



COMMUNITY PROFILE REPORT

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Disclaimer:

The information in this Community Profile Report is based on the work of the South 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.

Table of Contents

Executive Summary	1
Demographics and Statistics Review	1
Health Systems Analysis.....	3
Qualitative Data Overview	4
Conclusions: What We Learned, What We Will Do	5
Introduction	9
Affiliate History	9
Organizational Structure	10
Purpose of the Report.....	12
The Service Area.....	13
Demographics and Statistics	15
Process for Designating Target Areas.....	15
Target Areas Profiles	
The Glades	17
I95 Corridor	18
SW Seniors.....	19
Indiantown	19
Ft. Pierce	20
Populations of Primary Interest	21
African Americans	21
Hispanic/Latina.....	22
Ashkenazi Jews.....	23
Health Systems Analysis of Target Communities	24
Methodology	24
Overview of Target Area Assets.....	24
Health Systems Analysis Maps.....	29
Breast Cancer Perspectives in the Target Communities	30
Online Survey	30
Key Informant Interviews	31
Thomson Reuters Data.....	31
Lessons Learned.....	33
Conclusions: What We Learned, What We Will Do	34
Problem/Need #1: Diversity	34
Problem/Need #2: Advocacy	34
Problem/Need #3: Service Initiatives	35
Problem/Need #4: Financial and Human Resource Development	36
Problem/Need #5: Strategic Planning.....	37
Resources	38

Executive Summary

The purpose of the 2011 Community Profile is to provide current and comprehensive information on the status of breast health and breast cancer, and the delivery of related services in the three counties comprising the service area of the South Florida Affiliate of Susan G. Komen for the Cure® - Palm Beach, Martin and St. Lucie.

Komen for the Cure® is the world's largest grassroots network of breast cancer survivors and activists fighting to save lives, empower people, ensure quality care for all and energize science to find the cures.

Komen has more than 120 Affiliates in cities and communities around the globe. Six are located in the State of Florida, covering only 31 of 67 counties, but encompassing approximately 85% of the population.

Over the past ten years, the Affiliate has awarded grants totaling over \$13 Million for breast cancer screening, biopsies, treatment, and community education, as well as cutting-edge research. In 2010-11, \$1,740,294 was disbursed for these purposes. The Komen South Florida Race for the Cure® is the signature event of the Affiliate, held annually the last Saturday in January.

The Community Profile is a process of gathering information and assigning priorities that Affiliates complete every two years in order to understand the state of breast health and breast cancer in their service area and act upon it.

The process involves three stages – a Quantitative Phase of understanding demographic and breast cancer statistics; Health Systems Analysis in relationship to the continuum of care; and a Qualitative Data Phase of key informant interviews and surveys. These lead to a formulation of problems/needs, priorities, and objectives/action steps.

The priorities are intended to inform the work of the entire affiliate, including:

- Distribution of grant funds
- Public Policy Initiatives
- Outreach and education efforts
- Marketing and fund raising efforts
- Partnership needs/opportunities

The document presented here is the work of a dedicated committee of 15, and the time and effort of volunteers, staff, expert advisors and graduate students.

Demographics and Statistics Review

Our counties are very diverse, and each has areas of urban, suburban, and rural/agricultural life. We first reviewed actual demographic and breast health/breast cancer statistics that are available on a county-wide basis gathered from the U.S. Census Bureau, State Cancer Profiles (National Cancer Institute), and Florida Charts (Florida Department of Health).

Palm Beach County is by far the largest of the three counties, the third largest in population and second largest in land area in the State of Florida. Palm Beach County is the most densely populated and urbanized, yet nearly 550,000 people live in the unincorporated western portion of the county. Palm Beach County has the highest percentage of females, foreign born, language other than English spoken at home, education levels, and Hispanic population. Its median age and population percentage age 65+ rank it second among the three, but significantly higher than the State of Florida and the United States. Although the wealthiest county in the State in terms of Median Household Income, Palm Beach is a study of contrasts with wealthy coastal towns (e.g. Palm Beach, Manalapan) and poor agricultural communities in the far west (i.e. The Glades communities) adjacent to Lake Okeechobee.

Martin County is the smallest of the three counties and the least densely populated. It has the highest senior adult population and median age. Its White population percentage is extremely high, with minorities significantly lower than in the other counties. Median household income is high, approaching that of PBC, while families and individuals below the poverty level are relatively low. As deduced from the foregoing, there is significant number of retirees and retirement communities in the County.

St. Lucie County is the fastest growing of the three counties, far outpacing the others and the State of Florida. It has the youngest of the populations and the highest percentage of Black population. Its resident educational levels are the lowest and its population the poorest overall, even lower and poorer than found in the State of Florida.

In regard to breast health/breast cancer, Palm Beach County has the highest incidence and mortality rate of the three. However, rates of Clinical Breast Examinations and Mammograms appear to be falling over the latest three year period for which data is available in Martin and St. Lucie counties across the board in terms of race/ethnicity, age groups, educational levels and income brackets, while rising in Palm Beach County.

The South Florida Affiliate, unlike some other affiliates with scores of counties in their area, serves only three counties. As such, it cannot designate a single county or two as target areas. It must therefore look to pinpoint target areas within all three counties upon which to focus its attention. While everyone is important in our service area, great care was taken to delineate target areas using a combination of demographic and breast cancer statistics specially compiled and obtained from the Thomson Reuters healthcare information company, and supplemented by socioeconomic data and local studies. They “call out” for attention and service.

Five target areas were thus selected, zip codes noted and named.

- Three in Palm Beach County:
 - **The Glades** (33430, 33438, 33476, 33493)
 - **I95 Corridor** (33401, 33403, 33404, 33405, 33406, 33407, 33415, 33435, 33444, 33460, 33461)
 - **SW Seniors** (33434, 33437, 33446, 33484)
- One in Martin County
 - **Indiantown** (34956)

- One in St. Lucie County
- **Ft. Pierce** (34946, 34947, 34950)

This is not to say that there are not other zip codes close by that could have been included in the target areas. They may exhibit similar characteristics, but to a slightly lesser degree. Not everyone can officially be included in a target area, so as not diminish the meaning of the term. Programmatic efforts to reach target areas will, in most cases, spread beyond them to the benefit of other zip codes. The subsequent Community Profile comprehensive research confirmed that these five target areas were well chosen.

These five target areas are not new to the South Florida Affiliate. They have been of interest for some time, but were more carefully defined and comprehensively researched in this Community Profile. They have been, and will continue to be the focus of grant funding and educational efforts. Four of these target areas (the exception being SW Seniors) were, in general, high in minority female population; income below the poverty level; uninsured females; and late stage cancer diagnosis. By contrast the defining characteristics for SW Seniors were high numbers and percentages of females age 65+, as well as breast cancer incidence and mortality rates.

Populations of primary interest contained within these target areas are African Americans, Hispanics/Latinas, and Ashkenazi Jews.

Health Systems Analysis

The Health Systems Analysis is an effort to understand gaps, needs and limitations in the health system that affect a woman's transition through the continuum of care (education, screening, diagnosis, treatment, follow-up care and survivorship).

The Health Systems Analysis phase was accomplished through six tools/approaches:

- Key informant interviews with 15 community leaders and providers in the breast health field.
- A provider survey distributed via Survey Monkey to agencies and organizations of various types who impact on breast health and breast cancer in the community, asking them to delineate their services.
- A thorough review of the Breast Health Coalition Directory of Services for Martin and St. Lucie Counties. (A similar directory does not exist in Palm Beach County)
- Review of grant applications recently submitted to the Affiliate for funding consideration. These are rich in knowledge of the services provided by the applicant, as well as cooperative activity in the community.
- Review of agency and organizational websites to further understand their services.
- Mapping of resources utilizing Market Expert. The target areas are color coded in the full report.

Each target area presents a distinct picture, and the map displays the various types of resources available in each area.

In sum, while each target area is unique both in population and services offered, there were several recurrent themes that evolved that spoke to the formulation of specific action steps recommended in the Conclusion section of this report:

- Insufficiency in regard to continuum of care services
- Isolation for some (both geographic and economic) and the need for better transportation services
- Lack of services for the undocumented
- Need for empowerment of local communities
- Education for senior adult females that differs in content from the general female population
- Need for additional non-traditional partnerships to enable service delivery
- More comprehensive information provided by directories and coalitions of professionals

Qualitative Data Overview

Several different approaches were utilized in this phase with varying degrees of success:

- Online Survey
- Key informant interviews (were a part of HSA and this section)
- Thomson Reuters data, principally through Household Targeter and Health Status Profiler

Nonetheless, they yielded important information regarding peoples' attitudes, opinions, beliefs and behaviors, providing the community perspective as to what is working, what isn't and the various barriers that lead to gaps in access and services. They are an "eye opener" and suggest that even further research needs to be undertaken. The Thomson Reuters programs have significantly more information to offer, and partnerships need to be strengthened with local universities to provide the expertise and people power for surveys and focus groups.

It is further noteworthy that our providers and key informers do not appear to be heavily engaged in advocacy. In most cases, they are unable to spare the time from their service provision work. That responsibility will fall to the Komen South Florida Affiliate.

We also learned lessons that will serve us well in future Community Profile efforts:

- The use of Survey Monkey as a tool is a turnoff to some members of the African American community. The word "monkey" is viewed as a derogatory term. While we do not know exactly how many people this influenced, we would use a different online survey company next time.
- Online surveys will not reach people without computers, or for whom we do not have an email address. A post survey analysis revealed that our strength in email addresses lies in places outside our target areas - Jupiter, Palm Beach Gardens, Wellington, and western Lake Worth.
- We received weak responses from those racial/ethnic groups without strong connection to the Affiliate. Our experts tell us that they hesitate to participate in research unless it is clear that they will benefit from it.
- Graduate student interns with busy schedules and based far from the Affiliate area cannot be relied upon as the core staff to accomplish focus groups.

Conclusions: What We Learned, What We Will Do

This the most important section in the report. What follows is an abbreviated version. Full elaboration on these conclusions and time targets appear in the body of the report.

Problem/Need #1: Diversity

The South Florida Affiliate of Susan G. Komen for the Cure is “perceived as a white, middle/upper class organization”. Perception is reality for those doing the viewing, and every indicator shows that the perception of us is right on target.

Priority: In word and deed to change the identity of the South Florida Affiliate to make it more truly representative of the populations we serve. If we are going “to talk the talk, we must walk the walk”.

Objectives/Action Steps:

- A. Strengthen efforts to recruit and place minority individuals in positions of responsibility and visibility within the Affiliate.
- B. Solicit vendor bidding from qualified minority contractors located in our service area, particularly those based in our target areas.
- C. Replicate educational events like this year’s luncheon (focused on the Black Community) for other racial and ethnic groups in our service area.
- D. Fund and utilize model of community empowerment in an effort to outreach, educate, and service minority communities in our target areas.
- E. Reevaluate resources budgeted for “Focus for the Cure” to determine whether the medically underserved are benefitting from this program.

Problem/Need #2: Advocacy

“The burden is too great; we cannot do it alone”. In these times of economic scarcity and cuts in state budgets, the challenges become even greater. Komen has no presence in 36 of 67 counties, or in the State Capital of Tallahassee. The Florida affiliates are in the fledgling state of joint advocacy efforts. In Palm Beach County we are not participants in the Breast and Cervical Cancer Early Detection Program because no site is located within our boundaries or even close.

Priority: Expand capacity to influence government priorities, policies and funding. Focus in on most important issues of the day recognizing that they will change from year to year.

Objectives/Action Steps:

- A. Continue to take a leadership role in the development of the Florida Advocacy Alliance of Susan G. Komen for the Cure.
- B. In concert with other affiliates, outreach to legislators in all areas of the State.
- C. Support the continued funding for BCCEDP for the State of Florida.
- D. Support Breast Cancer Bill of Rights initiative of the Advocacy Alliance of Komen national.
- E. Investigate a non-legislative solution requiring physicians to speak to their patients about breast density, so that women are made aware of their risk, and their options for moving forward.

- F. Continue to partner with other cancer organizations in urging support of legislation requiring insurance plans to provide coverage for oral cancer drugs on a basis that is no less favorable than intravenously-administered chemotherapy.
- G. Promote County transportation plans that will enable the poorest of our clients to reach breast health and breast cancer services.

Problem/Need #3: Service Initiatives

As we would expect, no service system is perfect. “There are gaps that need to be plugged.” It varies from target area to target area, and covers the continuum of care model categories of education, screening, diagnosis, treatment, follow-up care and survivorship.

Priority: Plug at least one hole in each target area, and address three needs in the broader service area.

Objectives/Action Steps:

- A. In the Glades, facilitate the execution of a partnership between Lakeside Medical Center and Palms West Hospital for services, beyond screenings, so as to alleviate the extremely long trip to Boca Raton Regional Hospital. Once established, a navigator should be put in place.
- B. In the I95 Corridor, utilize the community empowerment model to organize and train local volunteers in pursuit of increased education, screening, support groups and other services through established churches, organizations and other entities in the area.
- C. Provide educational programs in the SW Seniors target area on the need for continued screening beyond menopause. The benefits of BRCA gene testing also need to be explained for the patient, as well as educating in regard to the implications for family members.
- D. Provide a grant to the Martin County Department of Health for screening of the undocumented in Indiantown.
- E. Provide breast health and referrals by partnering with churches and community organizations in the Ft. Pierce Area.
- F. Create directory of breast health and breast cancer services for Palm Beach County.
- G. Foster new coalitions of breast health providers and practitioners in Palm Beach County, and continue to support the existing ones in Martin and St. Lucie Counties.
- H. Continue to provide education/networking sessions for all grantees where the objectives will be to understand what each grantee does, to collaborate, and to encourage them to help recipients understand Komen’s funding role in the provision of services.

Problem/Need #4: Financial and Human Resource Development

“We have so much to do, and so little money to do it with”. When we show the State our willingness to “step it up”, they too will be further motivated. And to make this happen, we have only one resource – people – who will be our volunteers and donors in this effort. We, and many other charities, are not taking full advantage of the tax laws of the United States in regard to philanthropic giving. In the past couple of years, we have lost some donors, and efforts must be mounted to recapture them.

Priority: Increase the funds available to the Affiliate that will enable us to increase the breast health and breast cancer services afforded to our population.

Objectives/Action Steps:

- A. The Board should revisit and reconfirm its obligation to raise funds and ensure that adequate funds are secured to support the Affiliate's services and programs. It should examine various strategies, agreeing upon and implementing those approaches that will likely prove most successful.
- B. Utilize Market Expert to identify households with highest propensity to give to health care organizations. Create a fund raising plan that includes a direct mail campaign, individual solicitation for major gifts, and additional events targeted to high prospect donors.
- C. Create a comprehensive Affiliate planned giving program to maximize long term benefit from the gifts of our large senior population.
- D. Communicate the advantages of the Tax Relief, Unemployment Insurance Reauthorization, and Job Creation Act of 2010 allowing taxpayers over the age of 70 ½ to make contributions of Individual Retirement Account (IRA) assets of up to \$100,000 per year **directly** to a charity. There is no federal tax impact and the gift will be counted toward the required minimum distribution.
- E. Attempt to recapture significant contributions from third-party events and the Race that were lost as a result of the "Egyptian Conference Controversy" that created a negative image for Komen. Certain country clubs and individual donors should be afforded the opportunity to return to the fold.
- F. The Affiliate should help build the capacity of grantees to find additional financial resources.
- G. Staff education should be strengthened and career path development instituted within the Affiliate. This will enable us to minimize staff turnover and provide better and more informed services to the community.

Problem/Need #5: Strategic Planning

As much as we have learned in this Community Profile that will better enable us to address the challenges of the next two years, we must force ourselves to "look beyond today to the challenges of tomorrow". Once a problem can be seen for what it really is, the solution is not far behind.

Priority: We must make planning a priority for the South Florida Affiliate. "What isn't planned for just will not happen on its own".

Objectives/Action Steps:

- A. The employment of a new Executive Director is an opportune time to set a course for the next five years. It is a time frame of this length, plus comprehensiveness, which distinguishes the process of strategic planning from short term planning efforts like the Community Profile. Once such a process is completed, it needs to be continually evaluated and updated as conditions change – to be "evergreen".

- B. In the Community Profile we have touched on areas – mission and non-mission – that need further research. Provide training to staff on Market Expert to enable them to use this tool for service planning, fund raising, marketing and communications.
- C. Given the diversity of our service area, we need to do more qualitative research - focus groups and surveys - with various constituencies. Relationships with local university programs should be strengthened to enable this to happen. Language and cultural sensitivities will be required.

Introduction

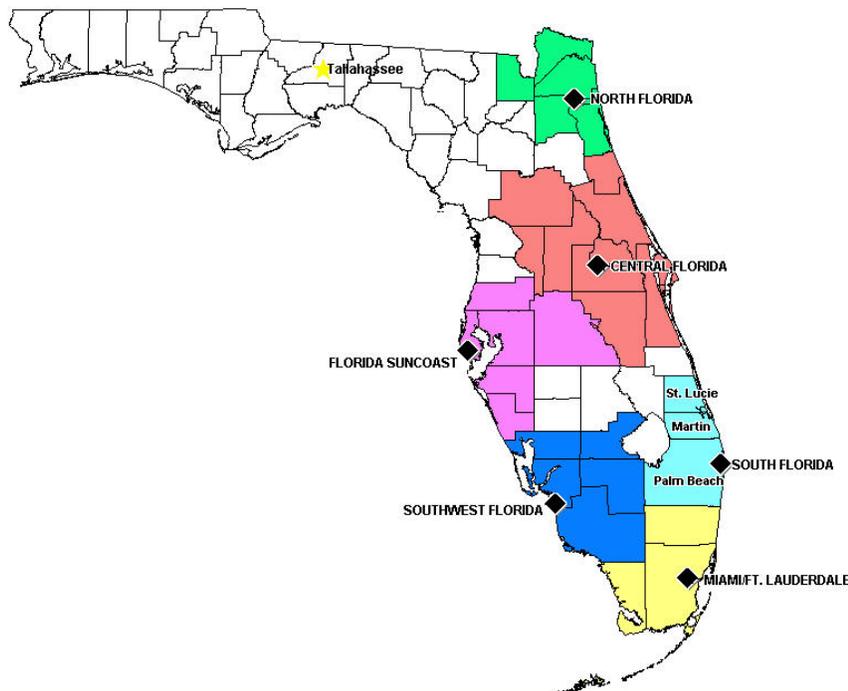
Affiliate History

Ambassador Nancy G. Brinker promised her dying sister, Susan G. Komen, she would do everything in her power to end breast cancer forever. In 1982, that promise became Susan G. Komen for the Cure® and launched the global breast cancer movement. Today, Komen for the Cure is the world's largest grassroots network of breast cancer survivors and activists fighting to save lives, empower people, ensure quality care for all and energize science to find the cures. Thanks to events like the Komen Race for the Cure®, more than \$2 billion has been invested to fulfill our promise, becoming the largest source of nonprofit funds dedicated to the fight against breast cancer in the world. For more information about Komen for the Cure, breast health or breast cancer visit www.komen.org or call 1-877-GO KOMEN.

Komen for the Cure has more than 120 Affiliates in cities and communities around the globe. Six are located in the State of Florida. The South Florida Affiliate of Susan G. Komen for the Cure® encompasses Palm Beach, Martin and St. Lucie counties, all located along the Atlantic Coast. Komen South Florida Affiliate was established in 1991 and hosted its first Komen South Florida Race for the Cure® in 1992. Today, the Affiliate has more than 650 volunteers and raises approximately \$2.5 million annually. On April 1, 2010, the Affiliate continued its commitment by awarding Research Grants (through Komen National), breast cancer screening, treatment and educational outreach grants totaling \$1,740,294.

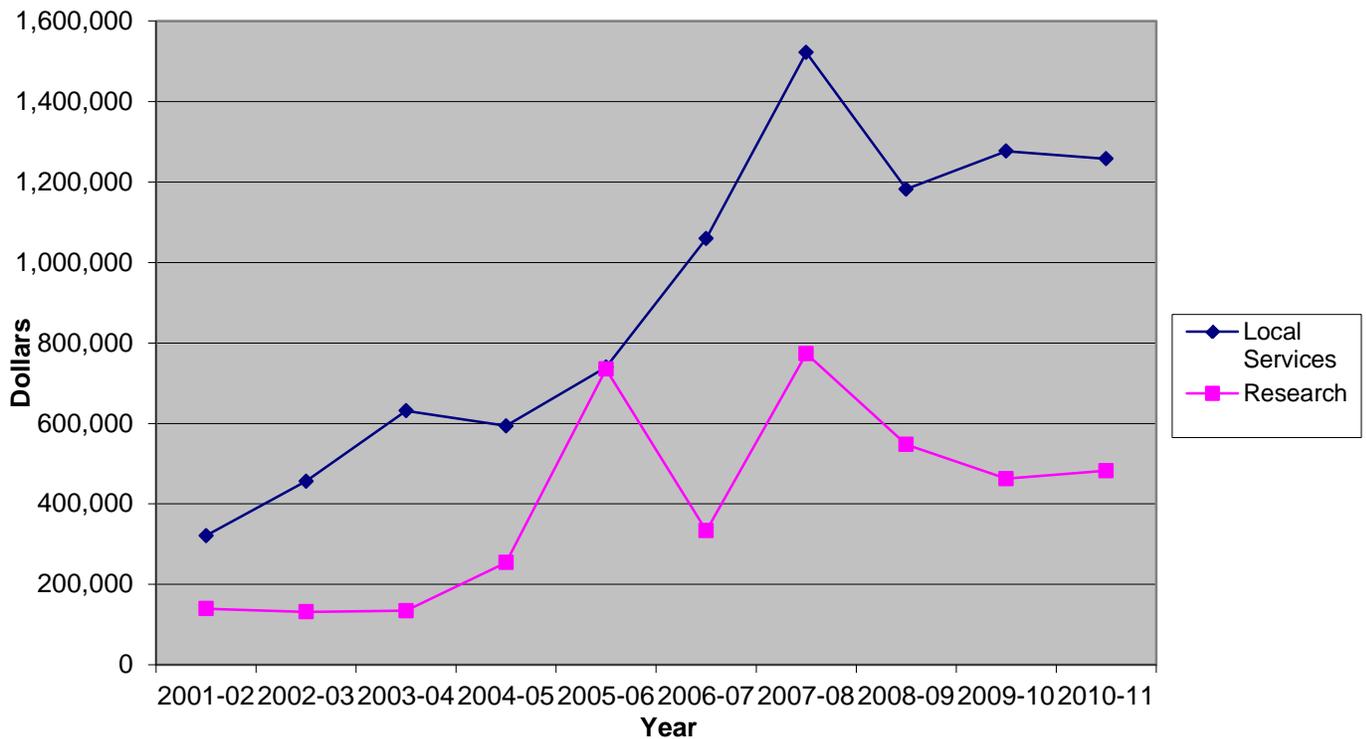
The six Florida Affiliates cover only 31 of Florida's 67 counties, but encompass approximately 85% of the population. However, there is no Komen presence in Tallahassee, the State Capital, or in any nearby counties.

Susan G. Komen for the Cure®
Florida Affiliates



The Komen South Florida Race for the Cure has become one of the largest 5K walk/runs in the Southeast United States. The January 2011 Race attracted 20,000 participants and raised nearly \$1.8 million to help fund local breast cancer programs and national research efforts. Over the past ten years, the Affiliate has awarded grants totaling \$13,036,033 for breast cancer screening, biopsies, treatment, and community education, as well as cutting-edge research. Further information on the South Florida Affiliate may be obtained by calling 561-514-3020 or viewing the website at www.komensouthflorida.org.

Grants Funded, 2001-2011



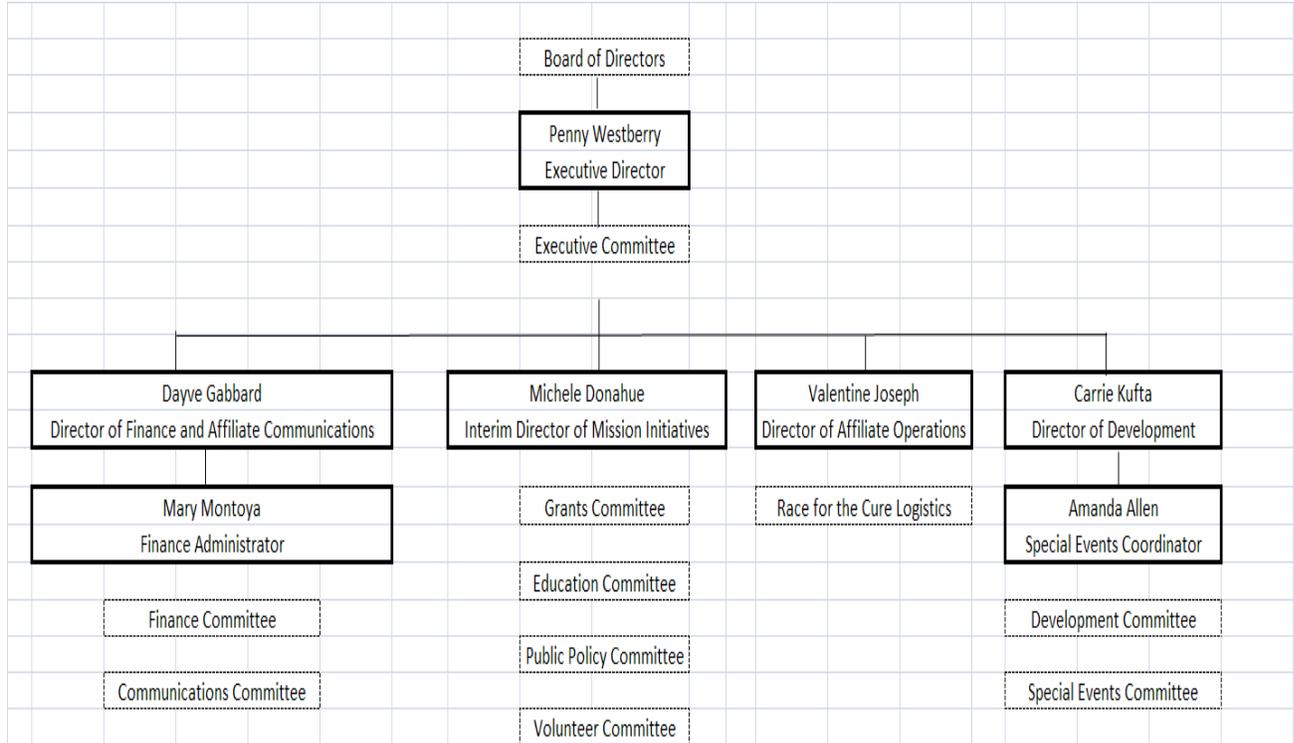
Organizational Structure

The Affiliate is governed by a volunteer Board of Directors. Membership for 2010-11 includes the following individuals:

- * Dave Ragsdale, President
- Kathleen Bocek
- * Mary Booher, Secretary
- Wes Cawley
- Don Chester
- * Elizabeth DeWoody
- Fern Duberman
- Ellie Goodman
- Jane Herring-Choate

- Amy Kabcenell
- Dr. Yvette Laclaustra
- * Teresa A. Licamara, Treasurer
- Dr. Fausta Nazaire
- P. Kristen Pressly
- Deborah 'DB' Wienke
- Marc Yavinsky
- *Denotes member of Executive Committee

The day-to-day operations of the Affiliate are managed by a staff of six full-time and one part-time professionals. Their functional and committee responsibilities are shown below:



The volunteer(lay) / professional partnership is key in successfully achieving the Affiliate’s mission. Non-profits really have only one resource – people. For the latest year (2008-09) that Affiliate rankings have been published, South Florida scores in the top quintile (20%) in seven of the eight categories among the 121 affiliates. This is an achievement both to be celebrated and built upon.

#19	Gross Revenue with In-kind	\$3,447,942
#20	Gross Revenue Without In-Kind	\$2,557,329
#16	Race Gross Revenue with In-Kind	\$2,542,844
#23	Race Gross Revenue Without In-Kind	\$1,681,360
#20	Race Participants	22,050
#22	Non-Race Revenue with In-Kind	\$ 905,098
#19	Total Mission Expense	\$1,886,866
#43	Race Fund Raising Revenue Per Participant	\$33.54

Purpose of the Report

The Community Profile is a process of gathering information and assigning priorities that Affiliates complete every two years in order to understand the state of breast health and breast cancer in their service area and act upon it.

The process involves three stages – a Quantitative Phase of understanding demographic and breast cancer statistics; Health Systems Analysis in relationship to the continuum of care; and a Qualitative Data Phase of key informant interviews and surveys. These lead to a formulation of problems/needs, priorities, and objectives/action steps.

The priorities are intended to inform the work of the entire affiliate, including:

- Distribution of grant funds
- Public Policy Initiatives
- Outreach and education efforts
- Marketing and fund raising efforts
- Partnership needs/opportunities

The document presented here is the work of a dedicated committee and the time and effort of volunteers, staff, expert advisors and graduate students.

Special thanks to the Community Profile Committee who met together three times for a free exchange of information and views. The Committee included board members, committee chairs, a past president, interested community volunteers, expert advisors, and staff:

Dave Ragsdale, Chairman	Dayve Gabbard
Richard Jacobs, Team Leader	Tina Jacobs
Amanda Allen	Valentine Joseph
Jane Berkey	Amy Kabcenell
Jane Herring-Choate	Susan Kristoff
Michele Donahue	Deborah “DB” Wienke
Fern Duberman	

Expert Advisors:

Rosario Medina-Shepherd, PhD, ARNP, FNP-BC, ACNP

Assistant Professor, Florida Atlantic University

Gwendolyn Randall, PhD, CRNA, ARNP

Adjunct Faculty, Nova Southeastern University and Wolford College

Various committee/operational areas of the Affiliate were represented so that continuity “from understanding to action” would be ensured. “You own what you help to create.”

Our graduate students from Florida International University worked hard to produce the raw data and questionnaires that “fed” the discussion process. We believe it was an important learning experience for them, and we thank each of them for their efforts:

Ida Tanoë Aka, MPH

Kantica Arora

Debbie Maxwell, MPH

Rozina Parbtani, MPH

Trang Van, MPH

The full team was very diverse in terms of race, ethnicity, age, religious beliefs, and geographic residence.

Lastly, three additional people need to be thanked for their assistance in this effort:

Melissa Howard, PhD, FIU Robert Stempel School of Public Health, Assistant Dean for Student Services and Coordinator of the Internship Program

Mark Pedigo, Client Services Manager, Thomson Reuters

Ira Sheskin, PhD, Professor, Department of Geography and Regional Studies, and Director of the Jewish Demographic Project of the Miller Center for Contemporary Jewish Studies, University of Miami.

The Service Area

DEMOGRAPHIC SNAPSHOT

	Palm Beach	Martin	St. Lucie		
	County	County	County	Florida	USA
Population, 2000	1,131,190	126,731	192,695		
Population, 2009 Estimated	1,279,950	139,794	266,502		
Population Growth 2000-2009, Percent	13.2	10.3	38.3	16.0	9.1
Area (Sq. Mi.)	1,974	556	572		
2009 Density (Pop/Sq. Mi.)	648	251	466	344	87
Population, Percent Female	51.1	50.4	50.8	50.9	50.7
Population, Percent Ages 65+	21.3	26.3	20.2	16.9	12.6
Median Age	42.5	48.2	41.9	39.7	36.5
Foreign Born, Percent	21.2	10.1	15.5	18.7	12.4
Language Other than English Spoken @ Home (Pop. 5 yrs & Over), Percent	25.8	13.2	19.4	25.8	19.6
Race and Ethnicity:					
% White, Alone	63.5	81.5	65.7	60.5	65.8
% Black, Alone	15.5	5.5	16.5	14.8	12.1
% Hispanic of Any Race	17.2	10.1	14.5	20.6	15.1
% All Other	3.8	2.9	3.3	4.1	7.0
Educational Attainment (% Pop 25 yrs & Over)					
% Did Not Graduate High School	13.5	11.5	17.1	15.1	15.5
% High School Graduate or Equivalent	47.4	51.2	56.7	50.9	49.6
% Undergraduate Degree (Assoc. or Bachelor's)	27.7	27.0	19.8	25.0	24.8
% Graduate or Professional Degree	11.4	10.3	6.4	9.0	10.1
Median Household Income	\$53,538	\$52,734	\$46,656	\$47,450	\$51,425
Families Below the Poverty Level, Percent	8.0	6.6	8.3	9.5	9.9
Individuals Below the Poverty Level, Percent	11.5	10.6	12.0	13.2	13.5

Source: U.S. Census Bureau, American Community Survey 5 year Estimate, 2005-09; 2009 Population Estimate; American Factfinder

Palm Beach County is by far the largest of the three counties, the third largest in population and second largest in land area in the State of Florida. Geographically, it is larger than the State of

Rhode Island. As highlighted above, Palm Beach County is also the most densely populated - consequently the most urbanized - with seven municipalities boasting populations of 50,000 people or more (Boca Raton, Boynton Beach, Delray Beach, Jupiter, Palm Beach Gardens, Wellington, West Palm Beach), while nearly 550,000 people live in the unincorporated western portion of the county. There are vast hinterlands containing thousands of square miles of wetlands, wildlife refuges, and agricultural land. Palm Beach County has the highest percentage of females, foreign born, language other than English spoken at home, education levels, and Hispanic population. Its median age and population percentage age 65+ rank it second among the three, but significantly higher than the State of Florida and the United States. Although the wealthiest county in the State in terms of Median Household Income, Palm Beach is a study of contrasts with wealthy coastal towns (e.g. Palm Beach, Manalapan) and poor agricultural communities in the far west (i.e. The Glades communities) adjacent to Lake Okeechobee. PBC is an equestrian sports and golf mecca for the rich and famous that swells its ranks during the winter season. Major employers produce jet engines, computers, and sugar. West Palm Beach is the county seat.

Martin County is the smallest of the three counties and the least densely populated. It has the highest senior adult population and median age. Its White population percentage is extremely high, with minorities significantly lower than in the other counties. Median household income is high, approaching that of PBC, while families and individuals below the poverty level are relatively low. As deduced from the foregoing, there is significant number of retirees and retirement communities in the County. Health care, aerospace and tourism are the county's major private industries, with agriculture found in the west. Stuart, a small city in the northeastern part of the County, is the county seat.

St. Lucie County is the fastest growing of the three counties, far outpacing the others and the State of Florida. It has the youngest of the populations and the highest percentage of Black population. Its resident educational levels are the lowest and its population the poorest overall, even lower and poorer than found in the State of Florida. Major private employers are focused in health care, communications, retailing, and citrus concentrate. The county seat is located in Ft. Pierce in the northeast portion of the County.

Breast Health/Breast Cancer Snapshot					
		Palm Beach	Martin	St. Lucie	
		<u>County</u>	<u>County</u>	<u>County</u>	<u>Florida</u>
Percentage of Women Who Had a					
CBE in the Past Year	2007	70.2	72.7	68.9	66.1
	2010	70.8	60.2	60.3	63.2
Percentage of Women Who Received a					
Mammogram in the Past Year	2007	70.3	68.1	72.1	64.9
	2010	71.2	57.6	61.9	61.9

Incidence Rate - All Races, All Ages					
2004-08	120.4	112.2	102.9	113.6	
3-Year Age Adjusted Incidence	2006-2008	116.6	107.6	96.3	110.9
Death Rate/Trend Comparison, Death Years through 2007, Florida vs. US		Priority 8 Falling & Similar	Priority 8 Falling & Similar	Priority 9 Falling & Below	Priority 8 Falling & Similar
5 Year Rate Change - Mortality	2003-2007	21.6	20.8	20.7	22.1
		-2.9%	-1.9%	-1.4%	-2.5%
Age Adjusted 3-Year Death Rate	2007-2009				
		21.2	18.8	19	20.4

Source: Florida Department of Health, Florida Charts; National Cancer Institute, State Cancer Profiles

The picture of breast health and breast cancer in the South Florida Affiliate is a little bit more complicated than might be expected. Palm Beach County has the highest incidence and mortality rate of the three, despite the fact that Martin County has a higher percentage of White and Age 65+ population. St. Lucie County is lowest on incidence rate, as might be predicted based on highest percentage of Black population and lowest percentage of Age 65+ population. Mortality rates are pretty close for the three.

Perhaps the most critical fact in the chart is that with the exception of Palm Beach County, rates of Clinical Breast Examinations and Mammograms appear to be falling over the three year period. Further analysis of these numbers - not shown on the chart presented here – shows declines for White non-Hispanics (the only racial/ethnic group reported), and all age groups, educational levels, and income brackets. Again, the few exceptions are attributed to Palm Beach County. These declines are disturbing.

Demographics and Statistics

Process for Designating Target Areas

The South Florida Affiliate of Susan G. Komen for the Cure, unlike some other affiliates with scores of counties in their area, serves only three counties. As such, it cannot designate a single county or two as target areas – it must look to pinpoint target areas within all three counties upon which to focus its attention. These areas might include single or multiple zip codes to which to direct services.

In approaching the designation of target areas for the 2011 Community Profile, the first step taken was to review certain key variables by zip code included in the data sets from Thomson

Reuters provided by Komen national. Because of the significant differences among the three counties involved, we chose to search for zip codes scoring highest in these characteristics within each of our counties, as compared to the county as a whole in which they were located. While the data is estimated, rather than actual, it does allow for “apples to apples” comparison for counties and zip codes. No 2009 actual data was available for zip codes.

- Female Population – Percent Black
- Female Population – Percent Hispanic
- Percent of Families Below the Poverty Level
- Percent of Uninsured Females
- Late Stage Breast Cancer Diagnosis
- Breast Cancer Incidence Rate (per 100,000 Population)
- Breast Cancer Mortality Rate (per 100,000 Population)
- Percent of Females Age 65+

These were supplemented by two data sets not used in the 2009 Community Profile:

- PRIZM®NE classifies every U.S. Household into one of 66 consumer segments. The 66 segments are numbered according to socioeconomic rank, which takes into account characteristics such as income, education, occupation and home value. The five most prevalent cluster group number designations were recorded for each zip code and summed. Zip codes with the highest scores were deemed to be of greatest interest.
- Data from the 2005 community studies of the Jewish Federation of Palm Beach County and the Jewish Federation of South Palm Beach County were examined for zip codes with highest concentration of older Jewish females – age and ethnicity (higher propensity to inherit BRCA1 and BRCA2 breast cancer genes) being the factors of interest.

These were used as “tie breakers” in determining which zip codes to include or exclude.

For several years, the South Florida Affiliate has been focusing attention on certain sub-areas within its service area. Grant funding and educational efforts have been geared in their direction. These same areas were also referenced in the 2009 Community Profile of the Affiliate. However, they were never fully defined or comprehensively researched.

Zip codes scoring highest in multiple demographic and breast cancer statistical categories were designated to be included in target areas. Relative geographic contiguity was required. Five target areas were thus selected and named:

- Three in Palm Beach County:
 - **The Glades** (33430, 33438, 33476, 33493)
 - **I95 Corridor** (33401, 33403, 33404, 33405, 33406, 33407, 33415, 33435, 33444, 33460, 33461)
 - **SW Seniors** (33434, 33437, 33446, 33484)
- One in Martin County
 - **Indiantown** (34956)
- One in St. Lucie County
 - **Ft. Pierce** (34946, 34947, 34950)

Initial determining factor information was calculated for each and appears on the following pages. The Glades, I95 Corridor, Indiantown, and Ft. Pierce are all characterized by high female

minority populations, high percentage of families below the poverty level, high percentage of uninsured females and high incidence of late stage breast cancer diagnosis. SW Seniors presents a picture of high percentage of females age 65+, high breast cancer incidence and mortality rates.

This is not to say that there are not other zip codes close by that could have been included in the target areas. They may exhibit similar characteristics, but to a slightly lesser degree. Not everyone can officially be included in a target area, so as not to diminish the meaning of the term. Programmatic efforts to reach target areas will, in most cases, spread beyond them to the benefit of other zip codes. The subsequent Community Profile comprehensive research confirmed that these five target areas were well chosen.

In this Community Profile, extensive use was made of information and data available from Market Expert, a Thomson Reuters product. As configured for Komen, Market Expert offers the following programs:

- Demographics Expert
- Insurance Coverage Estimates
- Continuum of Care
- Household Targeter
- Health Status Profiler

Market Expert facilitated calculation of statistics for the initial determining factors on an aggregated basis, as well as providing additional information on median household income, wealth and home value, educational attainment levels, health status, mammogram within the past year, and prevalence. Other information will appear later in the report.

A two page profile was also prepared on each target area, but is not included in this report. These are intended as “stand alone” documents that can provide a brief comprehensive snapshot of the area, and be used in fund raising, advocacy, education, marketing and communication efforts. They will also be invaluable to grant committee decision making. These will be available not only for use by the Affiliate, but breast health and breast cancer organizations in the community will also be able to incorporate them in their financial resource development efforts.

The Glades

In The Glades, the Black Female percentage is nearly four times that of Palm Beach County. The Hispanic percentage is nearly twice that of PBC. When combined the Minority Population of Black and Hispanic Females is nearly three times that of PBC.

	Female Population	Black Females	Black Percent	Hispanic Females	Hispanic Percent	B&H Total Females	B&H Percent
Palm Beach Cty	669,270	99,721	14.9%	111,099	16.6%	210,820	31.5%
The Glades	15,801	8,954	56.7%	4,734	30.0%	13,688	86.6%

The percentage of families below the Poverty Level is nearly five times higher in The Glades than PBC.

	Income Below Poverty Level		
	2009 Families	Families	Percent
Palm Beach Cty	344,643	23,136	6.7%
The Glades	6,951	2,164	31.1%

Females in The Glades are two and one-half times more likely to be uninsured.

	2009 Female	Uninsured Females	
	Population	Population	Percent
Palm Beach Cty	669,270	95,629	14.3%
The Glades	15,801	5,692	36.0%

Late stage breast cancer diagnosis percentages are significantly higher in this target area than in PBC.

	Female Population	Incidence Rate	% New Cases		% New Cases	
			Stage I	Stage II	Stage III	Stage IV
PBC	669,270	149.16	65.8%	26.1%	3.5%	4.6%
The Glades	15,801	77.48	58.8%	30.2%	4.7%	6.3%

I95 Corridor

In the I95 Corridor, the Black Female percentage is more than twice that of Palm Beach County. The Hispanic percentage is more than 50% greater. When combined, the Minority Population of Black and Hispanic Females is nearly twice that of PBC.

	Female Population	Black Females	Black Percent	Hispanic Females	Hispanic Percent	B&H	
						Total Females	B&H Percent
Palm Beach Cty	669,270	99,721	14.9%	111,099	16.6%	210,820	31.5%
I-95 Corridor	158,232	53,950	34.1%	40,316	25.5%	94,266	59.6%

The percentage of families below the Poverty Level is more than twice that of Palm Beach County.

	Income Below Poverty Level		
	2009 Families	Families	Percent
Palm Beach Cty	344,643	23,136	6.7%
I-95 Corridor	71,269	10,051	14.1%

Females in the I95 Corridor are more than 50% likely to be uninsured.

	2009 Female Population	Uninsured Females Population	Percentage
Palm Beach Cty	699,270	95,629	14.3%
I-95 Corridor	158,232	34,434	21.8%

Late stage breast cancer diagnosis is higher in this target area than Palm Beach County.

	Female Population	Incidence Rate	% New Cases Stage I	% New Cases Stage II	% New Cases Stage III	% New Cases Stage IV
PBC	669,270	149.16	65.8%	26.1%	3.5%	4.6%
I95 Corridor	158,232	120.58	63.6%	27.3%	3.9%	5.2%

SW Seniors

Females age 65+ are two and one-half times more likely to be found in this target area than in PBC.

	2009 Female Population	# Females Age 65+	% Females Age 65+
Palm Beach County	669,257	162,616	24.3%
SW Seniors	51,570	31,607	61.3%

Incidence and Mortality are extremely high in this target area as compared to Palm Beach County.

	Female Population	Incidence Rate	Number New Cases	Mortality Rate	Number New Deaths
PBC	669,270	149.16	998	22.41	150
SW Seniors	51,559	262.22	135	42.47	22

Indiantown

In Indiantown, the Hispanic Female percentage is six and one-half times that of Martin County. The Black Female percentage is nearly three times. When combined the Minority Population of Hispanic and Black Females is more than five times that of MC.

	Female Population	Black Females	Black Percent	Hispanic Females	Hispanic Percent	B&H Total Females	B&H Percent
Martin County	73,791	3,616	4.9%	6,272	8.5%	9,888	13.4%
Indiantown	4,097	569	13.9%	2,253	55.0%	2,822	68.9%

The percentage of families below the Poverty Level is three times higher in Indiantown than Martin County.

	Income		
	2009 Families	Below Poverty Level Families	Percent
Martin Cty	42,055	2,387	5.7%
Indiantown	2,016	358	17.8%

Females in Indiantown are 40% more likely to be uninsured.

	2009 Female	Uninsured Females	
	Population	Population	Percentage
Martin County	73,791	7,639	10.4%
Indiantown	4,097	592	14.5%

Late stage breast cancer diagnosis percentages are higher in this target area than in Martin County.

	Female Population	Incidence Rate	% New	% New Cases	% New Cases	% New
			Cases Stage I	Stage II	Stage III	Cases Stage IV
Martin Cty	73,791	159.59	66.8%	25.4%	3.3%	4.5%
Indiantown	4,097	79.85	64.0%	27.7%	3.6%	4.7%

Ft. Pierce

In Ft. Pierce, the Black Female percentage is about three and one-half times that of St. Lucie County. The Hispanic percentage is about 14% greater. When combined the Minority Population of Black and Hispanic Females is more than two and one-half times that of SLC.

	Female Population	Black Females	Black Percent	Hispanic Females	Hispanic Percent	B&H	B&H
						Total Females	Percent
St. Lucie Cty	138,323	24,068	17.4%	21,302	15.4%	45,370	32.8%
Ft. Pierce	17,481	11,024	63.1%	3,063	17.5%	14,087	80.6%

The percentage of families below the Poverty Level is three and one-half times higher in Ft. Pierce than St. Lucie County.

	Income		
	2009 Families	Below Poverty Level Families	Percent
St. Lucie Cty	76,686	6,410	8.4%
Ft. Pierce	7,822	2,310	29.5%

Females in Ft. Pierce are more than twice as likely to be uninsured.

	2009 Female	Uninsured Females	
	Population	Population	Percentage
St. Lucie Cty	138,323	27,837	20.1%
Ft. Pierce	17,481	7,635	43.7%

Late stage breast cancer diagnosis percentages are significantly higher in this target area than in St. Lucie County.

	Female Population	Incidence Rate	% New Cases Stage I	% New Cases Stage II	% New Cases Stage III	% New Cases Stage IV
St. Lucie Cty	138,323	89.48	65.0%	26.7%	3.6%	4.7%
Ft. Pierce	17,481	61.89	59.3%	29.5%	4.8%	6.4%

Populations of Primary Interest

Because our target areas are relatively small, it is sometimes difficult to draw conclusions from the data presented. Therefore, we have included this section to draw information from national and State resources to better describe the situation of our populations of primary interest.

African Americans

Breast cancer is the most common cancer among African American women. While the overall breast cancer incidence rate for African American women is about 10 percent lower than for white women, African American women have higher rates of distant stage breast cancer than white women and a mortality rate that is 37 percent higher. In the U.S. they are less likely than white women to survive five years: 77 percent vs. 90 percent respectively.

A Florida Cancer Data System (FCDS) study of Cancer in Florida Persons of African Descent 1988 – 2007, showed that throughout the time period, the age-adjusted rates of breast cancer were greater for White Females compared to females of African Descent. Both groups experienced increases in incidence rates early in the time period which later reversed, significantly so for females of African Descent. However, there was a recent, but non-significant increase in rates for this group starting in 2005 which, in combination with declining rates in Whites, led to the near elimination of the race gap in rates in 2007.

Further in the same study, initially both White females and females of African Descent were increasingly diagnosed at local stage, with an eventual decrease among White females for local and regional stage. There were modest but significant reductions in the incidence of regional stage cancer in Whites with little change in rates for females of African Descent. Despite a lower overall breast cancer incidence rate among persons of African Descent, this race group experienced significantly higher rates of distant-stage breast cancer throughout the survey period.

The causes of all of the above are complex and not completely understood. Aggressive tumor characteristics linked to poorer prognosis appear to be more common in African American women and may contribute to lower survival rates. Even when controlling for these factors, African American women have poorer survival rates – explainable in part by unequal receipt of prompt, high quality treatment when compared to white women.

Social determinants also play a major role:

- **Poverty:** A higher proportion of African Americans live in poverty than do whites. Barriers related to poverty include the lack of a primary care physician, inadequate health insurance and limited knowledge about breast cancer. Further, through lifelong dietary and reproductive habits, poverty may influence disease pathology and genetic markers of disease.
- **Culture:** Studies show that cultural factors affect an African American woman's decision to be screened and treated for breast cancer. Barriers related to culture include low perception of risk for breast cancer, myths handed down within families and communities, and mistrust of the health care system.
- **Social Injustice:** Racial prejudice and discrimination have been shown to have negative health effects, including African American women being referred to mammography less often.

Hispanic/Latina Women

Hispanics are the largest, fastest-growing, and youngest minority group in the United States. Mexicans, Puerto Ricans and Cubans are the nation's three largest Hispanic groups. Although persons of Hispanic origin may be of any race, about 97 percent of U.S. Hispanics are white. The Hispanic population is very diverse, including 29 subgroups. Significant differences exist among Hispanics in regard to country/region of origin, customs and beliefs, education, socioeconomic status, and other characteristics. Spanish is not the only language of Hispanics. In our Affiliate service area, Mayans, mainly from Guatemala, speak Q'anjob'al (Kanjobal).

Breast cancer is the most commonly diagnosed cancer among Hispanic women in the United States. In the U.S. the breast cancer incidence rate in Hispanic women is about 27 percent lower than in non-Hispanic white women. This difference may be due in part to having a first child at a younger age and having more children. However, it may also reflect less use of postmenopausal hormones, a lower utilization rate of screening mammography or possible variations in genetic factors.

Since 1997, breast cancer incidence rates have decreased 0.9 percent per year among Hispanic women (1.5 percent per year among non-Hispanic white women) in the U.S.

A Florida Cancer Data System (FCDS) study of Cancer in Florida Hispanics 1989 – 2006, found that the age-adjusted rates of breast cancer were substantially greater for non-Hispanic White females compared to Hispanic females. Over the time period, the breast cancer rate decreased for both Hispanic and non-Hispanic White females, with the largest decrease among non-Hispanic White females.

Over the time period, both non-Hispanic White and Hispanic females were decreasingly diagnosed at distant and regional stage, and increasingly diagnosed at a local stage particularly for non-Hispanic White females, possibly indicating increased early screening for this cancer.

Breast cancer is the leading cause of cancer death among Hispanic women in the United States. Breast cancer is less likely to be diagnosed at the earliest stage in Hispanic women compared to non-Hispanic white women after differences in age, socioeconomic status and method of

detection are controlled. Breast cancer is often detected at a more advanced stage in Hispanics than in non-Hispanic white women in the U.S. This difference has been largely attributed to lower use of mammography screening and longer intervals between mammograms, as well as the lack of timely follow-up of an abnormal mammogram. During 2002-2006, 55 percent of breast cancers among Hispanic women were diagnosed at a local stage compared to 63 percent of cases among non-Hispanic white women. Hispanic women are about 20 percent more likely to die of breast cancer than non-Hispanic white women who are diagnosed at a similar age and stage. Difference in access to care and treatment likely contribute to the disparity.

Ashkenazi Jews

South Florida is the second largest concentration of Jews in the United States, and Palm Beach County alone is the fourth largest with an estimated 255,000 people. Based on the results of the 2005 Community Surveys undertaken by the Jewish Federation of South Palm Beach County (Boca Raton, Delray Beach and Highland Beach) and the Jewish Federation of Palm Beach County (balance of the county), 62% of all senior citizens in the county are Jewish. The median age for the Jewish population is about 70 years old. After being a woman, the second factor that may increase your risk of breast cancer is age – the older you get, the greater your risk of breast cancer. This is a population at high risk.

Although no study to date has shown that breast cancer is more common in Jewish women than in the population at large, more Jewish women carry genetic alterations that may increase the likelihood that they will develop breast or ovarian cancer in their lifetime. Specifically, 1 in 40 Jewish women of Ashkenazi descent (from central and eastern Europe) carry an alteration in what are referred to as BRCA1 or BRCA2 genes, compared to 1 in 345 women in the general population who carry an alteration in those genes. These alterations can be passed from generation to generation, from both mothers and fathers. While not all women who carry an altered gene will develop breast cancer, recent studies suggest that there may be as high as an 82% risk that someone who carries an altered gene will develop breast cancer by the age of 70.

It is therefore recommended that any Ashkenazi woman with breast or ovarian cancer consider exploring genetic counseling and testing. Both men and women who carry a BRCA1 or BRCA2 mutation have a 50% chance of passing that alteration on to their daughters and sons, whether or not they are diagnosed with cancer themselves. Not all children of people who have an altered gene will inherit the alteration, and not all of those who inherit the alteration will develop breast or ovarian cancer in their lifetime. However, the information received can influence family members' health care decisions.

In sum, while our service area is relatively small in terms of counties, each county is very diverse in its makeup and contains target areas of concern that cry out for the attention of the Affiliate. In this Community Profile (and in supplemental reports) we have been able to create comprehensive pictures of each of these target areas that will serve us well in planning and resource development. Each target area is significantly different in size, demographic makeup and economic resources. As we will see in the next section, breast health and breast cancer

resources differ markedly as well, which ultimately lead to the formulation of particularized recommendations for filling the service gaps.

Health Systems Analysis of Target Communities

The Health Systems Analysis is an effort to understand gaps, needs and limitations in the health system that affect a woman's transition through the continuum of care (education, screening, diagnosis, treatment, follow-up care and survivorship).

Methodology

The Health Systems Analysis phase was accomplished through six tools/approaches:

- Key informant interviews with 15 community leaders and providers in the breast health field.
- A provider survey distributed via Survey Monkey to agencies and organizations of various types who impact on breast health and breast cancer in the community, asking them to delineate their services.
- A thorough review of the Breast Health Resource Directory for Martin and St. Lucie Counties. (A similar directory does not exist in Palm Beach County)
- Review of grant applications recently submitted to the Affiliate for funding consideration. These are rich in knowledge of the services provided by the applicant, as well as cooperative activity in the community.
- Review of agency and organizational websites to further understand their services.
- Mapping of resources utilizing Market Expert. The target areas are color coded.

Each target area presents a distinct picture.

Overview of Target Area Assets

The Glades (Yellow) is a self-contained area, bordering Lake Okeechobee, and separated from the balance of Palm Beach County by almost 30 miles of mostly agricultural land. The City of Belle Glade is the unofficial capital of the area, which also includes Pahokee, Canal Point, and South Bay. While the zip codes in this area are large geographically, the population is relatively small.

Lakeside Medical Center is the new, nonprofit hospital that replaced Glades General Hospital just over one year ago. This hospital, operated by the tax supported Health Care District of Palm Beach County, is relatively limited in its breast cancer services, providing education, digital screening and diagnostic mammograms, and ultrasounds. If a patient has an abnormal mammogram or ultrasound, currently they must travel 60 miles to Boca Raton Regional Hospital (BRRH) in order to get further free testing or a biopsy. BRRH is the only non-profit hospital that will take these people. The distance barrier and lack of transportation is often insurmountable. Some women are screened by the mobile van of the H.O.P.E. Project, particularly undocumented individuals who feel more comfortable not going to Lakeside because of their immigration issues, even though the hospital accepts undocumented. Health Care District serves the poorest of the poor in Palm Beach County.

Currently there are no breast surgeons, oncologists, or radiation oncologists in The Glades. Establishing a relationship with a private hospital nearly 30 miles away is a partial answer, with Komen paying Lakeside, and Lakeside passing it through to Palms West Hospital. If the patient qualifies for Medicaid or Health Care District funding, they can go to any hospital that takes these forms of insurance, not just the non-profits funded by Komen.

Language and trust issues limit Komen's educational efforts in the area. A recent hire of a young lay navigator, born and raised in the area is making inroads. So too are newly mobilized Hispanic and Haitian volunteers who talk with the women in their own language.

Education is provided by Florida Community Health, Minority Community Development, H.O.P.E. Project and Sojourners with Healing Hearts, who also provide a support group.

Financial assistance is available from a couple of different sources. The Goodall Foundation provides financial assistance for transportation to the medically underserved for screening and treatment. Under special circumstances individual doctors/surgeons from out of the area are prevailed upon to do pro-bono surgery.

The **I95 Corridor** (Orange) in Palm Beach County runs from Delray Beach in the south, through Boynton Beach, Lake Worth, to West Palm Beach and neighboring cities and towns in the north, and is by far the most populated and urbanized of the target areas. Consequently, breast cancer education, screening, diagnosis, treatment and surgery are available to most patients depending upon where they live and immigration status.

There are three non-profit hospitals located in this target area. Komen qualified patients, including undocumented, can go to Boca Raton Regional Hospital for all diagnostic services. Undocumented, will however not get treatment. This hospital is located in the southeastern corner of the county. Bethesda Memorial Hospital is a little further north and offers comprehensive services, and will take undocumented for screening, diagnosis, and some help with treatment. Jupiter Medical Center will service a small number of patients from the northern tier of this target area, but does not take undocumented patients at all. As can be readily seen, the situation of the undocumented, of which we have a substantial number in the county, is not pretty. Sometimes these patients are encouraged to "go back home" for treatment.

Clinical Breast Examinations are offered at most health department sites throughout the county, with the largest center located in West Palm Beach, Referrals are made based on financial status and immigration status. The H.O.P.E. Project has eleven sites in the county which they visit regularly, providing free (most funded by Komen), or low cost screening mammograms. However, their services are limited to females between the ages of 40-64, without breast lumps or other presenting issues. The mobile mammography van recently funded at BRRH fills in some of the gaps.

There are many other services located in or servicing this target area including the Caridad Center which focuses on education and health care for the Hispanic and Haitian population.

Sojourners with Healing Hearts is an organization providing support groups in the African American community; and the Marie Louise Cancer Foundation does the same in the Haitian community. Bosom Buddies is another support group that serves the general community. Healing Touch Buddies trains message therapists in the healing touch method and provides free services to a limited number of people based on a grant from Komen. Most of the hospitals, for-profit and nonprofit, have support groups to which all are welcome, and to which patients can go depending upon how far they are willing to drive, and the comfort level they may have with the group and its leader.

The Sari Center of the Palm Beach Cancer Institute provides help dealing with the physical, emotional, financial, and nutritional issues that survivors face; and also offers therapeutic message, counseling, acupuncture and healing touch for a fee. The Annie Appleseed Project, is a nonprofit providing complementary and alternative therapies for breast cancer survivors.

Planned Parenthood and Hadassah provide breast health education to high school students throughout Palm Beach and Martin counties, with the hope that the students themselves will benefit, and also bring this knowledge home to their parents and families. A small grant to El Sol funds breast health education to a number of women in the northern part of this target area, most of whom are Hispanic (Guatemalan) and undocumented. Komen also funds a radio show directed at the Haitian population in Creole; and a TV spot of 90 seconds aired weekly during the early evening news broadcast. The audience for this is more likely to be the Caucasian population and may bear some rethinking.

American Cancer Society provides breast health education materials and funds transportation services for patients undergoing breast cancer treatment. Requests for prosthetics, mastectomy supplies, breast forms, bras and swimwear are funneled through ACS as well, in Palm Beach (and Martin) County.

The Cancer Alliance of Health and Hope provides need-based financial assistance for breast cancer patients residing anywhere in Palm Beach County for normal everyday expenses – rent, mortgage, car payments, utilities – while they are going through treatment.

The **SW Seniors** target area (Pink) encompasses four zip codes west of the cities of Boca Raton, Delray Beach and Boynton Beach in Unincorporated Palm Beach County. Boca Raton Regional Hospital, Bethesda Memorial Hospital and Bethesda Women's Health Center service this area. The majority of people are on Medicare, therefore insurance or money is not the primary issue.

Lack of education is a big problem. Many women believe that once they pass through menopause that they no longer need an annual mammogram. Statistics show the opposite to be true. The average age of breast cancer diagnosis is 61; and the highest incidence is between 73 and 79. The older you get the higher the risk. In this area with a very significant, probable majority, Ashkenazi Jewish senior population, there is also a significant lack of knowledge of the BRCA gene.

Transportation can be an issue here. The H.O.P.E. Project does not have a regular site in this area. The new BRRH mobile mammography van will go to senior communities and Medicare will pay for this service. In the State of Florida, no prescription is needed for a screening mammogram. However, Komen requires a prescription for its funded patients in an effort to make the doctor/nurse practitioner responsible for the follow-up care of that patient.

Education should be expanded to various locations and groups using the “over organized” nature of this area (i.e. home owner associations, synagogues, organizations, etc). Support groups can be found at the hospitals. The Jewish Community Center with a grant from Komen, recently launched a special program to keep breast cancer patients and survivors physically fit and nutritionally healthy.

The **Indiantown** (Blue) target area in Martin County is another isolated community. While it looks extremely large on the map, its population is relatively small and concentrated, with the balance of land being agricultural. Hispanics are a majority, with a significant black population as well. Significant numbers of the population are undocumented.

The only hospitals in Martin County are the nonprofit hospitals operated by Martin Memorial Health Systems located in Stuart some 23 miles away. Martin Memorial Medical Center is the chief provider of breast health and breast cancer services – screening, diagnosis, surgery, treatment and navigation. Komen, Medicaid, Medicare and hospital charity care are the funding sources. There is no Health Care District in Martin County. Martin Memorial will not service the undocumented. There is small utilization of the Breast and Cervical Cancer Early Detection Program, which operates out of Broward County for this area.

Indiantown Community Outreach, the Martin County Health Department, H.O.P.E. Project and Florida Community Health Clinics work in close cooperation to educate in different languages, screen, navigate and transport. English, Spanish, and Kanjobal are the languages of necessity.

Pink Tie Friends has established contracts with hospitals and doctors to provide biopsies and treatment. They run fund raisers and also receive a grant from Komen.

Volunteers in Medicine is a free clinic located in Stuart staffed by volunteer doctors and nurses, and utilized by Indiantown residents who can get there. Komen reimburses them for clinical breast examinations. They do not take undocumented.

The American Cancer Society in Stuart provides breast health education materials and transportation for treatment.

In a location like Indiantown, there can never be enough money for transportation.

In the **Ft. Pierce** (Grey) target area, the population is majority Black with a significant percentage of Hispanics. The population is very poor and in many respects is the least served of our target areas. Komen has very little presence in this area.

There are no nonprofit hospitals in St. Lucie County. Martin Memorial will serve people up to Midway Road in St. Lucie County, but this excludes the northern half of the county where Ft. Pierce is located.

Florida Community Health Clinics have a location in Ft. Pierce. This is a Federally Funded Health Clinic in which you must become a patient. You can get a clinical breast exam here, but there is no screening available. FCHC has a contract with Radiology Imaging whereby they pay them, and Komen pays FCHC for qualified patients.

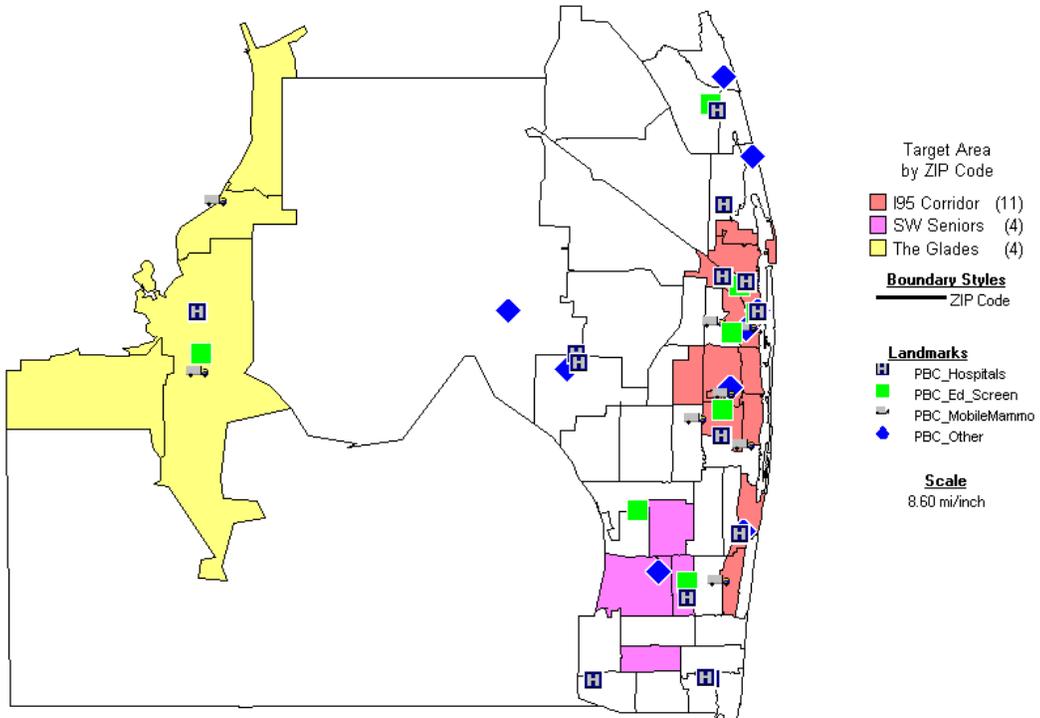
Of the two for-profit hospitals in St. Lucie County, Lawnwood Medical Center is located in Ft. Pierce and is known as the “heart hospital”. St. Lucie Medical Center, about 12 miles south in Port St. Lucie is the “cancer hospital”. Pink Tie Friends has a contract with them for surgery and some treatment; and a contract with a surgeon to do biopsies. All have agreed to accept Komen reimbursement rates which are passed through Pink Tie Friends.

In sum, while each target area is unique both in population and services offered, there were several recurrent themes that evolved from the Health Systems Analysis that spoke to the formulation of specific action steps recommended in the Conclusion section of this report:

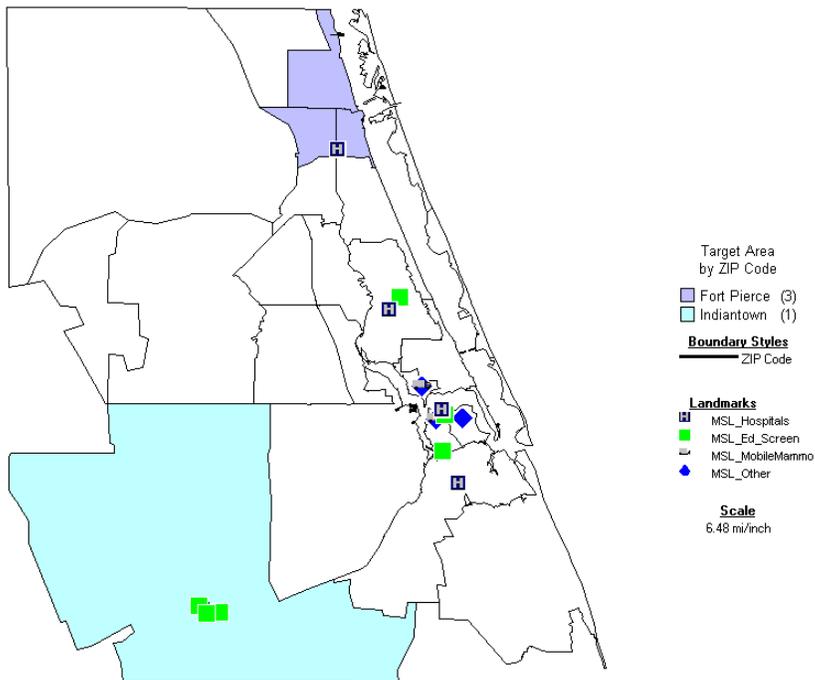
- Insufficiency in regard to continuum of care services
- Isolation for some (both geographic and economic) and the need for better transportation services
- Lack of services for the undocumented
- Need for empowerment of local communities
- Education for senior adult females that differs in content from the general female population
- Need for additional non-traditional partnerships to enable service delivery
- More comprehensive information provided by directories and coalitions of professionals

Health Systems Analysis Maps

Palm Beach County



Martin and St. Lucie Counties



Breast Cancer Perspectives in the Target Communities

Several different approaches were utilized in this phase with varying degrees of success:

- Online Survey
 - Key informant interviews (were a part of HSA and this section)
 - Thomson Reuters data, principally through Household Targeter and Health Status Profiler
-

Online Survey

An online survey was carefully prepared and marketed to the community. We actually received 472 full responses and 34 less than complete responses – three times the number received in the 2009 Community Profile survey. The survey branched to focus on four specific groups: survivor/patient (n=163), family member/caregiver (n=107), community member female (n=189) and community member male (n=12)). Keys to the response rate were marketing efforts via the Affiliate e-newsletter, posting on the Affiliate’s Facebook page, and most importantly a separate emailing to all known addresses.

Unfortunately, responses in target areas, were not strong; nor were responses from Blacks and Hispanics, our most important minority groups. We did get overall responses of interest which are worth noting, and which prompted research through the Thomson Reuters programs to see if we could hone in on our target areas that way.

In the survivor/patient survey:

- Main source of information about breast health and breast cancer is health professionals, by far.
- Breast cancer was diagnosed by mammogram most of the time, therefore mammogram adherence is crucial.
- Fear/emotional upset and family disruptions were the main obstacles faced during breast cancer diagnosis and treatment.
- Health professionals were the key information sources regarding all types of support services available for breast cancer.
- The need for navigators and advocates, more education, and support was also expressed.
- Problems with insurance are an issue for some.

Among family member/caregivers:

- Health professionals are still the key players.
- Fear/emotional upset and finances were the main obstacles.
- Providing emotional support was the toughest thing.

Among community members:

- Most females rated their knowledge “good” of breast health and breast cancer
 - Most females believe that family history is more important than age in being the most important factor that influences screening for breast cancer.
 - A very high percentage of females have had a mammogram and have one yearly
 - Among males, the single most important thing that stands out is lack of education/awareness.
-

Key Informant Interviews

In some cases, we would expect our target area residents to have responses “even more so”. In other instances, as seen in our Key Informant Interviews, information would suggest very divergent views. Our Key Informants, community leaders and agency provider professionals, talked a lot about “no shows” for mammograms in our target communities. Clients are sometimes too busy, fearful of the results, don’t want to know the result, or just don’t seem to care about their own health. There are taboos as well – e.g. touching their breasts being a sex act. This suggests that a lot more education and navigation is needed in these areas. Written educational information must be geared to low reading levels, and preferably offered (written or orally delivered) in native languages. Mobile mammography needs to be extended to St. Lucie County, particularly Ft. Pierce. Financial constraints are clear as well, with reports in The Glades and Ft. Pierce of recession impact loss of jobs and foreclosures. Public transportation is an issue in Indiantown and The Glades when treatment becomes a priority.

The least responded to questions among the key informants dealt with questions of advocacy. It became clear that most key informants were too busy with service delivery issues to devote much time to this area. It falls to the South Florida Affiliate, whose primary mission is not service, to take a lead in this area.

Many problems can be solved with money – more for education, diagnoses, treatment, follow-up, support programs, transportation, etc. It becomes incumbent on the Affiliate to seek innovative ways to raise more dollars to address the pressing needs.

Thomson Reuters Data

Using the Thomson Reuters programs mentioned at the beginning of this section, we were able to uncover important information about our target areas – some actual statistics, and propensity of the population residing there to act in certain ways in comparison to the county, state or national norm. We have pages of these that will guide further planning by the Affiliate. A few examples appear below:

- Except for our SW Seniors, all other target groups score lower than the norm for getting health information from any source – doctors, websites, newsletters, and libraries. The SW Seniors are predominately tuned in to their doctors and newsletters.
- Again, except for our Seniors, all other areas score low on questions like “Expect Doctors Treatments to Work All the Time”; “Rely on Doctor to Guide Me on Medicine/Health Matters”; “Don’t See Doctors/Nurses Unless Very Ill”; “I Always Do What My Doctor Tells Me to Do”. Clearly there is distrust of the health care system, which in many cases is justified for minority group members. However, data shows that this does not lead them to alternative medicine practitioners.
- When it came to how I treat myself in regard to health care, it was a mixed and sometimes contradictory target area response to questions like “Too Busy to Take Care of Myself as I Should” and “Pay Anything When It Comes to My Health”. Of course, many other factors impact on these questions.
- For females age 40+, we know from the Quantitative analysis done for this report, that all target areas show lower percentages of mammograms than their county norm. In the Glades, Indiantown and SW Seniors, the second most important reason, after didn’t have time, was “chose not to”. SW Seniors also scored high on “didn’t need”. Unfortunately

responses related to fear/pain were not significant enough to be specified and were grouped under “other”.

- We were also able to look at primary reason for having a mammogram performed in the past year. All target areas except SW Seniors were low on annual and high on baseline. The Glades, Indiantown, and Ft. Pierce were high on diagnostic. This information corroborates what we know about delayed screening and higher late stage diagnosis in Blacks and Hispanics.
- Several questions related to healthy eating, dieting and exercise were explored. The Glades, I95 Corridor, Indiantown, and Ft. Pierce score very poorly on all these - factors which can be related negatively to cancer.
- Job losses and job changes within the past year were particularly high in The Glades and Ft. Pierce, sometimes resulting in the loss of insurance. However, residents of all our target areas are less likely to have insurance through their employers than the norm.
- Except for SW Seniors, our other four areas, not surprisingly, have issues with money. Higher percentages go without credit cards, ATM cards, savings accounts, and checking accounts. This often means that they won't go for medical services unless the care is provided free, or they have cash in their pockets.
- If we are looking to introduce more educational programs, the place in most target areas is the churches and synagogues, much more so than civic clubs, fraternal orders, local PTA's, religious clubs, unions, veterans clubs, or AARP.
- We explored information on where people notice ads – bus stops, buses, taxis, and movie theaters. There are new avenues to consider, different ones in different target areas.
- The statistics also suggest that different media vehicles need to be tested. The Affiliate's most expensive TV effort (i.e. Focus for the Cure – a two minute breast health educational spot on a local TV news station) may not be reaching the poor minority people of four of our target areas. When we're ready to study this in depth, we can find the time of day when people are listening and watching, and what they are tuned into, to enable us to derive maximum impact. For example, Indiantown which is heavily Hispanic, shows that potential exists for reaching adults by advertising or educating on kids programs, since Hispanic adults like watching them with their children.
- Questions related to altruism, faith, and volunteerism showed highest propensity in the SW Seniors Area and Indiantown. Low responses in other areas probably reflect greater day to day hardships.
- Other than SW Seniors, other target groups are relatively low on making charitable contributions, although their participation is probably significantly higher than might be expected given their dire economic status.
- In an effort to solve the money problem, we did a review of zip codes and block groups that have the propensity to make a contribution of at least \$100 to a health care organization other than a hospital. There are some surprising results which show that PRIZM cluster groups slightly removed from the top of the socioeconomic ladder may be the most willing to make these kinds of contributions. Individual household names and addresses, by block group, need to be tested.

To reiterate, this is just the “tip of the iceberg” in terms of what Market Expert can offer in regard to mission and non-mission work of the Affiliate – for the Community Profile and far beyond in our planning efforts.

In the discussion of breast cancer perspectives in the Community Profile committee, we were reminded about the important role that staff plays within our agencies and most particularly at the Komen Affiliate itself. It's critical to retain staff. Once they can see beyond the basics of their day-to-day jobs, they can become visionaries and move the Affiliate in important new directions.

The workforce should not be taken for granted – turnover and burnout should be avoided whenever possible. A revolving door produces real loss. Those who stay create institutional consistency and knowledge.

In sum, as an Affiliate we could do a much better job understanding our target area populations and how best to serve them. Some of the results in this section are “eye-opening”. We need to use tools like surveys, focus groups, and Market Expert to a greater degree in this effort. Most importantly we need to broaden the participation of our most important minority groups, and be open to new methods of communication and engagement.

Human resources are our only resource, both lay and professional. They will drive the activities and fund raising of the Affiliate. To a significant degree the former depends on the latter. Our objective needs to be “to increase the pie, rather than have competing demands fighting over the crumbs”. Proven resource development avenues must be incorporated within the scope of the Affiliate.

Lessons Learned

- The use of Survey Monkey as a tool is a turnoff to some members of the African American community. The word ‘monkey’ is viewed as a derogatory term. While we do not know exactly how many people this influenced, we would use a different online survey company next time.
- Online surveys will not reach people without computers, or for whom we do not have an email address. A post survey analysis revealed that our strength in email addresses lies in places outside our target areas – Jupiter, Palm Beach Gardens, Wellington, and western Lake Worth.
- We received weak responses from those racial/ethnic groups without strong connection to the Affiliate. Our experts tell us that these groups hesitate to participate in research unless it is clear that they will benefit from it.
- Graduate student interns with busy schedules and based far from the Affiliate area cannot be relied upon as the core staff to accomplish focus groups.

Conclusions: What We Learned, What We Will Do

Given that we have collected so much data and so much information, it is no easy task to pull it all together. Priorities and action steps could be identified that could keep us busy for years. We have attempted, however, to pick out those few that are most pressing, and focus on them for the next two years.

Problem/Need #1: Diversity

The South Florida Affiliate of Susan G. Komen for the Cure is “perceived as a white, middle/upper class organization”. Perception is reality for those doing the viewing, and every indicator shows that the perception of us is right on target. This is a blunt truth that we have come to understand over the course of this study.

Priority: In word and deed to change the identity of the South Florida Affiliate to make it more truly representative of the populations we serve. If we are going “to talk the talk, we must walk the walk”.

Objectives/Action Steps:

- A. Strengthen efforts to recruit and place minority individuals in positions of responsibility and visibility including, but not limited to, board membership, committee chairmanships and membership, office volunteers, race leadership positions, and Warriors in Pink. (By Apr 2013)
- B. Solicit vendor bidding from qualified minority contractors located in our service area, particularly those based in our target areas. (April 2011; Ongoing)
- C. Replicate educational events like this year’s luncheon (focused on the Black Community), partnering with other racial and ethnic groups in our service area. Each must be specifically designed to a community – no cookie cutter approach will work. (First by Sep 2011)
- D. Fund and utilize model of community empowerment in an effort to outreach, educate, and service minority communities in our target areas. (Begin Aug 2011)
- E. Reevaluate resources budgeted for “Focus for the Cure” to determine whether the medically underserved are benefitting from this program. (By Dec 2011)

Problem/Need #2: Advocacy

Encouraging breast health and fighting breast cancer is an awesome undertaking. “The burden is too great; we cannot do it alone”. In these times of economic scarcity and cuts in state budgets, the challenges become even greater. Komen has no presence in 36 of 67 counties, or in the state capital of Tallahassee. The Florida affiliates are in the fledgling state of joint advocacy efforts. In Palm Beach County we are not participants in the Breast and Cervical Cancer Early Detection Program because no site is located within our boundaries or even close.

Priority: Expand capacity to influence government priorities, policies and funding. Focus in on most important issues of the day recognizing that they will change from year to year.

Objectives/Action Steps:

- A. Continue to take a leadership role in the development of the Florida Advocacy Alliance of Susan G. Komen for the Cure through the devotion of lay and professional staff time and energy. (Ongoing)
- B. In concert with other affiliates, outreach to legislators in all areas of the State, understanding that not all districts have Komen affiliates. Each and every vote counts. (Ongoing)
- C. Support the continued funding for BCCEDP for the State of Florida. (Ongoing)
- D. Support Breast Cancer Bill of Rights initiative of the Advocacy Alliance of Komen national. (Ongoing)
- E. Investigate a non-legislative solution requiring physicians to speak to their patients about breast density, so that women are made aware of their risk, and their options for moving forward. (Ongoing)
- F. Continue to partner with other cancer organizations in urging support of legislation requiring insurance plans to provide coverage for oral cancer drugs on a basis that is no less favorable than intravenously-administered chemotherapy. (Ongoing)
- G. Promote County transportation plans that will enable the poorest of our clients to reach breast health and breast cancer services. (Ongoing)

Problem/Need #3: Service Initiatives

As we would expect, no service system is perfect. “There are gaps that need to be plugged.” It varies from target area to target area, and covers the continuum of care model categories of education, screening, diagnosis, treatment, follow-up care and survivorship.

Priority: Plug at least one hole in each target area, and address three of the needs in the broader service area.

Objectives/Action Steps:

- A. In the Glades, facilitate the execution of a partnership between Lakeside Medical Center and Palms West Hospital for services, beyond screenings, so as to alleviate the extremely long trip to Boca Raton Regional Hospital. Once established, a navigator should be put in place. (By Mar 2012)
- B. In the I95 Corridor, utilize the community empowerment model to organize and train local volunteers in pursuit of increased education, screening, support groups and other services through established churches, organizations and other entities in the area. (Begin by Aug 2011)
- C. Provide educational programs in the SW Seniors target area on the need for continued screening beyond menopause. Risk increases with age and this point needs to be driven home. The benefits of BRCA gene testing also need to be explained for the patient, as well as educating in regard to the implications for family members. Active adult and senior communities in this area are readily available as sites, and the new mobile mammography van at Boca Raton Regional Hospital can be enlisted. (Begin by Dec 2011)
- D. Provide a grant to the Martin County Department of Health for screening of the undocumented in Indiantown. (Begin Apr 2011)

- E. Provide breast health education and referrals by partnering with churches and community organizations in the Ft. Pierce Area. (Begin by Dec 2011)
- F. Create directory of breast health and breast cancer services for Palm Beach County. Can be done as a “stand alone” or as an addition to the one that exists in Martin and St. Lucie Counties. Will require hard copy and on-line versions, as well as careful translation and adaptation. (By March 2012)
- G. Foster new coalitions of breast health providers and practitioners in Palm Beach County, and continue to support the existing ones in Martin and St. Lucie Counties. (Begin Sep 2011)
- H. Continue to provide education/networking sessions for all grantees where the objectives will be to understand what each grantee does, to collaborate, and to encourage them to help recipients understand Komen’s funding role in the provision of services. (Begin Aug 2011)

Problem/Need #4: Financial and Human Resource Development

“We have so much to do, and so little money to do it with”. When we show the State our willingness to step it up, they too will be further motivated. And to make this happen, we have only one resource – people – who will be our volunteers and donors in this effort. We, and many other charities, are not talking full advantage of the tax laws of the United States in regard to philanthropic giving. In the past couple of years, we have lost some donors, and efforts must be mounted to recapture them.

Priority: Increase the funds available to the Affiliate that will enable us to increase the breast health and breast cancer services afforded to our population.

Objectives/Action Steps:

- A. The Board should revisit and reconfirm its obligation to raise funds and ensure that adequate funds are secured to support the Affiliate’s services and programs. It should examine various strategies, agreeing upon and implementing those approaches that will likely prove most successful. (By Mar 2012)
- B. Utilize Market Expert to identify households with highest propensity to give to health care organizations. Create a fund raising plan that includes a direct mail campaign, individual solicitation for major gifts, and additional events targeted to high prospect donors. (Begin Oct 2011)
- C. Create a comprehensive Affiliate planned giving program to maximize long term benefit from the gifts of our large senior population. The Community Foundation of Palm Beach and Martin Counties might be both a resource and partner in this effort. (By Dec 2012)
- D. Communicate the advantages of the Tax Relief, Unemployment Insurance Reauthorization, and Job Creation Act of 2010 allowing taxpayers over the age of 70 ½ to make contributions of Individual Retirement Account (IRA) assets of up to \$100,000 per year **directly** to a charity. There is no federal tax impact and the gift will be counted toward the required minimum distribution. Unless renewed, this opportunity expires at the end of 2011. (By Aug 2011)
- E. Attempt to recapture significant contributions from third-party events and the Race that were lost as a result of the “Egyptian Conference Controversy” that created a negative image for Komen. The facts tell a very different story and certain country clubs and

individual donors should be afforded the opportunity to return to the fold. (Begin Apr 2011)

- F. The Affiliate should help build the capacity of grantees to find additional financial resources. (Ongoing)
- G. Staff education should be strengthened and career path development instituted within the Affiliate. This will enable us to minimize staff turnover and provide better and more informed services to the community. (Begin Apr 2011; Ongoing)

Problem/Need #5: Strategic Planning

As much as we have learned in this Community Profile that will better enable us to address the challenges of the next two years, we must force ourselves to “look beyond today to the challenges of tomorrow”. Once a problem can be seen for what it really is, the solution is not far behind.

Priority: We must make planning a priority for the South Florida Affiliate. “What isn’t planned for just will not happen on its own”.

Objectives/Action Steps:

- A. The employment of a new Executive Director is an opportune time to set the course for the next five years. It is a time frame of this length, plus comprehensiveness, which distinguishes the process of Strategic Planning from short term planning efforts like the Community Profile. Once such a process is completed, it needs to be continually evaluated and updated as conditions change – to be “evergreen”. (By June 2012)
- B. In the Community Profile we have touched on areas – mission and non-mission – that need further research. Provide training to staff on Market Expert to enable them to use this tool for service planning, fund raising, marketing and communications. (Begin June 2011)
- C. Given the diversity of our service area, we need to do more qualitative research - focus groups and surveys - with various constituencies. Relationships with local university programs should be strengthened to enable this to happen. Language and cultural sensitivities will be required. (By Sept 2011)

Resources

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Susan G. Komen for the Cure – national website, www.komen.org

Susan G. Komen for the Cure, South Florida Affiliate – website, www.komensouthflorida.org

Thomson Reuters healthcare information company – special data sets and programs (including Market Expert)

U.S. Census Bureau – American Community Survey, 2005-09; 2009 Population Estimate; American Factfinder; www.census.gov