



# COMMUNITY PROFILE REPORT

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**Disclaimer:**

The information in this Community Profile Report is based on the work of the Southwest Florida Affiliate of Susan G. Komen for the Cure® in conjunction with key community partners. The findings of the report are based on a needs assessment public health model but are not necessarily scientific and are provided "as is" for general information only and without warranties of any kind. Susan G. Komen for the Cure and its Affiliates do not recommend, endorse or make any warranties or representations of any kind with regard to the accuracy, completeness, timeliness, quality, efficacy or non-infringement of any of the programs, projects, materials, products or other information included or the companies or organizations referred to in the report.

## **Acknowledgments**

Thank you to the Community Profile Committee who worked together to compile the 2011 Community Profile Report for the Southwest Florida Affiliate of Susan G. Komen for the Cure. This committee consists of the following individuals:

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### **Sources of Qualitative Data**

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# Executive Summary

## Introduction

The Susan G. Komen for the Cure Southwest Florida Affiliate was established in November 2002. The Affiliate is led by a proactive Board of Directors, Mariann MacDonald, Board President, and an Executive Director, Miriam Ross. Consistent with the mission of the organization, education and fundraising are of paramount importance with limited staff leading each of these priority areas. As in all Komen organizations, volunteers are the backbone and human energy behind all that is accomplished. Nearly 800 Affiliate volunteers serve five counties in southwest Florida—Charlotte, Collier, Glades, Hendry and Lee—a large geographic area comprised of 1,112,941 people with a Hispanic population of approximately 210,000<sup>1</sup>.

Within the short eight years since our Affiliate's inception, it has grown in all aspects, particularly in the scope of services it provides. These services include participation in health fairs, distribution of grant funding, and community education and awareness.

As a fairly new organization, the financial capacity of the Affiliate is extremely sound and continues to flourish. Through the enthusiastic efforts of the Board of Directors, staff, and volunteers, our Affiliate has awarded over \$3.7 million in grants to the local community; contributed over \$1.2 million for ground-breaking research; and provided nearly \$275,000 in educational materials to the community.

Seventy five percent of net proceeds raised by this Affiliate stay within the local area to fund outreach programs and initiatives that address the specific unmet breast health needs within the five county service area. These projects are selected based on an annual needs assessment performed by the Affiliate.

An effective Community Profile is done every two years and helps the Komen Southwest Florida Affiliate align its programs, funding and support activities towards the same goal. The Community Profile will allow our Affiliate to:

- Include a broad range of people in the Affiliate's work and become more diverse
- Fund, educate, and build awareness in the areas of greatest need
- Make good decisions about how to use resources in the best way – to make the greatest impact
- Bring the message closer to home, into the community, to strengthen relationships with sponsors
- Give information to public policymakers to focus their work
- Give direction to marketing and outreach programs
- Create synergy between strategic plans and operational activities<sup>2</sup>

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<sup>1</sup> U.S. Census Bureau; State and County Quick Facts; August 16, 2010 based on 2009 data.

<sup>2</sup> The Community Profile Guidebook, 2011

## **Statistics and Demographic Review**

The Community Profile begins by analyzing the statistics and geography of the Affiliate region. The Affiliate has expanded its presence in Southwest Florida in the past few years. In the fall of 2008, we acquired Charlotte, Glades and Hendry Counties in addition to Collier and Lee Counties. The five county service area is comprised of 1,112,941 people according to the US Census Bureau report estimate for 2009. This is approximately 6% of the state total. The area has experienced a 16.7 percent increase in population growth since 2000. Our five counties encompass a total of 6,552 square miles. Forty eight percent of the population is female as compared with 51 percent in both the state and the nation. Twenty three percent of the population is 65 or older, as compared to 17 percent in the state and 13 percent in the nation, with wide ranges from county to county. The median household income for the area is \$47,328, as compared to \$44,755 in the state and \$50,221 in the nation, again with wide ranges from county to county. Fifteen percent of the area is considered below the poverty level which is equal to the state and one percent higher than the nation. The area is also ethnically diverse, with the average number of White persons not Hispanic at 65.5 percent compared to 58 percent in the state and 64 percent in the nation; 23 percent Hispanic compared to 22.5 percent in the state and 16 percent in the nation and 9 percent Black compared to 16 percent in Florida and 12.6 percent in the nation. (see Table 1 Service Area Information)

## **Breast Cancer Impact**

Unless otherwise noted, the 2011 demographic and breast cancer statistics used to compile this Community Profile report were provided by the Healthcare Business of Thomson Reuters. Several variables were examined to help us determine the breast cancer impact on our service area. Those variables included incident rate by age, incident rate by stage of diagnosis, mortality rates, mammography rates, rates of no insurance, rates by ethnicity, and poverty rates by county (see Tables 2-6). These variables were chosen because of their correlation to breast cancer either directly or indirectly. There is a direct correlation between age and breast cancer diagnosis. The older the individual, the higher the incidence rate. There is a direct correlation between stage of diagnosis and mortality, with the later stages yielding higher mortality rates. There is also a direct correlation between mammography and stage of diagnosis, with regular mammograms resulting in earlier diagnosis. Indirectly, lack of insurance, ethnicity, and poverty are more likely to produce differences in access to care and treatment which likely contribute to this disparity. (Cancer Facts and Figures for Hispanics/Latinos 2009-2011, American Cancer Society)

The following communities were identified as those of greatest need based on the statistics and demographics gathered. They were chosen because they were high in two of the stated variables. Those target communities include Punta Gorda, Naples (zip code 34102), North Ft. Myers and Saint James City where the median age for females is significantly higher than the rest of the county and state. According to the American Cancer Society Breast Cancer Facts and Figures 2007-8 your chance of getting breast cancer is 1 in 40 by age 50, 1 in 28 by age 60, and 1 in 26

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by age 70. Therefore, these communities are likely to have higher incidences and mortality rates as age is a major factor in a women's chance of getting breast cancer. Immokalee, LaBelle, Clewiston, Moore Haven, St. James City, Lehigh Acres, and North Ft. Myers were chosen as target communities because they have a low average income compared to the county and state thus would be more likely to be uninsured or be unable to afford health care costs. Immokalee and LaBelle also have a high Hispanic population compared to the county and state and although race is not considered a factor that might increase a woman's chance of getting breast cancer, the mortality rates are higher for Hispanic women due to different screening rates and access to treatment. Ft. Myers (Dunbar) was selected because it has a high Black population, which may also lead to a higher risk of mortality for the same reasons. (American Cancer Society Surveillance Research, 2009).

## **Health Systems Analysis**

Once the target communities were selected, the health systems located within our boundaries were analyzed and qualitative findings gathered. The expertise and experience of key individuals and health care providers within our five county Affiliate area is important in helping us assess the needs of our community. Key informants were selected from participants at our semi-annual breast health forum held in November 2010. These participants included our eleven grantees and several additional health care providers from our Affiliate area. A class of Occupational Therapy graduate students from Florida Gulf Coast University, in Ft. Myers, Florida, was utilized to gather input and design an asset map for each county in the affiliate region. They were able to develop a Google map of each county that includes all resources that might be needed during any phase within the continuum of care, their contact information, a general description of the services they offer, and directions to their site. The maps are strong visual indicators of the disparity in location of services within the counties we serve. Most resources in the coastal counties were located along the coast on Rt. 41 in the very western and wealthy part of the county. Glades and Hendry County residents have very few resources within the county and have to travel to other counties and sometimes other Affiliate areas for care. Poverty, language barriers, and lack of public transportation also impede their ability to enter and stay in the continuum of care (see page 24 for definition). These areas were identified as areas to focus on to close the gaps that exist in the continuum.

## **Key Informant Findings**

Fourteen surveys were completed by the key informants in our Southwest Florida Affiliate area. This tool helped provide a snapshot of the breast health and breast cancer services available in our community.

Based on the results of the surveys, women who are least likely to get regular screenings were described as low income or un/underinsured and low education. The biggest barriers preventing services were noted as money, lack of knowledge, fear, transportation, lack of time, culture, and religion. Outreach to low income areas, mobile units, ability to fund undocumented women, patient education services, and financial aid were noted as ways to improve delivery of breast health services. A large non-English speaking population including Spanish, Creole, and

German was identified as a barrier to care. Most agencies surveyed offered some educational information in Spanish and also provided interpreters. The agencies were interested in forming more partnerships to further provide needed breast health services and working with Komen on public policy initiatives.

The Komen Advocacy Alliance is actively involved in promoting and fighting for the Breast Cancer Bill of Rights. Even after the valuable patient protections in the new health reform law are fully phased in by 2014, there will be gaps in access to breast health services and quality of care issues. Komen will be supporting several pieces of legislation in the coming state session: one bill regarding oral chemotherapy and one bill concerning breast density. Increased education and access to screening associated with the risk and flaws of mammography for women with dense breasts is also a cause that the Komen Advocacy is actively supporting.

### **Breast Cancer Perspectives**

The need in the community far exceeds the resources that are available. With the downturn in the economy, the needs have grown since the 2009 Community Profile. Over 500 confidential surveys were distributed and collected through our grantees and volunteers covering our five county region to give us important random information about breast health in our community. In addition, five different focus groups of between eight to fifteen people each were held throughout our geographic area to capture deeper and richer information regarding the continuum of care.

Three major themes evolved from the focus groups and random surveys regarding knowledge, access, and support.

**Knowledge-** Providing better breast health education for all age groups and for all ethnic groups was a strong message from participants. Language barriers are particular problems for our Latina residents. Many recognize the Komen name, but the mission is not readily known to most of the residents surveyed or interviewed. In the rural counties, more than half of participants had not heard of the organization despite some of them receiving services through our grants program. In the sixty and older age group and the Latina group stigmas about cancer and touching yourself emerged. During most of the focus groups the US Preventive Services Task Force recommendations for mammography crept into the conversation and there were mixed reviews as a result. Fear of radiation, although not shared by most in the groups, was voiced strongly by those who did have the fear. There was interesting discussion about self-exams due to Task Force recommendations and internet information. As a result some no longer do self-exams.

**Access-** Fear of diagnosis, lack of insurance, lack of funds, time constraints, and discomfort were all cited as reasons to not enter and/or follow through with the continuum of care. In the rural communities, language barriers (it was discovered that our region hosts seven different Spanish dialects), transportation issues, legal status (no identification) were also cited frequently. Language barriers, fear, and lack of documentation are particular problems for our Latina residents. In addition, age bias by physicians was mentioned in the sixty and over group as well

as medical system bureaucracy and dual residencies with different healthcare providers and medical records locations. Sending reminders for mammograms was expressed often.

**Support-** The need for continuous support throughout the continuum of care for both the patient and their families was a recurring theme. Survivors spoke strongly about the need for support (mental, physical, emotional, and spiritual) throughout the continuum of care for themselves and their families as well as the need for post treatment support.

## **Conclusions**

As a result of the Community Profile process, the Southwest Florida Affiliate has established the following priorities and proposes the following action plan to address the needs in eliminating the barriers and closing the gaps in the continuum of care for our Affiliate area. These priorities are intended to assist us in the distribution of grant funds, focus our public policy initiatives, target our outreach and education efforts, develop partnership opportunities and coordinate marketing and fundraising efforts.

## **Priorities**

### **1. Expand Outreach to Hispanic Communities**

#### **Recommendations:**

- A. Join two Hispanic agencies in Immokalee and Labelle to build leadership capacity in the community by December 2011.
- B. Translate affiliate brochure and all breast education materials into Spanish by December 2011.
- C. Recruit a minimum of five new Hispanic volunteers to be part of our volunteer committees by December 2011.
- D. Articulate partnership with the Redlands Christian Migrant Association in Immokalee and Labelle by December 2011.
- E. Articulate partnership with the Guadalupe Center in Immokalee by August 2011.

### **2. Market Susan G. Komen message more effectively**

#### **Recommendations:**

- A. Hold at least one focus group in each county in 2011 and 2012.
- B. Schedule two Speaker's Bureau presentations in Glades County by December, 2011.
- C. Schedule two Speaker's Bureau presentations in Hendry County by December, 2011.

- D. Increase pool of speakers for Speaker's Bureau to 10 including 3 bilingual speakers by March 2012.
- E. Continue with Gap Workgroup meetings the first Wednesday of each month to target and close gaps in communication with the community.

### **3. Develop a better support system after diagnosis**

#### **Recommendations:**

- A. Articulate a partnership with FGCU Occupational Therapy graduate students to pilot a mentoring program with survivors in the fall of 2011.
- B. Launch a survivor mentoring program with FGCU Occupational Therapy graduate students by January 2012.
- C. Develop a lay breast health navigator system to augment services to those in need by June 2012.
- D. Continue to monitor and increase attendance by 10% in support group in Labelle by March 2012.
- E. Start a support group in Clewiston by March 2012.
- F. Start a support group in Moore Haven by March 2012.
- G. Negotiate a minimum of one new contract for Project Hope Initiative with health care providers in Glades and Hendry Counties by December 2011.

### **4. Actively pursue outreach in targeted zipcodes**

#### **Recommendations:**

- A. Attend at least one health fair each year in each of the following zipcodes- 33980 (Punta Gorda); 34102 (Naples); 34113(East Naples); 34142 (Immokalee); 33935(Labelle); 33440(Clewiston); 33471(Moore Haven); 33956 (St. James City); 33936 (Lehigh Acres); 33916 (Dunbar); 33917 and 33903 (N. Ft. Myers).
- B. Schedule mobile mammography unit for two events in Immokalee, Moore Haven and Clewiston by March 2012.
- C. Develop a satellite volunteer base in Immokalee by March 2012.
- D. Develop a satellite volunteer base in Glades County by March 2012.
- E. Develop a satellite volunteer base in Hendry County by March 2012.

# Community Profile Introduction

## Affiliate History

The Susan G. Komen for the Cure, Southwest Florida Affiliate, was established in November 2002. The Affiliate is led by a proactive Board of Directors, Mariann MacDonald, Board President, and an Executive Director, Miriam Ross. Consistent with the mission of the organization, education and fundraising are of paramount importance with limited staff leading each of these priority areas. As in all Komen organizations, volunteers are the backbone and human energy behind all that is accomplished. Nearly 800 Affiliate volunteers serve five counties in southwest Florida—Charlotte, Collier, Glades, Hendry and Lee—a large geographic area with a Hispanic population of approximately 210,000<sup>3</sup>.

Within the short eight years since our Affiliate's inception, it has grown in all aspects, particularly in the scope of services it provides. These services include participation in health fairs, distribution of grant funding, and community education and awareness.

As a fairly new organization, the financial capacity of the Affiliate is extremely sound and continues to flourish. Through the enthusiastic efforts of the Board of Directors, staff, and volunteers, our Affiliate has awarded over \$3.7 million in grants to the local community; contributed over \$1.2 million for ground-breaking research; and provided nearly \$275,000 in educational materials to the community.

75 percent of net proceeds raised by this Affiliate stay within the local area to fund outreach programs and initiatives that address the specific unmet breast health needs within the five county service area. These projects are selected based on an annual needs assessment performed by the Affiliate.

Our Affiliate's Education and Grants committees provide organizational oversight and leadership, providing regular reports to the Board of Directors. The Education Committee assumes responsibility for disseminating information on breast health, provides a vehicle for communication, and offers a Speaker's Bureau resource to the community. The Grants Committee oversees the accountability and effectiveness of all grants received and awarded.

The signature event of our Affiliate is the annual Southwest Florida Race For the Cure held each March at Coconut Point in Estero. In addition to this being our major fundraiser for the year, breast cancer and breast health education and awareness, celebrating survivors and those who have lost their battle with the disease remain vital elements of this inspirational event. Over 12,000 people overall participated in last year's event.

## **Organizational Structure**

### **Governing Board**

President – Mariann MacDonald  
Vice President – Heather Turco

Secretary – Robert Mangene  
Treasurer – Janus King

### **Directors**

Carol Conway  
Mary Ann Loh, RN, MSN  
Lou Pontius  
Dorothy L. Taylor, PhD

Dr. Thomas Fabian  
Charlotte Miller  
Jennifer Stanley, RN, BSN, MED  
Sandi Wilson

### **Staff**

Executive Director – Miriam Ross

Community Health Manager – Julie Sprague

Community Health Coordinator- Amy Austin

The Affiliate consists of a Board of Directors, three paid staff members and various Committees that support the Foundation's mission statement. Committees are comprised of volunteers who are the lifeblood of this organization.

- The Education Committee is available to provide breast health information to large and small groups.
- The Grants Committee oversees the application, review, and distribution of grant monies raised by the Race for the Cure and other Special Events.
- The Race for the Cure Committee organizes the Foundation's signature 5K run/fitness walk.
- The Volunteer Committee works to help staff both educational and fund-raising type events.
- The Public Policy Committee uses the power of activism to achieve important legislative objectives at federal, state, and local levels.

Over the years, the Affiliate Board has established strong community partnerships that have resulted in significant milestones.

March 13, 2010, marked our fourth annual Susan G. Komen Southwest Florida Race for the Cure. A record breaking 12,000 supporters raised an impressive \$897,000. The race included 781 breast cancer survivors and 399 teams.

## Description of Service Area

The five county service area is comprised of 1,112,941 people according to the US Census Bureau report estimate for 2009<sup>4</sup> (see Table 1). This is approximately six percent of the Florida State total of 18,537,969. It is located along Florida's gulf coast, south of the Tampa Bay area, west of Lake Okeechobee and includes areas of the Everglades. It consists of three coastal counties from Charlotte County south to Collier County, and includes two rural inland counties. The most populous county in the region is Lee County, and the region's largest city is Cape Coral. The Affiliate expanded its presence in Southwest Florida, in the fall of 2008, by acquiring Charlotte, Glades and Hendry Counties. Our five counties encompass a total of 6552 square miles. 23.4 percent of the population in the service area is 65 years old and older with ranges of Charlotte County being the highest at 34.3 percent and Hendry the lowest at 11.4 percent. 47.8 percent of the population is female. The area has experienced a 16.7 percent increase in population growth since 2000. The median household income for the region is \$47,328, with Collier County ranging the highest at \$61,379 and Hendry being the lowest at \$38,771. 15.3 percent of the area is below poverty level with a range of 23.8 percent in Hendry County and a low of 10.2 percent in Collier. The average number of White persons not Hispanic is 65.5 percent in the region with a range of 86.9 percent in Collier to 36.6 percent in Hendry County; Hispanic- average 23 percent with a high of 48.7 percent in Hendry County and a low of 5.1 percent in Charlotte; and black-8.9 percent with a range of 13.3 percent in Hendry to 5.7 percent in Collier.

## Service Area Information

Table 1.  
*Demographics of Five County Service Area*

		<b>Charlotte</b>	<b>Collier</b>	<b>Glades</b>	<b>Hendry</b>	<b>Lee</b>
<b>Latest Population Size</b> <sup>4</sup>		156,952	318,537	10,950	39,594	586,908
<b>Persons / sq. Mile</b> <sup>4</sup>		204.1	124.1	13.7	31.4	548.4
<b>Ethnicity</b> <sup>4</sup>	Caucasian	86.9 %	66.8 %	64.7 %	36.6 %	72.6 %
	Black/AD	5.8 %	5.7 %	11.5 %	13.3 %	8.1 %
	American Indian	0.2 %	0.4 %	5.3 %	1.9 %	0.4 %
	Asian	1.4 %	1.1 %	0.5 %	0.7 %	1.4 %
	Pacific Islander	<0.1 %	0.1 %	0.1 %	<0.1 %	0.1 %
	Hispanic/Latino	5.1 %	26.2 %	17.9 %	48.7 %	17.4 %
	2+ Races	1.0 %	0.7 %	1.3 %	0.8 %	1.1 %
<b>Median Household Income</b> <sup>5</sup>		\$46,378	\$61,379	\$39,251	\$38,771	\$50,863

<sup>4</sup> U.S. Census Bureau; State and County Quick Facts; August 16, 2010 based on 2009 data.

<sup>5</sup> <http://www.census.gov/> (From 2008-2009)

<sup>6</sup> <http://publicrecords.onlinesearches.com/> (Current)

<sup>7</sup> <http://www.bls.gov/> (From 2010)

<sup>8</sup> <http://www.realtytrac.com/home/> (From 2010)

<sup>9</sup> Thomson Reuters Data (2009)

<b>County Seat<sup>6</sup></b>	Punta Gorda	Naples	Moore Haven	La Belle	Fort Myers
<b>Persons Living Below Poverty Level<sup>4</sup></b>	10.3 %	10.2 %	21.8 %	23.8 %	10.6 %
<b>Unemployment Rate<sup>7</sup></b>	12.9 %	12.4 %	12.6 %	17.9 %	13.3 %
<b>Foreclosures<sup>8</sup></b>	0.4 % Rate 4,222 Total	0.2 % Rate 6,624 Total	0.0006 % Rate N/A Total	0.4 % Rate 423 Total	0.4 % Rate 18,076 Total
<b>Uninsured Females<sup>9</sup></b>	12.5 %	11.6 %	23.9 %	25.4 %	14.5 %

### **Overview of the Purpose and Objectives of the Profile**

An effective Community Profile will help the Komen Affiliate align its programs, funding and support activities towards the same goal. The Community Profile will allow Affiliates to:

- Include a broad range of people in the Affiliate's work and become more diverse
- Fund, educate, and build awareness in the areas of greatest need
- Make good decisions about how to use its resources in the best way – to make the greatest impact
- Bring the message closer to home, into the community, to strengthen relationships with sponsors
- Give information to public policymakers to focus their work
- Give direction to marketing and outreach programs
- Create synergy between strategic plans and operational activities<sup>10</sup>

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<sup>6</sup> <http://publicrecords.onlinesearches.com/> (Current)

<sup>7</sup> <http://www.bls.gov/> (From 2010)

<sup>8</sup> <http://www.realtytrac.com/home/> (From 2010)

<sup>9</sup> Thomson Reuters Data (2009)

<sup>10</sup> The Community Profile Guidebook, 2011

## Breast Cancer Impact in Affiliate Service Area

### Methodology

Unless otherwise noted, the 2011 demographic and breast cancer statistics used to compile this Community Profile report were provided by the Healthcare Business of Thomson Reuters. Several variables were examined to help us determine the breast cancer impact on our service area. Those variables included incident rate by age, incident rate by stage of diagnosis, mortality rates, mammography rates, rates of no insurance, rates by ethnicity, and poverty rates by county (see Tables 2-6). These variables were chosen because of their correlation to breast cancer either directly or indirectly. There is a direct correlation between age and breast cancer diagnosis. The older the individual, the higher the incidence rate. There is a direct correlation between stage of diagnosis and mortality, with the later stages yielding higher mortality rates. There is also a direct correlation between mammography and stage of diagnosis, with regular mammograms resulting in earlier diagnosis. Indirectly, lack of insurance, ethnicity, and poverty are more likely to produce differences in access to care and treatment which likely contribute to this disparity. (Cancer Facts and Figures for Hispanics/Latinos 2009-2011, American Cancer Society)

### Overview of the Affiliate Service Area

Table 2.

#### *Breast Cancer Incident Rate by County and Age Group*

County	Per 100K Pop.	Age 0-17/100K	Age 18-44/	Age 45-64/	Age 65+/ 100K
Charlotte	180.90	0.05	37.94	211.01	350.48
Collier	156.06	0.04	37.21	209.65	350.54
Glades	141.49	0.05	37.41	208.84	350.38
Hendry	99.49	0.04	36.72	204.44	336.68
Lee	138.31	0.04	35.06	196.08	327.69

Table 3.

#### *Breast Cancer Incident Rate by County and Stage*

County	Stage I%	Stage II%	Stage III%	Stage IV%
Charlotte	66.8	25.3	3.4	4.5
Collier	66.7	25.5	3.3	4.5
Glades	65.6	26.4	3.5	4.6
Hendry	64.3	27.6	3.5	4.6
Lee	66.1	26.0	3.4	4.5

Table 4.

***Breast Cancer Deaths by County***

County	2009 Female Population	Mortality Cases
Charlotte	83,034	19
Collier	165,654	30
Glades	2,901	1
Hendry	18,575	2
Lee	320,393	66

Table 5.

***Females 40+ without a Mammography***

County	Pop. 40+	% No Mammo	% Chose Not To	% Didn't Have Time	% Didn't Need
Charlotte	54,493	35.8	6.2	8.8	3.4
Collier	95,874	33.1	5.7	8.1	2.9
Glades	2,768	39.5	7.6	8.9	3.3
Hendry	7,194	44.4	7.9	10.7	3.2
Lee	177,038	35.0	6.0	9.1	3.1

% Have Scheduled	% Other Reasons
3.8	13.2
3.6	12.5
3.9	15.3
4.6	17.7
3.5	12.9

Hendry, Glades and Charlotte Counties are higher than the average of 34.8 percent of the total counties with no mammograms. Hendry, Glades and Charlotte Counties were also above the total average of 6.0 percent who chose not to have mammograms. Hendry, Glades, and Lee Counties were above the total average of 8.8 percent who didn't have time for a mammogram; and Charlotte, Glades, and Hendry Counties were above the 3.1 percent total average that didn't need mammograms.

Table 6.

***Uninsured Females by County***

County	Female Pop.	Uninsured Female Pop. / %	Uninsured Females 18-64
Charlotte	83,034	10,376 / 12.5	8,470 / 19.2
Collier	165,654	19,210 / 11.6	14,641 / 16.8
Glades	2,901	693 / 23.9 *	534 / 31.1
Hendry	18,575	4,717 / 25.4 *	3,754 / 35.9
Lee	320,393	46,476 / 14.5	37,807 / 21.1

\*The high rates for uninsured females in Glades and Hendry County are of significant note.

**Communities of Interest**

The following tables list the zip codes by counties that were selected as communities of interest because they were high in mortality rate, percentage of late diagnosis, percentage of uninsured females, or percentage of no mammography.

Table 7.

***Charlotte County***

Zip Code	City	High Mortality Rate	High % Late Diagnosis	High % Uninsured Females
33946	Placida	Yes		
33950	Punta Gorda	Yes		
33952	Pt Charlotte		Yes	
33953	Pt Charlotte		Yes	
33954	Pt Charlotte		Yes	
33955	Punta Gorda	Yes		
33980	Punta Gorda	Yes	Yes	

Percentage of No Mammography in Charlotte County – 35.8%

Table 8.

***Collier County***

Zip Code	City	High Mortality Rate	High % Late Diagnosis	High % Uninsured Females
34102	Naples	Yes	Yes	
34103	Naples	Yes		
34105	Naples			Yes
34108	Naples	Yes		
34110	Naples	Yes		
34113	Naples		Yes	Yes
34142	Immokalee		Yes	Yes
34145	Marco Island	Yes		

Percentage of No Mammography in Collier County – 33.1%

Table 9.

***Glades County***

Zip Code	City	High Mortality Rate	High % Late Diagnosis	High % Uninsured Females
33440	Clewiston			Yes
33471	Moore Haven			Yes

Percentage of No Mammography in Glades County – 39.5%

Table 10.

**Hendry County**

Zip Code	City	High Mortality Rate	High % Late Diagnosis	High % Uninsured Females
33935	Labelle			Yes

Percentage of No Mammography in Hendry County – 44.4%

Table 11.

**Lee County**

Zip Code	City	High Mortality Rate	High % Late Diagnosis	High % Uninsured Females
33901	Ft. Myers		Yes	
33903	N. Ft. Myers	Yes		Yes
33905	Ft. Myers			Yes
33908	Ft. Myers	Yes		
33912	Ft. Myers	Yes		
33916	Ft. Myers		Yes	Yes
33917	N. Ft. Myers	Yes		Yes
33921	Boca Grande	Yes		
33922	Bokeelia			Yes
33924	Captiva	Yes		
33928	Estero	Yes		
33931	Ft Myers Beach	Yes		
33936	Lehigh Acres		Yes	Yes
33956	St. James City	Yes		Yes
33957	Sanibel	Yes		
34134	Bonita Springs	Yes		

Percentage of No Mammography in Lee County – 35%

**Target Areas**

Based on the communities of interest, the following target areas were chosen because they were high in two of the above categories- high mortality rate, high percentage of late diagnosis, high percentage uninsured females, or high percentage of no mammography. Source- Zipareacode.net

Florida Demographic Information: Female median age- 40.1;Population-15,982,378; White-12,465,029; Black-2,335,505; Other-477,107 (Zipareacode.net); Median household income-\$47,802 (US Census Bureau QuickFacts 2009)

**Charlotte County:** Female Median Age-55.5 (Zipareacode); Population-156,952; White Not Hispanic-86.9%; Hispanic-5.1%; Black-5.8%; Median Household Income(2008)-\$46,378; Persons Below Poverty Level-10.3% (US Census Bureau QuickFacts 2009)

**Punta Gorda, 33980:** Population-11,408; White-8,031; Black-761; Hispanic-335; Average Income-\$31,865; Median Age Female-66.4

The median age is significantly higher than the county, region, and state. Low average income.

**Collier County:** Female Median Age-46.3 (Zipareacode); Population- 318,537; White Not Hispanic-66.8%; Hispanic-26.2%; Black- 5.7%; Median Household Income-\$61,379; Persons Below Poverty Level-10.2% (US Census Bureau QuickFacts 2009)

**Naples, 34102:** Population-15,173; White-10,393; Black-950; Hispanic-278; Average Income-\$55,648; Median Age Female-55.5  
The median age is significantly higher than the county, region, and state.

**Naples, 34113 (East Naples):** Population-14,298; White-11,173; Black- 1,032; Hispanic-4,365; Average Income-\$43,630; Median Age Female- 46.7

**Immokalee, 34142:** Population-23,853; White-9,797; Black-4,367; Hispanic—16,081; Average Income-\$25,189; Median Age Female-24.3  
The median age is significantly lower than the county, region, and state. Low average income with high Hispanic population(\*\*)

**Hendry County:** Female Median Age-31.6 (Zipareacode); Population- 39,594; White Not Hispanic-36.6%; Hispanic-48.7%; Black- 13.3%; Median Household Income-\$38,771; Persons Below Poverty Level-23.8% (US Census Bureau QuickFacts 2009)

**Labelle, 33935:** Population-18,336; White-12,584; Black-935; Hispanic-8,293; Average Income-\$33,049; Median Age Female-32.0  
Low average income with high Hispanic population(\*\*)

**Clewiston, 33440:** Population-15,939; White-11,572; Black-4,024; Hispanic-6,488; Average Income-\$33,290; Median Age Female-31.1  
County median age is significantly lower than the Affiliate area. Low average income

**Glades County:** Female Median Age-41.9 (Zipareacode); Population-10,950; White Not Hispanic-64.7%; Hispanic- 17.9%; Black- 11.5%; Median Household Income-\$39,251; Persons Below Poverty Level- 21.8% (US Census Bureau QuickFacts 2009)

**Moore Haven, 33471:** Population-5,700; White-4,144; Black-1,084; Hispanic-755; Average Income-\$29,819; Median Age Female-41.6  
Low average income

(\*\*)National findings from the American Cancer Society indicate that breast cancer is less likely to be diagnosed at the earliest stage in Hispanic women compared to non-Hispanic white women even after differences in age, socioeconomic status, and method of detection are controlled

(Figure 1).<sup>11</sup> For example, during the period 2002-2006, 55% of breast cancers among Hispanic women were diagnosed at the local stage, compared to 63% of cases among non-Hispanic white women. Hispanic women are also more likely to be diagnosed with larger breast tumors than non-Hispanic white women.<sup>12, 13</sup> Differences in mammography utilization and delayed follow-up of abnormal screening results may contribute to this difference.<sup>14, 15</sup> Hispanic women are about 20% more likely to die of breast cancer than non-Hispanic white women diagnosed at a similar age and stage.<sup>16</sup> Differences in access to care and treatment likely contribute to this disparity.<sup>17, 18</sup> Intervention programs that follow patients throughout treatment in order to enhance communication between the surgeon, oncologist, and patient have been shown to reduce disparities in breast cancer care.<sup>19</sup>

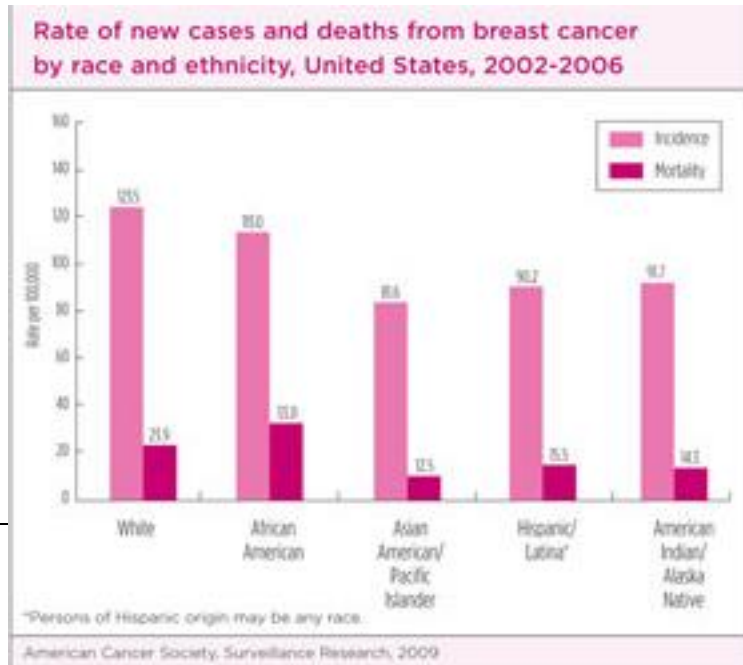


Figure 1. American Cancer Society Cancer Facts and Figures for Hispanics/Latinos 2009-2011

<sup>11</sup> Risendal B, Hines LM, Sweeney C, et al. Family history and age at onset of breast cancer in Hispanic and non-Hispanic white women. *Cancer Causes Control*. Dec 2008;19(10):1349- 1355.

<sup>12</sup> Lantz PM, Mujahid M, Schwartz K, et al. The influence of race, ethnicity, and individual socioeconomic factors on breast cancer stage at diagnosis. *Am J Public Health*. Dec 2006; 96(12):2173-2178.

<sup>13</sup> Surveillance, Epidemiology, and End Results (SEER) Program ([www.seer.cancer.gov](http://www.seer.cancer.gov)) SEER\*Stat Database: Incidence - SEER 17 Regs Public-Use, Nov 2008 Sub (2000-2006) - Linked To County Attributes - Total U.S., 1969-2006 Counties, National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2009, based on the November 2008 submission.

<sup>14</sup> Miller BA, Hankey BF, Thomas TL. Impact of sociodemographic factors, hormone receptor status, and tumor grade on ethnic differences in tumor stage and size for breast cancer in US women. *Am J Epidemiol*. Mar 15 2002; 155(6):534-545.

<sup>15</sup> American Cancer Society. *Cancer Prevention & Early Detection Facts & Figures 2009*. Atlanta, GA: American Cancer Society; 2009

<sup>16</sup> Press R, Carrasquillo O, Sciacca RR, Giardina EG. Racial/ethnic disparities in time to follow-up after an abnormal mammogram. *J Womens Health (Larchmt)*. Jul-Aug 2008; 17(6):923-930

<sup>17</sup> Jemal A, Clegg LX, Ward E, et al. Annual report to the nation on the status of cancer, 1975-2001, with a special feature regarding survival. *Cancer*. Jul 1 2004; 101(1):3-27.

<sup>18</sup> Ward E, Halpern M, Schrag N, et al. Association of insurance with cancer care utilization and outcomes. *CA Cancer J Clin*. Jan- Feb 2008; 58(1):9-31

<sup>19</sup> Freedman RA, He Y, Winer EP, Keating NL. Trends in racial and age disparities in definitive local therapy of early-stage breast cancer. *J Clin Oncol*. Feb 10 2009; 27(5):713-719.

**Lee County:** Female Median Age-46.9 (zipareacode.com); Population- 586,908; White Not Hispanic-72.6%; Hispanic-17.4%; Black-8.1%; Median Household Income- \$50,863; Persons Below Poverty Level 10.6% (US Census Bureau QuickFacts 2009)

**St. James City, 33956:** Population-5,376; White-4,039; Black-4; Hispanic-31; Average Income-\$35,746; Median Age Female-62.6  
Median age significantly higher than county. Low average income

**Lehigh Acres, 33936:** Population-21,928; White-13,786; Black-1,345; Hispanic-2,518; Average Income-\$33,276; Median Female Age-44.2  
Low average income

**Ft. Myers, 33916 (Dunbar):** Population- 20,034; White-5,752; Black-11,929; Hispanic-3,474; Average Income- \$24,050; Median Female Age- 28.3  
Median Age significantly lower than county. Low average income. Black population significantly higher than county, region and state.

**North Ft. Myers, 33917:** Population-34,141; White-27,770; Black-119; Hispanic-803; Average Income-\$33,120; Median Female Age-54.2  
Median age significantly higher than county. Low average income

**North Ft. Myers, 33903:** Population-23,107; White-21,902; Black-356; Hispanic-1,098; Average Income-\$33,946; Median Female Age-60.2  
Median Age significantly higher than county, region and state. Low average income

## **Conclusion**

The communities of greatest need based on the statistics gathered are Punta Gorda, Naples (zip codes 34102), North Ft. Myers and Saint James City where the median age for females is significantly higher than the rest of the county and state. According to the American Cancer Society Breast Cancer Facts and Figures 2007-8, your chance of getting breast cancer is 1 in 40 by age 50, 1 in 28 by age 60, and 1 in 26 by age 70. Therefore, these communities would be more likely to have higher incidences and mortality rates as age is a major factor in a woman's chance of getting breast cancer. Immokalee, LaBelle, Clewiston, Moore Haven, St. James City, Lehigh Acres, and North Ft. Myers have a low average income compared to the county and state thus would be more likely to not have insurance or be able to afford health care costs. Immokalee and LaBelle also have a high Hispanic population compared to the county and state leading to a higher risk of mortality. Ft. Myers (Dunbar) has a high Black population, which may also lead to a higher risk of mortality.

# Health Systems Analysis of Target Communities

## Overview of Continuum of Care

### The Continuum of Care

The continuum of care is a model to ensure the most comprehensive and efficient services are provided to a patient from the point of entry into the medical system throughout the entire treatment for the disease and/or reentry into the system (Figure 2). It emphasizes the importance of continuous care and is a valuable tool throughout the health systems analysis. The goal is that once an individual enters the cycle, they will remain in the cycle to ensure a continuous progression of care at all levels. The continuum was used to help define and understand existing and needed partnerships, advocacy efforts needed and legislator priorities. The gaps in service, barriers to care, and issues presented at each phase of the continuum will be included in the analysis of the target communities. By using this model, gaps in service and barriers to care can be identified and remedied, so the cycle may continue. Barriers to the initial screening include lack of information, lack of funds, time constraints, fear, lack of transportation, language barriers and cultural and religious beliefs. Once an abnormal screening is found, these same barriers reappear again for many women and men which prevent them from proceeding forward in the continuum of care to pursue further medical care and treatment.

The continuum was also used to create the questionnaire for data collection and help organize the data collected. The following questions were included in the surveys and focus groups:

- What outreach is taking place?
- How do we know that outreach efforts are effective?
- Who refers women to screening?
- What barriers to care are encountered at different phases of the continuum?
- Have you heard of Susan G. Komen for the Cure? What do they do?

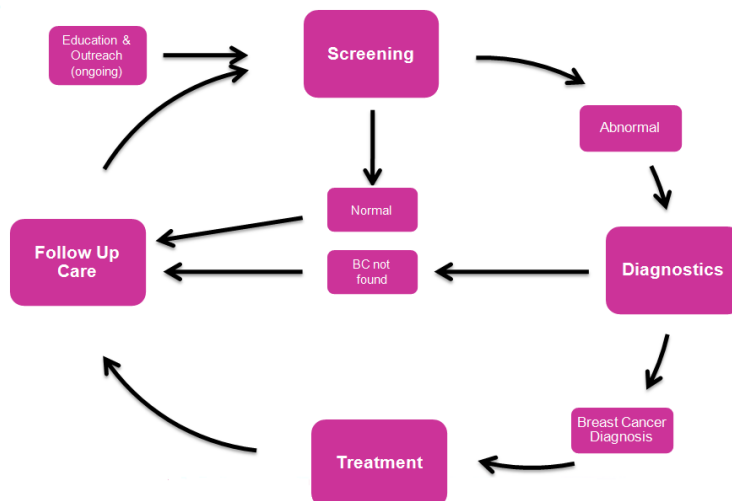


Figure 2. Continuum of Care Chart, Denver Affiliate Susan G Komen for the Cure

## Methodology

The expertise and experience of key individuals and health care providers within our five county Affiliate area is important in helping us assess the needs of our community. Therefore, over 500 confidential surveys and twelve health care provider surveys were collected. In addition, five focus groups from various geographic and socio-economic areas were conducted to help us better understand and evaluate our needs.

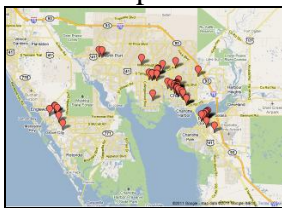
A class of Occupational Therapy graduate students from Florida Gulf Coast University was utilized to gather input and design an asset map for each county in the affiliate region. They were able to develop a Google map of each county that includes all resources that might be needed during any phase of the continuum of care, their contact information, a general description of the services they offer, and directions to their site.

Key informants were selected from participants at our semi-annual breast health forum held in November 2010. These participants included our eleven grantees and several additional health care providers from our affiliate area.

## Overview of Community Assets

### Charlotte County Resources

Link to map-



[http://maps.google.com/maps/ms?source=s\\_q&gl=us&hl=en&g=2343+Aaron+St,+Port+Charlotte,+FL+33952-5305&ie=UTF8&vps=1&jsv=289a&oe=UTF8&msa=0&msid=112711461089163126735.00049287e307a1f2bf64f](http://maps.google.com/maps/ms?source=s_q&gl=us&hl=en&g=2343+Aaron+St,+Port+Charlotte,+FL+33952-5305&ie=UTF8&vps=1&jsv=289a&oe=UTF8&msa=0&msid=112711461089163126735.00049287e307a1f2bf64f)

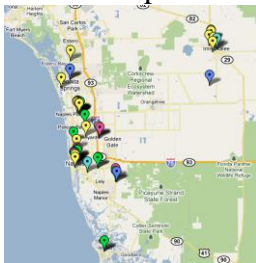
This map provides a list of services for breast cancer screening, diagnosis, treatment, rehabilitation and any other service needed in the continuum of care for breast cancer. General surgeons, diagnostic radiology/MRI services, medical oncology, family practice clinics, OB/GYN clinics, hospital/surgery centers, mammography centers, chemotherapy and radiation treatment centers, lymphedema specialists, mastectomy prosthesis stores, public transportation and support groups are included.

Grantees: *Health Centers of Southwest Florida, Inc* : Provides education and assessment services aimed at early detection of breast cancer in women from low-income, African-American and Hispanic communities; *Lymphedema Resources, Inc.*: Funds education, outreach, and treatment for uninsured/underinsured breast cancer survivors at risk of developing lymphedema

and those already coping with this affliction. Financial assistance for physician prescribed lymphedema therapy and compression garments is provided to qualified clients; *Manatee County Health Department* :Provides mammograms, diagnostics and follow-up to underinsured women under 50 too young to qualify for the Florida Breast and Cervical Cancer Program (FBCCP). Assists with screening and diagnostics for FBCCP-enrolled women (50-64) in the 5-county region. Project participants diagnosed with cancer will be assisted to obtain treatment; *Virginia B. Andes Volunteer Community Clinic* :Funds low income, uninsured women for preventive mammogram screenings and quality diagnostic testing for women with abnormal screening results.

### Collier County Resources

Link to map-



<http://maps.google.com/maps/ms?hl=en&ie=UTF8&vps=1&jsv=289a&oe=UTF8&msa=0&msid=100561427528652236940.000490ddc201f66a4d90c>

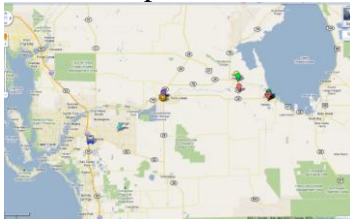
Services for breast cancer diagnosis, treatment rehabilitation and screening are predominantly in Naples, with few services and facilities in Immokalee and eastern Collier County. The map is a strong visual indicator of the disparity in locations within the county. All seven oncologists are located in Naples. The Collier County Health Department operates out of Naples, but also has an office in Immokalee and a mobile unit that provides services in Golden Gate and Immokalee to women and infants in need. Of the 21 health centers in the county, only three are located in Immokalee which can provide some health services. Of the 13 radiology facilities, none are located in Immokalee. There is a public library location in Immokalee which is an information resource for Health Department events, screenings and is a location for residents there to research assistance.

Grantees: *CHS Healthcare - Marion E. Fether*: Funds breast care education, screening, diagnostic procedures and transportation for predominately uninsured/underinsured, low income, rural minority women for whom no other funding is available. A Breast Health Educator will educate women of the importance of proper breast health; assist patients in scheduling routine breast exams, mammograms and diagnostic procedures. Transportation provided for patients for breast care appointments; *L.I.G.H.T. of SW FL: Uninterrupted Breast Cancer Care*: Their goal is to ensure that the patient has uninterrupted cancer treatment by providing funds to pay high cost of deductibles, co-pays, coinsurance and/or insurance premiums. Approved applicants may then submit their bills to LIGHT for payment, allowing them to continue or begin their treatment; *Lee Memorial Health System/Regional Cancer* : Provides under/uninsured, low income individuals diagnosed with breast cancer access to diagnostic and staging procedures, treatment, genetic

screening, stipends, psychosocial support, and education. A Breast Health Navigator works with other organizations and physicians to identify those in need of services and to remove care barriers; *Lymphedema Resources, Inc.*: Funds education, outreach, and treatment for uninsured/underinsured breast cancer survivors at risk of developing lymphedema and those already coping with this affliction. Financial assistance for physician prescribed lymphedema therapy and compression garments is provided to qualified clients; *Manatee County Health Department* :Provides mammograms, diagnostics and follow-up to underinsured women under 50 too young to qualify for the Florida Breast and Cervical Cancer Program (FBCCP). Assists with screening and diagnostics for FBCCP-enrolled women (50-64) in the 5-county region. Project participants diagnosed with cancer will be assisted to obtain treatment; *NCH Healthcare System*: A Breast Health Navigator, guides patients through the complex healthcare system, advocates for financial aid to reduce treatment barriers, assists in arranging screening and diagnostic services and ensures follow-up care, as well as helps with appropriate social services and local resources for support; *Neighborhood Health Clinic, Inc*: Provides health care for the working low income and uninsured adults of Collier County using a volunteer professional staff and funded by private philanthropy. They provide breast health to all female Clinic patients by giving them self-breast exam instruction. As needed they receive a clinical exam by a physician; screening mammograms; diagnostic procedures; surgery; and treatment.

### Glades County Resources

Link to map-



<http://maps.google.com/maps/ms?hl=en&ie=UTF8&oe=UTF8&msa=0&msid=100508089831544619503.000490dd85c0e7e402c0b>

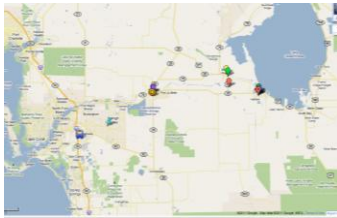
The Glades County Health Department opened its doors on January 21, 2011. Although this is a very positive step, the building is located a mile out of town and transportation may be an issue for some patients. Prior to this, patients were referred to Hendry Regional Medical Center or Lehigh Regional Medical Center. The map is for the surrounding counties of Palm Beach, Highlands and Okeechobee as well as Glades County to assist in finding the closest center for the client. Many of the needed resources are closer to the South Florida Affiliate area than ours which poses some unique problems for both affiliates.

Grantees: *Lucy's Angels for Breast Cancer Care, Inc.*: Goal is to reach out and educate the underserved Hispanic and Black communities, as well as the younger population ages 18 to 50 on the importance of early detection and the assistance available for breast cancer and breast cancer screening; *Lymphedema Resources, Inc.*: Funds education, outreach, and treatment for uninsured/underinsured breast cancer survivors at risk of developing lymphedema and those already coping with this affliction. Financial assistance for physician prescribed lymphedema

therapy and compression garments is provided to qualified clients; *Manatee County Health Department* : Provides mammograms, diagnostics and follow-up to underinsured women under 50 too young to qualify for the Florida Breast and Cervical Cancer Program (FBCCP). Assists with screening and diagnostics for FBCCP-enrolled women (50-64) in the 5-county region. Project participants diagnosed with cancer will be assisted to obtain treatment.

## Hendry County Resources

Link to map-



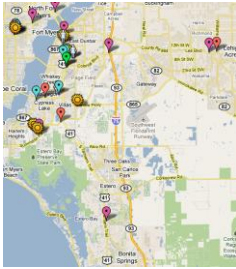
<http://maps.google.com/maps/ms?hl=en&ie=UTF8&oe=UTF8&msa=0&msid=100508089831544619503.000490dd85c0e7e402c0b>

Resources for individuals affected by breast cancer in Hendry County include hospitals, locations for screenings and diagnostics, medical centers, breast cancer societies and support groups. Transportation resources for this county are minimal.

**Grantees:** *Lucy's Angels for Breast Cancer Care, Inc.:* Goal is to reach out and educate the underserved Hispanic and Black communities, as well as the younger population ages 18 to 50 on the importance of early detection and the assistance available for breast cancer and breast cancer screening; *Lee Memorial Health System/Regional Cancer:* Provides under/uninsured, low income individuals diagnosed with breast cancer access to diagnostic and staging procedures, treatment, genetic screening, stipends, psychosocial support, and education. A Breast Health Navigator works with other organizations and physicians to identify those in need of services and to remove care barriers; *Lymphedema Resources, Inc.:* Funds education, outreach, and treatment for uninsured/underinsured breast cancer survivors at risk of developing lymphedema and those already coping with this affliction. Financial assistance for physician prescribed lymphedema therapy and compression garments is provided to qualified clients; *Manatee County Health Department* : Provides mammograms, diagnostics and follow-up to underinsured women under 50 too young to qualify for the Florida Breast and Cervical Cancer Program (FBCCP). Assists with screening and diagnostics for FBCCP-enrolled women (50-64) in the 5-county region. Project participants diagnosed with cancer will be assisted to obtain treatment.

## Lee County Resources

Link to map-



<http://maps.google.com/maps/ms?hl=en&ie=UTF8&msa=0&msid=103208542105360000520.000492bf1366d84827522&ll=26.530794,-81.795959&spn=0.269693,0.615921&z=11>

This map lists clinics, radiology centers, OB/GYN and breast cancer centers, financial resources and support groups to assist with treatment throughout the continuum of care. There was a notable lack of resources available in the Dunbar and Lehigh Acres area of the county.

**Grantees:** *Family Health Centers of Southwest Florida, Inc:* Provides education and assessment services aimed at early detection of breast cancer in women from low-income, African-American and Hispanic communities; *Lee Memorial Health System/Regional Cancer* Provides under/uninsured, low income individuals diagnosed with breast cancer access to diagnostic and staging procedures, treatment, genetic screening, stipends, psychosocial support, and education. A Breast Health Navigator works with other organizations and physicians to identify those in need of services and to remove care barriers; *L.I.G.H.T. of SWFL: Uninterrupted Breast Cancer Care:* Their goal is to ensure that the patient has uninterrupted cancer treatment by providing funds to pay high cost of deductibles, co-pays, coinsurance and/or insurance premiums.

Approved applicants may then submit their bills to LIGHT for payment, allowing them to continue or begin their treatment; *Lymphedema Resources, Inc.:* Funds education, outreach, and treatment for uninsured/underinsured breast cancer survivors at risk of developing lymphedema and those already coping with this affliction. Financial assistance for physician prescribed lymphedema therapy and compression garments is provided to qualified clients.; *Manatee County Health Department:* Provides mammograms, diagnostics and follow-up to underinsured women under 50 too young to qualify for the Florida Breast and Cervical Cancer Program (FBCCP). Assists with screening and diagnostics for FBCCP-enrolled women (50-64) in the five county region. Project participants diagnosed with cancer will be assisted to obtain treatment; *Partners for Breast Cancer Care:* The focus is to improve accessibility to breast healthcare including diagnostic testing, surgery and other breast cancer-related issues for both women and men. The services include case management, arranging physician office visits, mammograms, surgeries and payment for the diagnostic tests, physician fees and surgical fees.

As a result of the 2009 Community Profile, a committee was formed called the Gap Workgroup to prioritize and address the gaps in services in our Affiliate service area. This group will continue to function and address the priorities and objectives outlined as a result of the 2011 Community Profile.

The Florida Breast and Cervical Cancer Screening Program administered through the Manatee Health Department provides mammograms, diagnostics and follow up to underinsured women under 50 too young to qualify for FBCCSP in Charlotte, Glades and Hendry Counties. It assists with screening diagnostics for FBCCSP-enrolled women (50-64) in the five county region. Project participants diagnosed with cancer are assisted to obtain treatment. To be eligible for the Florida Breast and Cervical Cancer Screening Program the following conditions need to be met: Women age 50 over- Low-Income within 200 percent of poverty level, Does not have Medicaid or Medicare, Does not have insurance or underinsured. The Florida Breast and Cervical Cancer Screening Program provide women with a free examination from a qualified MD or ARNP. A breast exam, pelvic and pap smear is free of charge to all women who qualify. After the exam, the women are referred to an outside agency such as Manatee Diagnostic Center or Blake Outpatient Radiology for a screening or diagnostic mammogram. The clients are educated about breast and cervical health and the importance of their annual exams. Susan G. Komen for the Cure Southwest Florida grants additional funding to close the gaps. To be eligible for the **Susan G. Komen** Program the following conditions need to be met: Women ages 40-49, Low-Income within 200 percent of poverty level. Poverty level is defined by the Office of Management and Budget and updated for inflation using the Consumer Price Index. The weighted average poverty threshold for a family of four in 2009 was \$21,954.<sup>20</sup>

## **Legislative Issues**

The Komen Advocacy Alliance is actively involved in promoting and fighting for the Breast Cancer Bill of Rights. Even after the valuable patient protections in the new health reform law are fully phased in by 2014, there will be gaps in access to breast health services and issues of quality care. We promise to protect our newly acquired rights and keep fighting until the entire Breast Cancer Bill of Rights is enshrined in law and extended to all women. The Komen Advocacy Alliance also believes all women in the U.S. have a right to timely, affordable, high-quality breast health services. Komen will be supporting several pieces of legislation in the coming state session: one bill regarding oral chemotherapy and one bill concerning breast density. Increased education and access to screening associated with the risk and flaws of mammography for women with dense breasts is also a cause that the Komen Advocacy is actively supporting.

## **Key Informant Findings**

Fourteen surveys were completed by current and past Komen grantees, health clinics, and radiology centers in our Southwest Florida Affiliate area. This tool helped provide a snapshot of the breast health and breast cancer services available in our community. This information is important to build on to provide better health services for our citizens in the future. The following section is a synopsis of findings from the healthcare provider survey.

### **Breast Health Education.**

Women are most likely to go to the grantee agency, their private physician, Komen or the American Cancer Society for breast health information. All agencies offered educational

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<sup>20</sup> <http://www.census.gov/hhes/www/poverty/data/threshld/thresh09.html>

materials to their clients, the majority of which come from Komen, followed by the American Cancer Society, and the health department. There is a large non-English speaking population including Spanish, Creole, and German. Most agencies surveyed offered educational information in Spanish and also provided interpreters. The majority of agencies offered referrals if necessary to the following agencies- NDIC, Lee Cancer Care, Partners for Breast Cancer Care, and Radiology Regional. Half of the agencies said they would be interested in Komen offering breast health training to their staff and/or clients.

### **Screening and Diagnostic Services.**

The descriptions of women who are least likely to get regular screenings are low income or underinsured and low education. The biggest barriers preventing services were noted as money, lack of knowledge and fear, transportation, lack of time, culture, and religion also noted. Outreach to low income areas, mobile units, ability to fund undocumented women, patient education services, and financial aid were noted as ways to improve delivery of breast health services. All agencies surveyed provide adequate services to women with disabilities.

### **Financial Support.**

The majority of women paid for services through a Komen grant, followed by self-pay, and then private insurance, Medicaid, and Medicare. Uninsured women go to the hospital, one of our grantees, or Bosom Buddies for care. Most of the agencies surveyed offered financial assistance for uninsured or underinsured and low-income clients. Five offered Komen grants, two offered discounts and two offered payment plans.

### **Clinical Trials and Partnerships.**

The agencies had little knowledge of clinical trials and most said that they would be interested in more information. They also were interested in forming more partnerships to further provide needed breast health services and working with Komen on public policy initiatives.

### **Conclusions**

The previously identified target areas of Punta Gorda, North Ft. Myers, and St. James City in addition to having a high median age, also have the challenge of travelling to health systems resources that are not geographically located near them which may cause them to not enter the continuum of care in a timely manner or drop out of the continuum because of transportation issues. Immokalee, LaBelle, Clewiston, Moore Haven, Dunbar and Lehigh Acres residents are also at risk because of the geographic distances to needed resources combined with their average low income, thus making it difficult to access and pay for transportation. In addition, language barriers exist, especially in the target areas of Immokalee and LaBelle that may interfere with entrance into the continuum of care. The findings in this section corroborate that the target communities identified in the previous section based on mortality rates, late stage diagnosis, screening percentages, and insurance rates are on point and lead us to conducting focus groups and administering confidential surveys to further explore and qualify more details about the target areas we have selected.

# **Breast Cancer Perspectives in the Target Communities**

## **Methodology**

The expertise and experience of key individuals within our five county affiliate area is important in helping us assess the needs of our community. Therefore, over 500 confidential surveys were completed from the various geographic areas of our region. Surveys were distributed randomly through grantees, healthcare providers, health fairs and volunteers. In addition, five focus groups were conducted to help us better understand and evaluate our needs throughout the continuum of care. One focus group in Collier County concentrated on women over 60. One in LaBelle focused on our rural communities. One in Charlotte County focused on “snowbirds”, people residing both in our service area and in other states or countries. One in Dunbar focused on our low income, uninsured and underinsured residents and one in our Affiliate office focused on survivors. There were between eight to fifteen people in attendance at each group. The same facilitator and note taker were used for all sessions to maintain consistency. We went to groups that were already meeting and asked permission to hold the focus sessions as a part of their meeting. Snacks and refreshments were served at each group meeting.

## **Review of Qualitative Findings**

### **Confidential Breast Health Survey**

Over 500 confidential surveys were distributed and collected through our grantees and volunteers covering our five county region to give us important random information about breast health in our community.

The following section is a synopsis of the results.

Seventy one percent of those surveyed had received a mammogram in their lifetime. Fifty nine percent of those who had a mammogram had it within the last year, 5 percent were over two years and 6 percent were over three years. Twelve percent of those who had not received a mammogram were over the age of 40. Seventy one percent of those surveyed always had a yearly exam, 19 percent sometimes had a yearly exam and 8 percent had never had a yearly exam. Thirty percent of those surveyed had no health insurance coverage. Barriers to care that were cited were in rank order- money, lack of insurance, lack of time, painful exams, and worry about radiation.

### **Charlotte County- 40 surveys.**

Of those surveyed in Charlotte County 70 percent received mammograms. Seventy six percent always received their yearly exam, 22 percent sometimes, and 2 percent never. No insurance, lack of money and forgetting were given as reasons for not getting their screenings. Sixty three percent had insurance, 37 percent had no insurance. Fifty five percent had their mammogram in the last year, 12 percent never had one, and 5 percent were over two years ago, two percent were more than three years ago. In the target area of Punta Gorda (33980 zip) only two surveys were filled out. Both had mammograms within the last year and had insurance. Neither knew that 75 percent of the money raised locally stayed in the local region to assist with the continuum of care

for breast cancer and that 25 percent of the donations go to research to find a cure for breast cancer. This is a very small sample size so results should not be generalized to the entire population.

#### **Collier County-144 surveys.**

In Collier County 76 percent of those surveyed had received mammograms. Eighty four percent always had their yearly exam, 15 percent sometimes, and 5 percent never had a yearly exam. No insurance, no doctor, and no money were cited as reasons for not getting their mammograms. 88 percent had insurance, 12 percent did not have insurance. Fifty eight percent of those surveyed had their last mammogram within one year ago, 16 percent never had one, seven percent were over one year, two percent were over two years, and four percent were over three years. In the target area of Naples (34102 zip) six surveys were filled out. Two of the six had not received a mammogram; one was under 40 and the other between 30-40. All had insurance. In Immokalee (34142 zip) seven surveys were filled out. Two of the seven had no insurance. One in seven had not had a mammogram and three had been over one year ago. Four did not know about the 75/25 percent ratio. Because of the small sample size, these statistics are not reliable to generalize to the whole community.

#### **Glades County- 6 surveys.**

In Glades County, 50 percent of those surveyed had received mammograms. Thirty three percent had a mammogram in the last year and 17 percent had been over three years. Fifty percent never had a yearly exam, 33 percent always did, and 17 percent sometimes did. Reasons given were no insurance, no doctor, and don't like it. Five had insurance. Four did not know the 75/25 percent ratio. The six surveys were filled out in Moore Haven (33471 zip).

#### **Hendry County-25 surveys.**

Of those surveyed in Hendry County 50 percent had received mammograms. Thirty two percent had a mammogram in the last year, 36 percent never had one, 4 percent were over one year, 4 percent over three years ago. Forty eight percent always have a yearly exam, 26 percent sometimes did, and 16 percent never had one. Reasons cited were they forget, there was no access to services, no insurance, and no money. Seventy two percent had no insurance. Eight surveys were from Labelle (33935 zip). Two had mammograms. Two had insurance. Six did not know about the 75/25 percent ratio. Eleven surveys were from Clewiston (33440). Seven had mammograms, five within the last year. Nine had no insurance. Seven did not know the 75/25 percent ratio.

#### **Lee County-216 surveys.**

In Lee County, 75 percent had received mammograms. Fifty two percent had mammograms in the last year, six percent were over one year, six percent were over two years, and eight percent were over three years. Sixty seven percent always had yearly exams, 22 percent sometimes had them, and 8 percent never had them. Reasons cited were no insurance, no money, and forget. Fifty nine percent had insurance. Five surveys were gathered in Lehigh Acres (33936) Four had mammograms, three within the last year. Three had no insurance. Four did not know the 75/25 percent ratio. Ten surveys were from North Ft. Myers (33917). All had mammograms, six within the last year. Five had no insurance. Four did not know the 75/25 percent giving ratio.

After analyzing the data from the surveys received, focus groups were conducted to obtain more in-depth information from participants regarding the gaps in the continuum of care.

## **Focus Groups**

Five different focus groups of between eight to fifteen people each were held throughout our geographic area to capture more in depth information regarding the continuum of care. One group was all survivors, one group focused on the Latina population, one group focused on women over the age of 60, one group focused on the rural communities, and one was a group of snowbirds. The following themes emerged:

One of the general themes that played across all of the focus groups was the barriers to care that were cited in the surveys as well as the focus groups. Fear of diagnosis, lack of insurance, lack of funds, time constraints, and discomfort were all cited as reasons to not enter and follow through with the continuum of care. “I’m just lazy”, “I don’t think about it” and “It’s a pain in the ass” were given as reasons for not having annual screenings. In the rural communities language barriers (it was discovered that our region hosts seven different Spanish dialects), transportation issues, legal status (no identification), lack of education and lack of a support system were also cited frequently. In the Latina group one woman had been told by a receptionist in a doctor’s office “to go back to the country she came from”. Recent attention on immigration status has made many leery of seeking services if they are undocumented. In the 60 and older age group and the Latina group, stigmas about cancer and touching yourself emerged. In addition, age bias by physicians was mentioned in the 60 and over group as well as medical system bureaucracy and dual residencies with different healthcare providers and medical records locations.

Another theme that crossed all of the groups was their lack of information about Susan G. Komen for the Cure. In the coastal counties, most had heard of the organization, but could not articulate what we do. In the rural counties, more than half of participants had not heard of the organization despite some of them receiving services through our grants program.

During most of the focus groups the US Preventive Services Task Force recommendations for mammography crept into the conversation and there were mixed reviews as a result. Fear of radiation, although not shared by most in the groups, was voiced strongly by those who did have the fear. There was interesting discussion about self-exams due to Task Force recommendations and internet information. As a result some no longer do self-exams.

Another theme across all groups was the request for more information in multiple languages for all age groups starting in high school and located in multiple locations. Sending reminders for mammograms was also expressed often.

Survivors spoke strongly about the need for support (mental, physical, emotional, and spiritual) throughout the continuum of care for themselves and their families as well as afterward. The direct result is a partnership with the FGCU Occupational Therapy department to develop a

mentoring program. In addition, a support group was established for the first time in Labelle and it held its first meeting in December 2010.

Interesting discussion emerged about whether the private or public sector received better services. Those receiving private care thought public services were better because patients were viewed as dollar signs. Those receiving public care thought private were better because the patient developed a relationship with the provider. Two women had moved to rural Labelle from the urban east coast of Florida to receive better services in the rural area.

The need in the community far exceeds the resources that are available. With the downturn in the economy, the needs have grown since the 2009 Community Profile. Over 500 confidential surveys were distributed and collected through our grantees and volunteers covering our five county region to give us important random information about breast health in our community. In addition, five different focus groups of between eight to fifteen people each were held throughout our geographic area to capture deeper and richer information regarding the continuum of care.

## **Conclusion**

Three major themes evolved from the focus groups and random surveys regarding knowledge, access, and support. These areas were clearly identified as gaps in the continuum of care and are areas where intervention is needed.

**Knowledge-** Providing better breast health education for all age groups and for all ethnic groups was a strong message from participants. Language barriers are particular problems for our Latina residents. Many recognize the Komen name, but the mission is not readily known to most of the residents surveyed or interviewed. In the rural counties, more than half of participants had not heard of the organization despite some of them receiving services through our grants program. In the sixty and older age group and the Latina group stigmas about cancer and touching yourself emerged. During most of the focus groups the US Preventive Services Task Force recommendations for mammography crept into the conversation and there were mixed reviews as a result. Fear of radiation, although not shared by most in the groups, was voiced strongly by those who did have the fear. There was interesting discussion about self-exams due to Task Force recommendations and internet information. As a result some no longer do self-exams.

**Access-** Fear of diagnosis, lack of insurance, lack of funds, time constraints, and discomfort were all cited as reasons to not enter and/or follow through with the continuum of care. In the rural communities, language barriers (it was discovered that our region hosts seven different Spanish dialects), transportation issues, legal status (no identification) were also cited frequently. Language barriers, fear, and lack of documentation are particular problems for our Latina residents. In addition, age bias by physicians was mentioned in the sixty and over group as well as medical system bureaucracy and dual residencies with different healthcare providers and medical records locations. Sending reminders for mammograms was expressed often.

**Support-** The need for continuous support throughout the continuum of care for both the patient and their families was a recurring theme. Survivors spoke strongly about the need for support (mental, physical, emotional, and spiritual) throughout the continuum of care for themselves and their families as well as the need for post treatment support.

These major themes could serve as possible explanations as to why the mortality rates in the target zip codes are so high. This section continues to support the need in the target areas identified in each of the previous sections.

## **Conclusions: What We Learned, What Will We Do**

### **Review of Findings**

Breast cancer projections determined the target areas of Punta Gorda, Naples, Immokalee, Clewiston, Moore Haven, LaBelle, Ft. Myers, Lehigh Acres and North Ft. Myers. These locations were selected because they were high in two of the following areas- mortality rate, percentage of late stage diagnosis, percentage of uninsured females, or percentage of no mammography. Our health systems analysis identified the disparity in where health services are located versus the locations of greatest need. Gaps in the continuum of care were identified by key informants in the areas of education, screening and diagnostic services and financial support. Surveys and focus groups revealed three major gaps in the continuum of care in the areas of knowledge, access and support. These major themes could serve as possible explanations as to why the mortality rates in the target zip codes are so high.

Each of the previous sections continue to support the need in the target areas identified. They also point out the need for continuous support throughout the continuum of care for both the patient and their families. The need in the community far exceeds the resources that are available. With the downturn in the economy, the need seems to have grown since the 2009 Community Profile. Better education for all age groups and for all ethnic groups was a strong message. Language barriers, fear, and lack of documentation are particular problems for our Latina residents. Many recognize the Komen name, but the mission is not readily known to most of the residents surveyed or interviewed.

### **Conclusions**

Based on our quantitative data and corroborated by our qualitative findings several areas of need came to the surface to help us better bridge the gaps in the continuum of care. Those needs include expanding outreach to our Hispanic communities, expanding outreach in the rural areas of Collier, Glades and Hendry Counties; marketing the Susan G. Komen message better to our constituents; developing a better support system after diagnosis of breast cancer; and connecting our need for services to our fundraising efforts.

The Southwest Florida Affiliate has established the following priorities and proposes the following action plan to address the needs in closing the gaps in the continuum of care for our Affiliate area. These priorities are intended to assist us in the distribution of grant funds, focus our public policy initiatives, target our outreach and education efforts, develop partnership opportunities and coordinate marketing and fundraising efforts.

## **Action Plan**

### **Priorities**

#### **1. Expand Outreach to Hispanic Communities**

##### **Recommendations:**

- A. Join two Hispanic agencies in Immokalee and Labelle to build leadership capacity in the community by December 2011.
- B. Translate affiliate brochure and all breast education materials into Spanish by December 2011.
- C. Recruit a minimum of five new Hispanic volunteers to be part of our volunteer committees by December 2011.
- D. Articulate partnership with the Redlands Christian Migrant Association in Immokalee and Labelle by December 2011.
- E. Articulate partnership with the Guadalupe Center in Immokalee by August 2011.

#### **2. Market Susan G. Komen message more effectively**

##### **Recommendations:**

- A. Hold at least one focus group in each county in 2011 and 2012.
- B. Schedule two Speaker's Bureau presentations in Glades County by December, 2011.
- C. Schedule two Speaker's Bureau presentations in Hendry County by December, 2011.
- D. Increase pool of speakers for Speaker's Bureau to 10 including 3 bilingual speakers by March 2012.
- E. Continue with Gap Workgroup meetings the first Wednesday of each month to target and close gaps in communication with the community.

#### **3. Develop a better support system after diagnosis**

##### **Recommendations:**

- A. Articulate a partnership with FGCU Occupational Therapy graduate students to pilot a mentoring program with survivors in the fall of 2011.

- B. Launch a survivor mentoring program with FGCU Occupational Therapy graduate students by January 2012.
- C. Develop a lay breast health navigator system to augment services to those identified in need by June 2012.
- D. Continue to monitor and increase attendance by 10% in support group in Labelle by March 2012.
- E. Start a support group in Clewiston by March 2012.
- F. Start a support group in Moore Haven by March 2012.
- G. Negotiate a minimum of one new contract for Project Hope Initiative with health care providers in Glades and Hendry Counties by December 2011.

**4. Actively pursue outreach in targeted zipcodes**

**Recommendations:**

- A. Attend at least one health fair each year in each of the following zipcodes- 33980 (Punta Gorda); 34102 (Naples); 34113(East Naples); 34142 (Immokalee); 33935(Labelle); 33440(Clewiston); 33471(Moore Haven); 33956 (St. James City); 33936 (Lehigh Acres); 33916 (Dunbar); 33917 and 33903 (N. Ft. Myers).
- B. Schedule mobile mammography unit for two events in Immokalee, Moore Haven and Clewiston by March 2012.
- C. Develop a satellite volunteer base in Immokalee by March 2012.
- D. Develop a satellite volunteer base in Glades County by March 2012.
- E. Develop a satellite volunteer base in Hendry County by March 2012.