	2	3	1	2	2

Komen Southwest Michigan Breast Cancer Resource Manual.

There are 3 centers in Southwest Michigan where one can receive Radiation Therapy in most of its forms: The Cancer Care Center in Calhoun County, Lakeland Cancer Care Center in Berrien County, and West Michigan Cancer Center (WMCC) in Kalamazoo County.

Medical Oncology is widely available in Southwest Michigan. The three institutions listed for Radiation Therapy (Battle Creek, Lakeland and WMCC) are for the most part comprehensive cancer centers and have many services available including a number of medical oncologist on staff. Independent medical oncology practices are available in St. Joseph and Kalamazoo.

There is a full time medical oncology based cancer center at Community Health Center of Branch County, Coldwater. Oncology clinics, usually part time, are present at Allegan General Hospital, Allegan; Lakeland Community hospital, Niles; Watervliet Community Hospital, Watervliet; Oaklawn Hospital, Marshall; Borgess Lee Memorial Hospital, Dowagiac; Sturgis Hospital, Sturgis; Three Rivers Area Hospital, Three Rivers; Lakeview Community Hospital, Paw Paw; and South Haven Community Hospital, South Haven. One could travel outside the Southwest Michigan area to obtain radiation therapy, however except for very rare circumstances it is not necessary.

Radiologists and surgeons play an important role in the treatment of breast cancer particularly early in the course of the disease. A primary care provider is an important source of recommendations and referrals. If reconstruction is an option, a breast surgeon will make a recommendation and referral.

An asset map was created to show where the breast care health facilities are located in each of the targeted counties. Facilities were chosen based on the knowledge of the Community Profile team and the Southwest Michigan Breast Cancer Resource Manual.

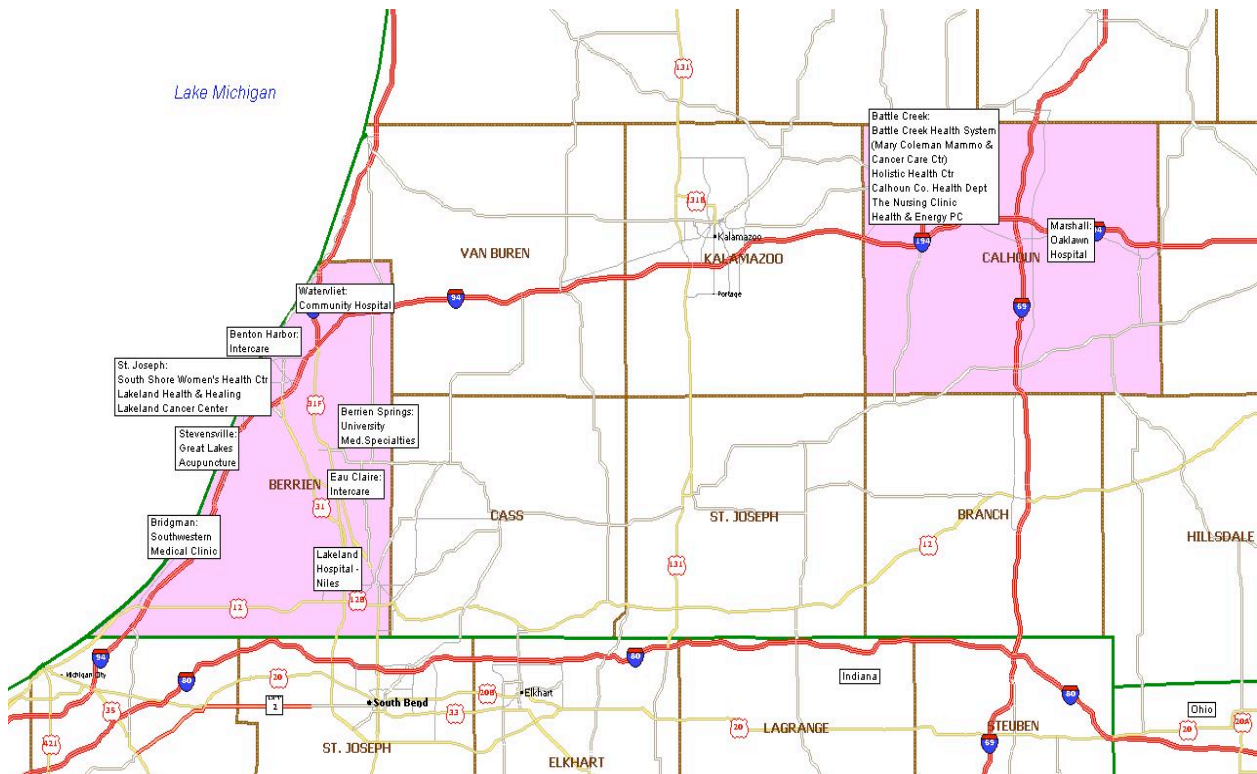


Figure 7. Asset Map of Service Areas

## **Legislative Issues of Target Communities**

### *50 and Over Statement*

BCCCP can only provide services for women 50 and over with the minimal state funding provided. Komen continues to advocate for mammogram funding to once again expand and include women 40 and up. At this time, we continue to monitor the State Budget process regarding BCCCP funding for the State's fiscal year 2012.

Furthermore, as the National Legislature continues to debate the future funding of Medicaid within the budget process, the affiliate is prepared to advocate for continued funding for Medicaid with growth in this program to ensure services for low-income women and their families.

The target communities have many low income women who do not have access to health insurance. The BCCCP program was developed to help serve these women through the provision of screening services. Due to the recent cuts (past three years) in the funding and the qualifying age being increased from 40 to 50, low income women between the ages of 40 and 49 are left with no options for publically funded breast screening.

The Southwest Michigan Affiliate will continue to work with legislators to ensure that this concern is heard.

### *Clinical Trial Drugs*

The Director of Customer Services at Blue Cross Blue Shield (BCBS) of Michigan was interviewed about the policy concerning clinical trial prescription coverage. She reported that any clinical "trial" drug is not covered by BCBS in any policy offered. A list of approved drugs based on the individual policy held by the patient can be found by logging onto their website and submitting their policy number. At that point a list of all approved drugs and the amount of the co-pay for that individual would appear. The question was asked if this policy has been challenged and she stated that she was aware of a couple of participants that wanted to take trial drugs but they were denied because the "drugs need to be on the approved list. These were not."

The phone representative from Priority Health stated that only drugs that appear on their "approved list" would be covered by insurance and only at the predetermined co-pay amount. Any drug that is in a "trial" status would not be covered by an individual's policy. However, policy holders can pay for the drug on their own if they want to utilize a non-approved prescription. When asked "what if the policy holder finds that there are great results for the patient from the use of the drug? Would there ever be any way of getting it approved? She stated that there was a process for this type of request from a policy holder but that she was not aware of any that had been presented or granted.

## Key Informant Findings

The interviews of the four key informants were conducted in the target communities. Three of the informants responded on services for Berrien county and 2 responded on services in Calhoun county. Many of the issues/gaps as well as opportunities to improve breast health care were similar between communities.

### Benton Harbor (Berrien County)

#### Issues/Gaps

- Lack of insurance to obtain services
- Breast cancer health is not a priority for women in poverty
- Lack of basic health education and awareness, particularly for marginalized groups – Native American women are less likely to discuss symptoms or concerns with anyone outside of their “Native Community”.
- Lack of knowledge of available services or how to access them
- Not enough practioners for the population – only one oncology office
- Lack of services available for women in need; those that qualify for Medicaid don’t know how to use it or do not have support services to utilize it (i.e. transportation)

#### Opportunities

- Provide Early Education
- Bring services to the neighborhood
- Komen having a greater presence in Benton Harbor

#### Difficult laws and policies

- There are no policies in place that help people to access the system
- BCCCP can only serve women over 50 – policy from State
- No “community” policies or laws that support healthy living

### St. Joseph – Lakeland (Berrien County)

#### Issues/Gaps

- Lack of awareness and education – do not address women before diagnosis
- Lack of transportation
- Primary care provider not making referrals
- Nurse navigators for referrals may be dropped due to funding and service areas
- Nothing in place to cover women without insurance
- Only one local oncologist
- Some financial assistance programs available but offer small amounts and can be difficult to access
- There are only 7 support groups in Berrien County
- Need a professional person to serve in the community as an outreach person to close gaps and address transportation and basic education needs

#### Opportunities

- Transportation service
- Funding those without insurance throughout continuum of care not just covering mammogram

- Navigator software
- Wig fund
- Good information on breast self exam

Difficult laws and policies

- 50 and over statement is a big issue

BCCCP – Berrien & Calhoun counties

Issues/Gaps

- Limited availability of services for women age 40-49
- No perception of importance of breast screening; life too chaotic to focus on breast health
- Do not realize financial assistance is available
- No transportation to health centers
- Too many ways to meet needs; women have to figure out how to get what paid for
- Women at poverty level have a hard time figuring out where to go for services and how to get them paid for

Opportunities

- Offer breast and cervical screening to women of any age who needs it and women without insurance, because some are caught in the gaps.
- Create one seamless system on protocols for eligibility and payment across agencies
- BCCCP may purchase additional caseload slots; however, the program does not receive money to coordinate the program for the additional women. It would be nice if someone could cover the coordination costs so more women may receive free screenings.
- Integrate the various state/federal programs that provide/pay for health screenings into one agency/program.

Difficult laws and policies

- Unaware of any

Oaklawn Hospital – Calhoun County

Issues/Gaps

- Women less likely to receive screening are the unemployed, elderly Caucasian, African Americans, single heads of households or widows

Opportunities

- Charity care if eligible
- Pink Saturdays expansion –service providing free mammograms in October
- Increase Oncology Nurse Navigator services

Difficult laws and policies

- State requirement for BCCCP to provide for 50 and over. Leaves gap.

## **Conclusions**

Based on the key informant interviews and surveying the assets in the target communities there are some similarities on issues/gaps, opportunities and difficult laws and policies. The women that are in need of breast health care and services are below the poverty level, African Americans, uninsured and/or the unemployed.

Issues and gaps that were common among the informants were women not realizing financial assistance is available or not knowing how to access the services, lack of transportation, perception of breast care health not being important, lack of insurance to get services, lack of awareness and education, and not enough practitioners for the service areas.

Opportunities that would help improve breast care health services in the target communities include offering screening to women of any age who needs it and uninsured women, increase Komen's presence in these counties, increase Oncology Nurse Navigator services, create a seamless system for eligibility and payment across agencies, provide transportation services and provide early education. Also ensure that information and services are provided in the neighborhoods that need it the most (uninsured, low income).

Laws or policies that make it difficult for women to get breast health services in the target communities are the 50 and over statement, no policies in place that help people access the system as well as no community policies or laws that support healthy living.

## **BREAST CANCER PERSPECTIVES IN THE TARGET COMMUNITIES**

### **Methodology**

After the key informant interviews were collected and reviewed, the Community Profile team held focus groups in the two target communities Berrien and Calhoun counties. The Calhoun County comprised of 8 women with varying degrees of experience with the health care system, age range from 38 – 66. Another focus group was conducted in Berrien County comprised of lesbian and transgendered individuals. There were four participants of age range from 46 -65. Each participant received a \$15.00 Meijer gift card. Each focus group took 45-70 minutes and was facilitated by the Affiliate's executive director and a note taker gathered the comments. We compared their responses to the key informant interview responses as well as the quantitative data to help determine where the major needs are.

### **Review of Qualitative Findings**

The focus group in Berrien County consisted of four lesbian and transgendered individuals ages 46 -65. Information about breast health and breast cancer was learned from a variety of ways through Susan G. Komen, being diagnosed with breast cancer, and internet searches. One participant did not know anything about breast health. Because of their sexual preference it is difficult for lesbian, gay, bisexual, and transgender (LGBT) persons to trust providers to provide fair and supportive services. There are biases among practioners and providers which make receiving fair and supportive services to same sex couples difficult. "My general practioner was not comfortable with my same sex relationship so I had to find another. Then I found another. I also had to say over and over that my partner was the contact person, even when I was prepared with the legal paperwork" stated one of the participants.

They stated that low income, LGBT persons, African American women and African American lesbians are in need of breast health messages and services. Barriers for these women include lack of insurance, difficulty understanding medical bills, lack of sensitivity to minorities (particularly African Americans and LGBT community). Group members also expressed concern for receiving poor treatment or no outreach services from the local hospital due to their race and/or sexual preference. Transportation is another barrier in this area.

Komen establishing a greater presence in LGBT, African American, Native American and low income communities would help to ensure breast health messages and services get to the women who really need them. Other opportunities include educational events for how to include LGBT persons in personal health care in general, messages in LGBT newsletter and participation at community health fairs.

One of the focus group participants shared an experience she had with a breast care provider. “I had to come out to my Doctor and had to get legal paperwork for my partner to be the spokesperson and the decision maker for my care. The doctor gave us a bit of a hard time and would not help with the paperwork so we had to get an attorney to draw it up for us. We then presented it to the doctor. Even then, the Doctor would still try to talk with anyone else in the room instead of looking my partner in the eye and planning for my recovery together. People just don’t understand how difficult it is to go through this when you are sick.” The other group members were in agreement – shaking heads – with this concern and experience.

Throughout the discussion, this theme concerning the legalities of having a same sex partner as the legal entity for making decisions on behalf of a partner who is diagnosed with breast cancer or any other medical concerns continued to appear. Another concern that was expressed had to do with the Southwest Michigan Affiliate’s Race for the Cure®. The focus group members stated they would like to see a race/walk in their county. In addition, they would all like to see Susan G. Komen “more present” in Berrien County.

The focus group in Calhoun County consisted of 8 women with varying degrees of experience with the health care system, of age range from 38-66. Participants agreed that information about breast health and breast cancer is not readily available in the general public. Most of the women did not become aware of information until they were diagnosed or from their doctor. They stated the local hospital, physician or friend would be the most credible places to receive information.

Group members reported that African American women, low income communities, rural areas, and young women are in need of breast health messages and services. Barriers for these women are transportation/gas prices for low income women, fear, some women don’t want to go to the local hospital, or insurances concerns (don’t have the co-pay or don’t understand their policy).

Opportunities to ensure breast health messages and services get to the women who really need them are: information can be posted in places throughout the county, public service announcements on the radio throughout the year, informational cards placed everywhere women go, and speakers at health clinics and emergency care centers.

The women shared their experiences with breast care providers:

- Insurance parameters cause a problem in the continuation of care because specialists can only provide services for their area.
- Understanding my insurance coverage has been difficult – the local hospital had a person explain to me what would happen and what would be covered but I still found all the bills confusing. There was really no direct conversation between my doctor and my insurance program. I had to do all the navigation of it and really was confused and very upset.
- Support groups are great but women don’t always want to go to them because they don’t know someone, don’t want to share their illness or symptoms, are

embarrassed they didn't get help sooner, can't get to the support group or are too tired to attend.

- The local hospital has some great information but you have to ask for it
- Difficulty with Insurance (MESA through school district) for a survivor. Once all vacation time was used, needed to access FMLA time, but while on FMLA time, she had to pay the full \$1700/month premium to keep policy. Couldn't afford this and the co-pays. Her employer didn't even understand this.

Several themes appeared in this focus group 1) women are not getting basic breast health information, particularly low income and African American women, 2) Komen is not noticed unless a diagnosis has been received and 3) there are several opportunities for Komen to engage Calhoun County.

One other item that was expressed had to do with the Southwest Michigan Affiliate's Race for the Cure<sup>®</sup>. The focus group members stated they would like to see a race/walk in their county as attending the one in Kalamazoo is too far and difficult. In addition, they would all like to see Susan G. Komen "more present" in Calhoun County.

## **Conclusions**

From the exploratory data, we learned support services and education were important to both survivors and key informants, although they had somewhat different perspectives on these issues. A key point of agreement between the focus group women and interviews includes getting basic breast health information to women of need (low income, African American women, uninsured, LGBT, other minorities). In terms of support services, the programs and services section shows a wealth of resources in the area, along with some gaps. The concern voiced by focus group women include understanding insurance policies how they are paid and what the policies cover. One limitation of the focus group data is that we did not reach a large number of African American women. These groups were identified in the programs and services area as lacking targeted support services. Their perspectives on community assets and benefits for women of color would have greatly added to the discussion. Future affiliate work will seek to reach out to this group in greater numbers and ensure that their voice is regularly heard and can contribute to decision-making.

## **CONCLUSIONS: WHAT WE LEARNED, WHAT WE WILL DO**

### **Review of the Findings**

From the exploratory data, we learned support services and education were important to both focus group and key informants, although they had somewhat different perspectives on these issues. A key point of agreement between the focus group women and interviews includes getting basic breast health information to the women of need (low income, African American women, uninsured, LGBT, other minorities). In terms of support services, the programs and services section shows a wealth of resources in the area, along with some gaps. The concern voiced by the focus group women include understanding insurance policies how they are paid and what the policies cover.

### **Selecting Affiliate Priorities**

The priorities were selected by the Community Profile team. The priorities and recommendations will influence the Southwest Michigan strategic plan request for proposals and other mission efforts. Based on the quantitative and qualitative data of the Community Profile the following priorities were proposed as needs and targets for the Berrien and Calhoun counties:

### **Conclusions**

#### Southwest Michigan Affiliate Service Area Priorities

Priority 1: Increase available information regarding breast health through partnerships with community based-outreach organizations in Calhoun and Berrien Counties.

Priority 2: Increase access to services through targeting funding of programs and services that work to improve transportation options and services in isolated areas.

Priority 3: Decrease the perceived and/or documented concerns regarding social barriers to access to services with a particular emphasis in Berrien County.

### **Action Plan**

Priority 1: Increase available information regarding breast health through partnerships with community based-outreach organizations in Calhoun and Berrien Counties.

Objective 1: Within one year, organize educational activities with the Tribal Council, the Benton Harbor City Council and Recreation Department, and Oaklawn Hospital.

Objective 2: Emphasize the importance of helping community members understand insurance programs and where to get additional information on how their insurance provider functions.

Priority 2: Increase access to services through targeting funding of programs and services that work to improve the transportation options and services in isolated areas.

Objective 1: Hold at least one grant writing workshop in the targeted communities aimed at identifying the transportation needs and encouraging applications that work to address this identified need.

Objective 2: Share this barrier with the community and encourage community solvency.

Priority 3: Decrease the perceived and/or documented concerns regarding social barriers to access to services with a particular emphasis in Berrien County.

Objective 1: Establish relationships with health care providers in Berrien County and within one year will convene 1-3 meetings discussing the need for understanding the cultures of the area, how these various cultures perceive their access to services and treatment and understanding this as a part of the overall continuum of care. A specific focus of the meeting would include creating a culture of inclusiveness within a health care organization or provider.

Objective 2: In year two, follow up with support documentation to meeting participants regarding the importance of the creation of an inclusive health care culture. Track activities of participating organizations.

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