



COMMUNITY PROFILE REPORT

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2011

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ACKNOWLEDGEMENTS

Community Profile Team

Alice Dukes, Community Profile Chair

Susan G. Komen, Acadiana Affiliate Board and Staff, Lafayette, LA

Toni Guillotte, President

Elizabeth Cole, Secretary

Jimmy Dupuis, Treasurer

Roxan Goudeau, Grants Chair

Shalondra Lewis, Education Chair

Susan Allardyce, Public Relations Chair

Sandi Hernandez, Board Member

Heather Blanchard, Executive Director

Breast Center of Acadiana, Lafayette, LA

Iberia Comprehensive Health Center, New Iberia, LA

Iberia Medical Center, Lafayette, LA

Lafayette Community Health Care Clinic, Lafayette, LA

Louisiana Oncology Associates, Lafayette, LA

OncoLogics, Inc., Lafayette, LA

Opelousas General Health System, Opelousas, LA

University Medical Center, Lafayette, LA

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Executive Summary

Introduction

Founded in 1999, the Acadiana Affiliate of Susan G. Komen for the Cure® held its first Race for the Cure® in 2000. A gradual change in leadership and dynamics in 2004 through 2006 led the affiliate to experience phenomenal growth in Race participants as well as funds raised, thus enabling the Affiliate to significantly increase grant funds available to community organizations. Since its inception, the Acadiana Affiliate has invested over \$1.8 million in the fight against breast cancer, with \$1.4 million being granted out to non-profit organizations in the Acadiana area. Local grants are restricted to breast cancer education, screening and treatment programs to educate the community about the importance of breast health and early detection, to assist the medically underserved in our community and to support those battling this disease.

Susan G. Komen for the Cure® and its affiliates are governed by a *Promise* to save lives and end breast cancer forever by empowering people, ensuring quality of care for all and energizing science to find the cures. As such, Komen Acadiana has a part to play in achieving this *Promise*, and that can be done by ensuring that our effectiveness in the community is optimized by strategically choosing areas of greatest need in the Acadiana community.

The purpose of the community profile is to provide Komen Acadiana with a tool that can be used to inventory current programs and determine the Affiliate's future course of action. The community profile includes an overview of statistics, of both demographics and breast cancer. These statistics lead to suggested courses of action that will garner the most impact in our service area. The community profile will aid us in effectively meeting our challenges, will help us to control our change creatively, and will guide us toward a future in a world without breast cancer.

Statistics and Demographic Review

The community profile relies on data obtained from Thomson Reuters© 2009 and The National Cancer Institute SEER data (2003-2007). To reach a targeted understanding of Acadiana, demographic analysis was performed at the parish level based on information obtained from the 2000 Census as well as detailed parish profiles from the US Census Bureau, Acadiana Regional Development District and the US Bureau of Labor Statistics. Health Provider information and cancer and insurance reports for each parish were obtained from the Louisiana Department of Health and Hospitals.

Following a review of relevant statistics, there are two separate, but related areas of concern in the Acadiana area.

First, according to the NCI State Cancer Profile 2003-2007, the mortality rate for African-American women in Lafayette Parish is significantly higher than mortality rates for any other race in any other parish in the Acadiana area and well above the state and national rates. This statistical significance is of particular concern as Lafayette Parish offers the majority of breast cancer resources for our area.

Second, African-American women in all six parishes are diagnosed in Stages 3 and 4 at double the rate of other races. Given the decreasing survival rates for late stage diagnosis, this statistic causes great concern for the chances of survival of African-American women once they are diagnosed.

Based upon these findings, the first target community is African-American women in all six parishes due to the high rate of late stage diagnosis. In addition, African-American women in Lafayette Parish, in particular the 70501 zip code, represent the second target community based upon the high mortality rate.

Health Systems Analysis

The information of services available in the Acadiana service area was obtained through personal interviews, phone interviews, and the utilization of medical services directories as a guide for the location of services. Key informant interviews were conducted with the following entities:

- Breast Center of Acadiana
- Iberia Comprehensive Community Health Center
- Lafayette Community Health Care Clinic
- Louisiana Oncology Associates
- OncoLogics, Inc.
- Opelousas General Health System
- University Medical Center

Within the Acadiana area, Lafayette is the most populated and most progressive parish, and as a result, it is home to the majority of breast screening resources within Acadiana. It is important to note, however, that comparable breast screening services are available in 4 of the 5 remaining parishes in Acadiana. These include Acadia, Iberia, St. Landry and Vermilion parishes. Our research yielded no information on breast screening providers in St. Martin parish.

Lafayette Parish is also the location of the only two Louisiana Breast and Cervical Health Program providers in our service area. LBCHP providers differ from other service-providing organizations in that women who are diagnosed through the LBCHP can be "fast-tracked" into the state Medicaid program for treatment. For uninsured women in Louisiana the critical element is awareness of the program's complexities and

limitations. The reason for this is that should a woman receive screening and/or treatment through a provider other than an LBCHP provider, they are disqualified from future service under the LBCHP program.

While the bulk of services available in our service area are located in Lafayette Parish, providers of free or low-cost screening services indicated that African-American women are not fairly represented in the individuals who take advantage of their services. The need to strengthen outreach efforts is high because providers felt they are still not reaching the most critical populations, those areas where there is a higher incidence of late stage breast cancer diagnoses. Education outreach can inform women of the risks of failing to receive preventative care and also make them aware of all of the resources available to them for screening and treatment. Outreach efforts are needed not only to individuals in the community but also to providers in the priority zip code areas to make them aware of the resources available for patients and of the role that the LBCHP plays.

There is also a need to create new ways of getting the targeted communities into the continuum of care. Providers indicated that merely offering free screenings does not always get individuals to take advantage of the services available.

Qualitative Data Overview

Following a review of the services in the area and discussions with providers about gaps within the continuum of care, the Acadiana Affiliate embarked on a mission to determine the perspective of the targeted community on these issues. Multiple sources were used to collect and compare data including the use of surveys, personal interviews and focus groups. Surveys were sent out throughout the community soliciting responses from African-American women throughout all six parishes. Special efforts were made to reach African-American women in Lafayette Parish, in particular the 70501 zip code. Surveys were received from fifty-six (56) individuals. Three focus groups were conducted. The participants in all three focus groups were African-American women between the ages of 25-65 and one focus group was limited to residents of Lafayette Parish. Interviews with breast cancer survivors were also conducted.

There were several recurring themes in both the focus groups and surveys as to the specific reasons that African-American women may not take advantage of services which are available, including lack of income/insurance, lack of awareness of available resources, and lack of treatment options.

Community awareness and education must be made a priority. Individuals in the targeted areas need to be made aware not only of the increased risk which they face based upon the failure to get regular mammograms but also of the services which currently exist in the community. Survey respondents and focus group participants indicated the significance that this knowledge has on their actions. If people are more

aware of the risks AND aware that there are services available, they are more likely to get screened.

Conclusions

In the Acadiana area, African-American women throughout all six parishes are at a higher risk based upon late stage diagnosis than other races in this area. In addition, African-American women in the 70501 zip code of Lafayette Parish have the highest breast cancer mortality rate of any race in any of our six parishes. As there are currently numerous free screening programs available to women in this area, the gap seems to be in education and awareness.

After analyzing the statistics and survey data, and evaluating the programs and services in the Komen Acadiana service area, the Acadiana Affiliate will implement the following Action Plan.

Priority 1: Expand awareness and educational outreach programs to African-American women throughout Acadiana.

Without knowledge of their increased risks and awareness of the existing programs, African-American women are failing to get screened and therefore failing to increase their chances of survival in the event they are diagnosed with breast cancer.

- *Objective 1:* Partner with the public health units, community health clinics, and other key resources to provide greater breast health educational materials to the targeted communities.
- *Objective 2:* Develop partnerships with groups within the African-American communities such as churches and sororities to increase education and awareness.
- *Objective 3:* Implement a “Pink Sunday” educational program in churches.

Priority 2: Increase awareness and educational outreach programs to African-American women in Lafayette Parish.

There are more services available in this area than in any other area of Acadiana, yet African-American women are still dying at a higher rate here. Getting these women screened has to be a priority.

- *Objective 1:* Develop an advertising campaign targeting African-American women to insure (1) awareness of the increased risk; and (2) awareness of available services.

- *Objective 2:* Compile a list of all breast health services available in Lafayette Parish and distribute that list throughout targeted communities.
- *Objective 3:* Work with providers to determine the best ways to get African-American women into the continuum of care.
- *Objective 4:* Identify “champions” or “ambassadors” within the African-American community to help promote education and awareness.

Priority 3: Educate providers as to the services available

Providers need to be aware of all of the services available in our service area and how they can work together to insure the best quality of care.

- *Objective 1:* Educate the public health units and community health clinics, as well as existing and past grantees, on all of the services provided by current Komen Acadiana grantees.
- *Objective 2:* Starting in 2011, conduct annual meetings of Komen Acadiana grantees to raise awareness of each other’s programs, to foster collaboration, and to build a stronger relationship with our affiliate.
- *Objective 3:* Continue to hold grant writing workshops to which all hospitals, community health clinics and public health units in all six parishes will be invited.

Priority 4: Establish a public policy committee to create and to implement a plan to maintain relationships with state and national legislators.

As we move forward as a community that is working to lessen the number of women dying from breast cancer each year it is critical that we develop relationships with our legislators so that we may have a voice toward positive change of programs that serve our under and uninsured women – a group of women who are most at risk.

- *Objective 1:* Proactively contact state and national officials that represent our service area to introduce Komen Acadiana to them and to maintain year round communications.
- *Objective 2:* Collaborate with the state officials who can be influential in addressing increases in funding for the Louisiana Breast and Cervical Health Program and moving Louisiana from an option two state to an option three state so that individuals can receive treatment under the program regardless of where they are diagnosed.
- *Objective 3:* Recruit public policy committee members to investigate the LBCHP program and find ways to get more of our providers qualified under the program.

Introduction

Affiliate History

Founded in 1999, the Acadiana Affiliate of Susan G. Komen for the Cure® held its first Race for the Cure® in 2000. A gradual change in leadership and dynamics in 2004 through 2006 led the affiliate to experience phenomenal growth in Race participants as well as funds raised, thus enabling the Affiliate to significantly increase grant funds available to community organizations. Since its inception, the Acadiana Affiliate has invested over \$1.8 million in the fight against breast cancer, with \$1.4 million being granted out to non-profit organizations in the Acadiana area. Local grants are restricted to breast cancer education, screening and treatment programs to educate the community about the importance of breast health and early detection, to assist the medically underserved in our community, and to support those battling this disease.

In 2011, the Acadiana Affiliate announced the largest grant slate in its history, granting \$408,000 to the following local programs:

Acadiana Medical Research Foundation: Louisiana Breast and Cervical Health Program. Provides evening screening events throughout the community and screening mammograms. Individuals screened in this program qualify for treatment under the Louisiana Breast and Cervical Health Program. Serving Lafayette, Iberia, Acadia, Vermilion and St. Landry parishes.

Breast Center of Acadiana Foundation: Outreach Screening Mammography Services for the Acadiana Area. Provides screening mammograms and transportation to screenings for the uninsured and underinsured women ages 35 and older with a special focus on Vermilion, Acadia and Lafayette parishes. Serving Vermilion, Acadia and Lafayette parishes.

Iberia Comprehensive Community Health Center, Inc.: ICCHC Mammography Access Program. Provides mammograms for uninsured women over the age of 40 who have not had a mammogram in the past year and breast health education with a focus on the African American community through partnerships with local churches. Serving Iberia, St. Martin, Vermilion and Lafayette parishes.

Iberia Medical Center Foundation: First Friday. Provides no-cost mammogram screenings to eligible residents and breast health education at an annual Women's Symposium. Serving Iberia, St. Martin and Vermilion parishes.

Lafayette Community Health Care Clinic: Mammograms for Life. Provides breast imaging procedures for low income, working, uninsured residents. Serving Lafayette Parish.

Lydia Cancer Association: Breast Cancer: Awareness, Early Detection & Treatment Assistance. Provides a Breast Cancer Awareness event, mammograms, financial assistance for supplements, prescriptions, medical expenses and transportation to and from treatment. Serving Iberia, St. Martin and Vermilion parishes.

Miles Perret Cancer Services: Survivorship – A Lifelong Journey. Provides programs and services of support to breast cancer patients, including emotional support, medication assistance, support groups, wigs, hats, turbans, scarves, oral supplements, mastectomy bras, prostheses, medical supplies and educational programs. Serving Lafayette, Acadia, St. Martin, Iberia, St. Landry and Vermilion parishes.

Miles Perret Cancer Services: Transportation to Treatment. Provides financial assistance to breast cancer patients to cover the cost of transportation to get to and from treatment. Serving Lafayette, Acadia, St. Martin, Iberia, St. Landry and Vermilion parishes.

Opelousas General Health System: Paint the Town Pink. Provides education, mammograms/ ultrasounds and a retreat for breast cancer survivors as well as a parish-wide education and awareness event. Serving St. Landry Parish.

Sallie Astor Burdine Breast Foundation Lafayette Affiliate: Ancillary Services Required as a Result of Radiation Therapy for Breast Cancer Patients. Provides financial assistance to breast cancer patients undergoing radiation therapy. Costs may include transportation, prescriptions, over the counter medications, treatment for side effects, diagnostic or other follow up scans or tests and physical therapy. Serving Lafayette, Acadia, St. Martin, Iberia, St. Landry and Vermilion parishes.

Sallie Astor Burdine Breast Foundation Lafayette Affiliate: Gentlewaves Treatment. Provides Gentlewaves treatment to radiation patients, which decreases the pain and skin reactions of radiation. Serving New Iberia and Lafayette parishes.

Sallie Astor Burdine Breast Foundation Lafayette Affiliate: Radiation Cost Assistance for Breast Cancer Patients. Provides financial assistance to breast cancer patients for radiation treatment costs. Serving Lafayette, Acadia, St. Martin, Iberia, St. Landry and Vermilion parishes.

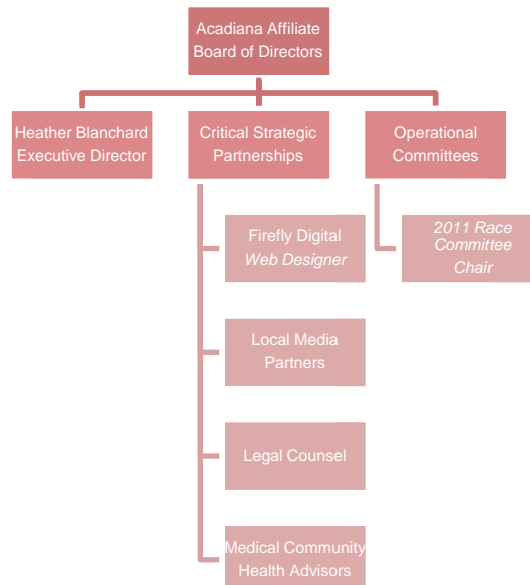
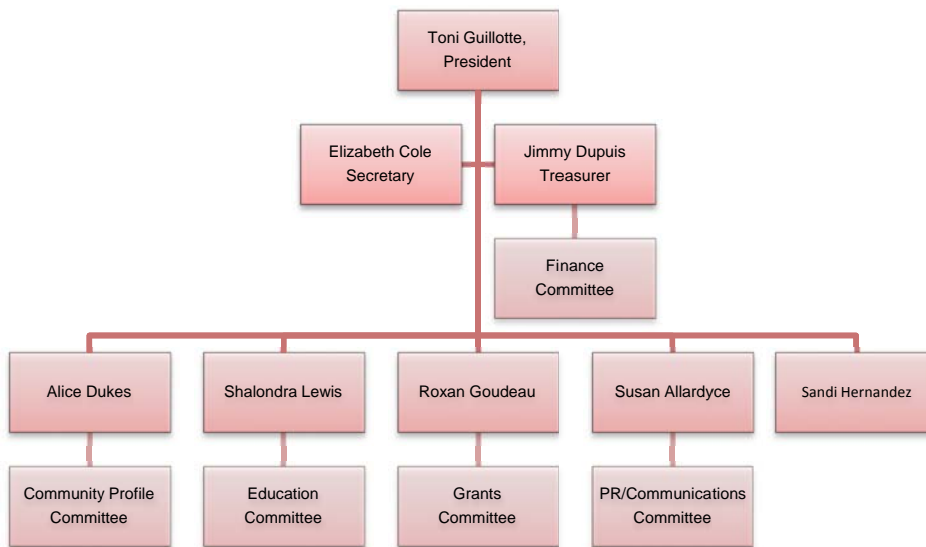
In addition to our grant program, local volunteers have acted on behalf of the Acadiana Affiliate through outreach programs designed to increase awareness and knowledge of breast health and Komen activities. Increasing awareness of breast health practices through distribution of educational materials and speakers is vital to achieving our Promise.

Organizational Structure

Komen Acadiana is primarily volunteer based with one full-time staff member. Within the past year, the Affiliate has acquired office space where board meetings are held and where our Executive Director works.

The following chart represents the current organizational structure of the Acadiana Affiliate.

Komen Acadiana Affiliate of Susan G. Komen for the Cure® August 2011



Description of Service Area

The Acadiana Affiliate's service area is defined by the region affectionately known as Acadiana. With the city of Lafayette as its hub, Acadiana consists of the following parishes: Acadia, Iberia, Lafayette, St. Landry, St. Martin, and Vermilion.

Lafayette is a metropolis, which displays an extraordinary mixture of tradition and progressiveness while the surrounding five parishes within our service area are primarily rural. Lafayette lies 15 miles west of the Atchafalaya Basin, 35 miles north of the Gulf of Mexico and exhibits the subtropical climate typical of South Louisiana. The city is situated in a geographical area of forests and prairies interlaced with bayous, swamps and marshes. Most cities, villages and towns are centered on agriculture, oilfield service and/or fishing industries. While not entirely, members of these rural communities are largely dependent upon medical services in Lafayette for treatment.

The following are statistics of the Komen Acadiana service area taken from Thomson Reuters© 2009 and the Louisiana Department of Health and Hospitals.

- **Acadia parish**
 - Located west of Lafayette, LA
 - Designated medically underserved
 - Total population is 58,894
 - Female population is 78.2% White and 20.5% African American
 - Median household income is \$36,844; 21.7% of families live below poverty
 - 26.1% of females age 18-64 are uninsured

- **Iberia parish**
 - Located southeast of Lafayette, LA
 - Designated medically underserved
 - Total population is 76,654
 - Classified rural by the LA Department of Health and Hospitals
 - Female population is 61.3% White and 34.2% African American
 - Median household income is \$40,686; 20.9% of families live below poverty
 - 26.1% of females age 18-64 are uninsured

- **Lafayette parish**
 - Considered the "Hub City" for surrounding parishes
 - Designated partially-medically underserved
 - Total population is 211,536
 - Female population is 69.0% White and 26.6% African American
 - Median household income is \$45,365; 11.7% of families live below poverty
 - 20.0% of females age 18-64 are uninsured

- **St. Landry parish**
 - Located north of Lafayette, LA
 - Designated medically underserved

- Total population is 97,684
 - Female population is 57.1% White and 41.2% African American
 - Median household income is \$27,653; 24.5% of families live below poverty
 - 37.4% of females age 18-64 are uninsured
- **St. Martin parish**
 - Located east of Lafayette, LA
 - Designated medically underserved
 - Total population is 45,923
 - Female population is 64.5% White and 33.4% African American
 - Median household income is \$42,087; 17.5% of families live below poverty
 - 24.3% of females age 18-64 are uninsured
 - Highest percentage (43.5%) of women over the age of 40 who have not had a mammogram in the past 12 months according to 2009 statistics
- **Vermilion parish**
 - Located southwest of Lafayette, LA
 - Classified rural and medically underserved
 - Total population is 56,164
 - Female population is 82.0% White and 14.5% African American
 - Median household income is \$38,264; 16.5% of families live below poverty
 - 24.9% of females age 18-64 are uninsured



Purpose of the Report

Susan G. Komen for the Cure® and its affiliates are governed by a *Promise* to save lives and end breast cancer forever by empowering people, ensuring quality of care for all and energizing science to find the cures. As such, Komen Acadiana has a part to play in achieving this *Promise*, and that can be done by ensuring that our effectiveness in the community is optimized by strategically choosing areas of greatest need in the community of Acadiana.

The purpose of the community profile is to provide Komen Acadiana with a tool that can be used to take an inventory of current programs and determine the Affiliate's future course of action. The community profile includes an overview of statistics; of both demographics and breast cancer. These statistics lead to suggested courses of action that will garner the most impact in our service area. The community profile will aid us in effectively meeting our challenges, will help us to control our change creatively, and will guide us toward a future in a world without breast cancer.

Breast Cancer Impact in Affiliate Service Area

Methodology

The community profile relies on data obtained from Thomson Reuters© 2009 and The National Cancer Institute SEER data (2003-2007). To reach a targeted understanding of Acadiana, demographic analysis was performed at the parish level based on information obtained from the 2000 Census as well as detailed parish profiles from the US Census Bureau, Acadiana Regional Development District and the US Bureau of Labor Statistics. These secondary data sources provide demographic data by parish on housing, real estate, cost of living, wages, employment levels, health and mortality statistics.

Additionally, parish incidence and mortality rates were obtained from Thompson Reuters© 2009 as well as the National Cancer Institute's (NCI) State Cancer Profiles. Health Provider information and cancer and insurance reports for each parish were obtained from the Louisiana Department of Health and Hospitals.

Issues with the Data

Data provided by The National Cancer Institute provides the most accurate look at breast cancer mortality and incidence as it reflects the actual numbers of individuals who are diagnosed and die from breast cancer. Due to the difficulty in gathering that real data, however, the NCI data always provides a view of the statistics several years in the past. Thompson Reuters provides a more current look at the rates but not via actual data, but rather by a projection based upon known information. Accordingly, we are always torn between relying on the NCI data which is not as current or the Thompson Reuters data which is more current but not an established fact. Further, with regard to the current data, the NCI SEER data currently available presents an additional problem. Due to Hurricanes Katrina and Rita, the NCI excluded data for Louisiana for a six-month period in 2005 due to the inaccuracy of information available. As such, when we review the NCI SEER data and see that Louisiana's mortality rate showed the largest drop among all states, we are not certain whether there was such a substantial drop or whether the lack of data for that six-month period is the cause for the change. When we examine the Thompson Reuters data for 2009 and see that the projection shows Louisiana to be second in the nation in breast cancer mortality, we are led to believe that the drop in mortality rate reflected in the NCI SEER data may not be entirely accurate. Therefore, we have concluded that we will proceed with our action plan with the understanding that while the state of Louisiana may be showing improvements in breast cancer mortality, our rates are still alarmingly high and a great cause for concern.

Overview of the Affiliate Service Area

According to the NCI State Cancer Profile 2003-2007, at 23.8 deaths per 100,000, Louisiana has the nineteenth highest breast cancer mortality rate in the United States. However, according to Thompson Reuters, as of 2009, Louisiana ranks second in breast cancer mortality. Furthermore, compared to all other parishes in Louisiana, the most populated and site of the most healthcare services in our service area, Lafayette Parish has the eleventh highest annual death rate for breast cancer.

Roughly 67 percent of the 546,677 people living in Acadiana are white and 28.5 percent are African American. The median household income is highest in Lafayette parish at approximately \$45,365. The lowest median income in Acadiana, \$27,653, is reported in St. Landry parish. Nearly 18 percent of families (or 25,705 families) living in Acadiana earn an income below the poverty level.

Over 25 percent of Acadiana females, ages 18-64, are uninsured. For these women, options for coverage of breast services are Medicaid and the Louisiana Breast and Cervical Health Program (LBCHP). LBCHP provides quality, no-cost, breast and cervical cancer early detection services to uninsured and underinsured, low and moderate-income Louisiana women aged 40 or over.

The Acadiana area also has a slightly higher rate of late stage diagnosis than the rest of the nation. The stage of diagnosis is vital in breast cancer patients as the rate of survival decreases significantly as the stage of diagnosis increases. According to Thompson Reuters, as of 2009, the national average for Stage 1 diagnosis is 64.2 percent with Stage 4, the worst-case scenario for breast cancer patients, at 4.6 percent. In Acadiana, fewer individuals (62.8 percent) than the national average are diagnosed in Stage 1, whereas 5.1 percent are diagnosed in Stage 4.

Communities of Interest

Following a review of relevant statistics, there are two separate, but related areas of concern in the Acadiana area.

First, according to the NCI State Cancer Profile 2003-2007, the mortality rate for African-American women in Lafayette Parish is significantly higher than mortality rates for any other race in any other parish in the Acadiana area and well above the state and national rates. In Louisiana as a whole, the mortality rate for white women is 23.9 and 37.7 for black women. Lafayette Parish's mortality rate is 26.3 for white women and 47.7 for black women. This statistical significance is of particular concern as Lafayette Parish offers the majority of breast cancer resources for our area.

The fact that Lafayette Parish has the highest mortality rate for black women is particularly troubling since overall, Lafayette Parish has the highest income, lowest percentage of uninsured women, lowest breast cancer incidence rate and lowest

percentage of women who have not had a mammogram in the past two years. A further break-down of demographics in Lafayette Parish reveals more concerns related to race. African-Americans make up 26% of Lafayette Parish's population. However, within Lafayette Parish, the 70501 zip code contains the largest black population with 75% of that population being black. In direct contradiction to the parish as a whole, the 70501 zip code has the lowest income of any zip code in the entire Acadiana area and the second highest percentage of uninsured women of any zip code in our area, higher even than rural areas where no medical services are present.

Second, African-American women in all six parishes are diagnosed in Stages 3 and 4 at double the rate as other races. Given the decreasing survival rates for late stage diagnosis, this statistic causes great concern for the chances of survival of African-American women once they are diagnosed.

Race	Parish	Stage I	Stage II	Stage III	Stage IV
White	St. Landry Parish	65.7%	26.8%	3.3%	4.2%
White	Vermilion Parish	65.5%	27.0%	3.3%	4.2%
White	Iberia Parish	65.4%	27.1%	3.3%	4.2%
White	Acadia Parish	65.4%	27.1%	3.3%	4.2%
White	St. Martin Parish	65.0%	27.6%	3.3%	4.2%
White	Lafayette Parish	64.9%	27.6%	3.3%	4.2%
White Total		65.2%	27.3%	3.3%	4.2%
Other	St. Landry Parish	65.0%	27.7%	3.2%	4.2%
Other	St. Martin Parish	63.9%	28.6%	3.3%	4.2%
Other	Lafayette Parish	62.5%	29.9%	3.4%	4.2%
Other	Iberia Parish	62.8%	29.7%	3.4%	4.2%
Other	Acadia Parish	63.2%	29.4%	3.3%	4.1%
Other	Vermilion Parish	62.1%	30.3%	3.4%	4.2%
Other Total		62.9%	29.6%	3.4%	4.2%
Black	St. Landry Parish	55.2%	31.0%	5.8%	8.1%
Black	St. Martin Parish	54.7%	31.5%	5.8%	8.1%
Black	Iberia Parish	54.8%	31.3%	5.8%	8.1%
Black	Acadia Parish	54.8%	31.3%	5.8%	8.1%
Black	Vermilion Parish	54.6%	31.5%	5.8%	8.1%
Black	Lafayette Parish	54.3%	31.8%	5.9%	8.0%
Black Total		54.7%	31.4%	5.8%	8.1%

Diagnosis by Stage, Race and Parish.

Thomson Reuters© 2009

The following chart, adapted from American Cancer Society and National Cancer Data Base materials illustrates the importance of early detection on survival rates, and more significantly, the devastating effect of late stage diagnosis.

Stage	Five-year overall survival
0 (non-invasive breast cancer, ductal carcinoma in situ (DCIS))	93%
I	88%
IIA	81%
IIB	74%
IIIA	67%
IIIB	41%
IIIC	49%
IV	15%

*Five-year Survival Rates by Stage of Diagnosis
American Cancer Society*

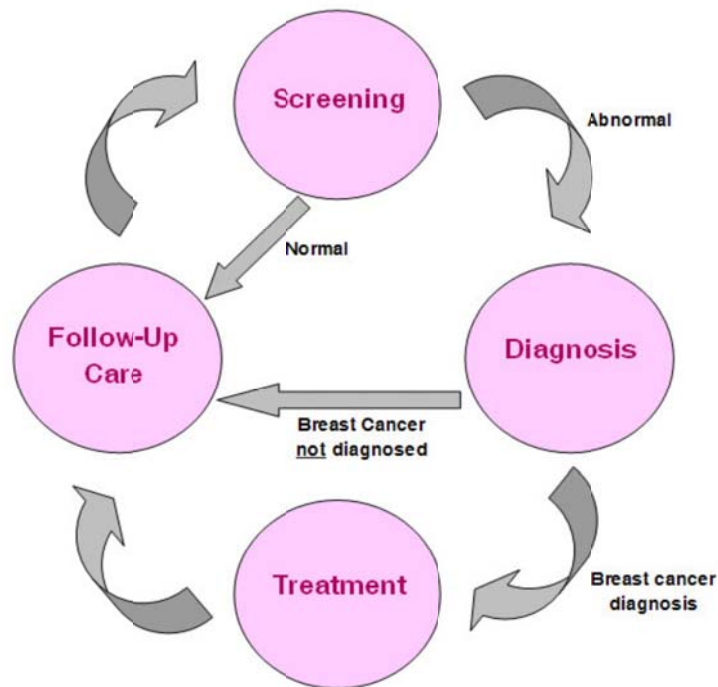
Conclusions

Based upon these findings, the first target community is African-American women in all six parishes due to the high rate of late stage diagnosis. In addition, African-American women in Lafayette Parish, in particular, the 70501 zip code, represent the second target community based upon the high mortality rate. Clearly the two areas of concern are related as individuals diagnosed in later stages have significantly lower chances of survival.

Health Systems Analysis of Target Communities

Overview of Continuum of Care

Continuum of Care



The continuum of care is the foundation for breast care. The four primary parts of the continuum of care include; screening, diagnosis, treatment and follow-up care. The first step in the continuum of care is screening. Providers indicated that the first challenge is often getting individuals into the continuum care by getting them into the screening process. Challenges cited through interviews and focus groups were lack of funds, time and a lack of awareness of the resources available.

If a woman has an abnormal reading providers arrange for a diagnostic screening, which is the second phase in the continuum of care. However, some providers noted that they are aware that some women do not follow up with additional screening when there is an abnormal reading. This gap in follow up was attributed to multiple factors including many of the same factors in the screening phase such as the lack of funds, time and awareness. Some providers shared that often, this gap is a result of the lack of guidance throughout the process. If an individual does not have a general health provider, they often get lost in the continuum of care if they do not have someone to guide them through each step. Providers indicated that patients are often unsure of

what to do next and without follow-up from a provider, patients will sometimes simply not take the next step.

In the event that a woman is diagnosed “positive” with breast cancer the next step is to treat the cancer. This is the most expensive phase of the continuum of care because most often the word “treatment” is not referencing singular care. In fact it often refers to a combination of treatments ranging from radiation, chemotherapy and surgeries. The primary challenge here is a lack of funds. This alone can stop a woman from moving forward in her breast cancer care, especially when patients are faced with paying their bills or receiving their breast cancer treatment. In this step, the process through which a patient is screened in the first step of the continuum plays a vital role. If the diagnosis comes from a Louisiana Breast and Cervical Health Program provider, an individual can be “fast-tracked” into the Medicaid program and all medical treatment will be covered. On the other hand, if the diagnosis comes from a non-Louisiana Breast and Cervical Health Program provider, an individual diagnosed with breast cancer could be left without treatment options. Many providers of free screenings are unaware of this important distinction and of the impact that the procedures which they employ in their screening process may have on an individual who is ultimately found to have breast cancer.

Along each phase of the continuum of care there is a constant need for education and outreach. Education and awareness of multiple locations to access free or low cost screening mammograms, diagnostic screenings and treatment procedures will allow providers to overcome the first hurdle in the continuum related to the lack of funds. Education will also assist in getting women in the targeted communities into the continuum of care as they become aware of the increased risk of delaying screening.

Methodology

The information of services available in the Acadiana service area was obtained through personal interviews, phone interviews and the utilization of medical services directories as a guide for the location of services. Key informant interviews were conducted with the following entities:

- Breast Center of Acadiana
- Iberia Comprehensive Community Health Center
- Lafayette Community Health Care Clinic
- Louisiana Oncology Associates
- OncoLogics, Inc.
- Opelousas General Health System
- University Medical Center

Overview of Community Assets

Screening Providers

Within the Acadiana area, Lafayette is the most populated and most progressive parish and as a result, it is home to the majority of breast screening resources within Acadiana. However, it is important to note that comparable breast screening services are available in 4 of the 5 remaining parishes in Acadiana. These include Acadia, Iberia, St. Landry and Vermilion parishes. Our research yielded no information on breast screening providers in St. Martin parish.

As previously stated, the gross majority of breast screening resources in Acadiana are found in Lafayette parish. Locations offering these services are:

- Breast Center of Acadiana
- Cancer Center of Acadiana at Lafayette General Medical Center
- Elaine M. Junca Women's Imaging Centre at Women's and Children's Hospital
- Laborde Diagnostics
- Regional Medical Center of Acadiana (formerly Southwest Medical Center)
- St. Agnes Breast Center at Our Lady of Lourdes Hospital
- University Medical Center

Screening resources provided at these locations include digital mammography, breast ultrasound, stereotactic breast biopsies, breast MRI, full-field direct acquisition digital mammography, CAD system, stereotactic aspiration, dedicated breast MRI and analog mammography. In addition to screening resources, some of these locations also provide post-diagnostic treatment through cancer care as well as breast cancer support groups.

In addition to the services offered in Lafayette parish, breast screening services, while limited, can also be found in Acadia parish at Crowley American Legion Hospital. There, patients have access to analog mammography and breast ultrasound. The same limited services are available in Vermilion parish at both Abbeville General Hospital and Abrom Kaplan Memorial Hospital.

Outside of Lafayette parish, the most comprehensive offering of breast screening services is in Iberia and St. Landry parishes. Patients in Iberia parish have inter-parish access to analog mammography, breast ultrasound, stereotactic breast biopsy, breast MRI and digital mammography. Services in Iberia parish can be found at three locations:

- Dauterive Hospital
- Total Women's Health
- Women's Clinic at Iberia Medical Center

Patients in St. Landry parish have inter-parish access to digital mammography, analog mammography, breast ultrasound, breast MRI, post-diagnostic cancer care and support groups. These services are available at the following three locations:

- Acadian Medical Center
- Opelousas General Health System (Main and South campuses)
- Opelousas General Hospital Imaging

Cancer Treatment Centers

Cancer treatment services are available at the following hospitals within the Komen Acadiana service area:

- Cancer Center of Acadiana at Lafayette General Regional Medical Center
- Opelousas General Health System
- St. Agnes Breast Cancer Center at Our Lady of Lourdes
- University Medical Center

In addition to hospital-based cancer treatment services, there are two cancer treatment specialists based out of Lafayette Parish: OncoLogics, Inc. and Louisiana Oncology Associates. Though based in Lafayette parish, both OncoLogics, Inc. and Louisiana Oncology Associates reach out to a number of the neighboring parishes.

OncoLogics, Inc. is a premier radiation oncology provider in the communities it serves, and is known as a source of education throughout those areas for preventative care, treatment and community resources for cancer patients. Though OncoLogics main offices are located in Lafayette parish, it also has locations in Acadia, Iberia and St. Landry, covering four of the six parishes in Komen Acadiana's service area. Not all treatment options are available in each location.

Louisiana Oncology Associates (LOA) offers a full range of medical services including chemotherapy administration. LOA currently has four freestanding offices: the main office in Lafayette and satellite clinics in New Iberia, Opelousas, and Crowley, offering services in 4 of the 6 parishes in Komen Acadiana's service area. These four parishes are Acadia, Iberia, Lafayette and St. Landry.

Community Health Centers

The Lafayette Community Health Care Clinic (LCHC) provides non-emergency healthcare services to low income, working, uninsured Lafayette Parish residents at no cost to the patients. LCHC provides programs to address community health care needs through collaborative partnerships. Since 2002, the Clinic has provided its "Mammograms for Life" program, which provides breast imaging and other procedures to aid in the diagnosis of breast disease. Women participating in the "Mammograms for

Life” program are provided the same level of care as those fortunate enough to have private healthcare coverage, giving them the peace of mind that comes from access to preventive health services and access to medical care to achieve the best possible outcome for identified conditions.

St. Bernadette Clinic was established in 1995 in collaboration with the Diocese of Lafayette and Our Lady of Lourdes in an effort to provide medical care to the non-working poor. The clinic provides non-emergency, medical care to the homeless and the poor at no charge, including breast and pelvic exams. While St. Bernadette Clinic has days allocated to outreach screening outside of Lafayette Parish, the challenge remains in finding a way to increase awareness of these programs among women in the area.

Breast and Cervical Cancer Early Detection Program

The goal of the LBCHP is to prevent unnecessary disease, disability, or premature death due to cancer of the breast and cervix in women who live in Louisiana. To accomplish this, LBCHP provides quality, no-cost breast exams, mammograms, and pap smears to women who qualify.

Women must meet the following guidelines in order to be enrolled in the LBCHP:

1. Must be between the ages of 40 - 64
2. Must have no insurance or be underinsured
3. Must meet income eligibility guidelines

The LBCHP continues to drive efforts to screen the maximum number of women possible based on its budget constraints. In 2008 the LBCHP filed a Freedom of Information Act with the CDC to obtain information on the budget allocation numbers. In doing so, they learned that Louisiana is the second worst funded state in the nation. There are approximately 100,000 eligible women in Louisiana and the LBCHP currently serves 10% of that number. Approximately 65% to 68% of the participants of the LBCHP are African American, the demographic that has the highest mortality in the state.

Partnerships

The Institute for Breast Health organizes an **Annual Breast Health Symposium**, an education and awareness event that is free to the public. The annual symposium also includes a fashion show celebrating Acadiana area breast cancer survivors. Komen Acadiana is an annual sponsor of this event.

The **Acadiana Tobacco and Cancer Coalition** is a group of local cancer organizations that meets monthly to discuss opportunities to collaborate and increase the impact that we, collectively, have on cancer in our community.

The **Community Foundation of Acadiana** was established to enhance philanthropy in the Acadiana region and the amount of financial support going towards charitable causes. This is a relatively new partnership that serves to assist Komen Acadiana in increasing the awareness of donors in our local community of our presence, educating our public on our available grants, and possibly creating new opportunities for future education and awareness events.

Though Komen Acadiana has contacted churches in our service area to promote our annual race, the faith-based community is an untapped resource. When it comes to important information, churches play a huge role in the lives of their members, especially in the African American community. A faith based outreach program that grows over time could be key to increasing awareness and educating their members on the breast health resources in Acadiana.

Public Policy Perspectives

The National Breast and Cervical Cancer Prevention and Treatment Act of 2000¹ allowed states to adopt a program, known as the state's breast and cervical cancer program (BCC). This program would consider women who were screened for and found to have breast or cervical cancer through the National Breast and Cancer Early Detection Program (NCCCEDP) as a special eligibility group for Medicaid. All states opted to participate in the program and selected one of the following three options that served to define qualifying factors for women:

- **Option 1:** Cover only women screened or diagnosed by the state's BCC program.
- **Option 2:** Cover only women screened or diagnosed by one of the state's BCC program providers. Option 2 differs from option one in that it includes women served by the provider but whose services are not paid for by BCC program.
- **Option 3:** Cover all women eligible for the state's BCC program, regardless of where they are screened or diagnosed.

As an option two state, Louisiana's Breast and Cervical Health Program (LBCHP) is a program that provides funding for breast and cervical screenings. The screenings are done by various organizations approved by LBCHP; LBCHP does not conduct the screenings, they merely provide the funding for said program. In addition, there are guidelines for participating organizations and eligibility requirements for women wishing to qualify for service under the LBCHP program.

LBCHP providers differ from other service-providing organizations in that women who are diagnosed through the LBCHP can be "fast-tracked" into the state Medicaid program for treatment. For uninsured women in Louisiana the critical element is awareness of the program's complexities and limitations. The reason for this is that should a woman receive screening and/or treatment through a provider other than an

¹ Public Law 106-354

LBCHP provider, they are disqualified from future service with an LBCHP provider. The implication of this is that should such a situation arise, a woman would be required to provide for her own treatment.

Enrollment in the Louisiana state Medicaid program is vital to low-income, uninsured women who are diagnosed with breast cancer. This affords these women the same treatment options as insured women. The challenge remains to raise awareness among uninsured women of the program and the importance of obtaining their initial screening and breast cancer diagnosis through the LBCHP.

In the Acadiana service area, there are only two LBCHP providers, Louisiana Oncology Associates and University Medical Center. If an individual receives a diagnosis of breast cancer at either facility under the LBCHP program, they qualify for Medicaid for all treatment. Not only does this assure them of treatment, they may select their own treatment providers

Conclusions

The need to strengthen outreach efforts is high because providers felt they are still not reaching the most critical populations, those areas where there is a higher incidence of late stage breast cancer diagnoses. Education outreach can inform women of the risks of failing to receive preventative care and also make them aware of all of the resources available to them for screening and treatment. Outreach efforts are needed not only in the community but also providers in the priority zip code areas to make them aware of the resources available for patients and of the role that the LBCHP plays.

There is also a need to create new ways of getting the targeted communities into the continuum of care. Providers indicated that merely offering free screenings does not always get individuals to take advantage of the services available. There need to be ways to make the screening process part of other services they are receiving. For example, Lafayette Community Health Care Clinic indicated that in general, individuals do not come in and ask for a mammogram. Rather, when the clients are at the clinic for other services, they are asked whether they have had a mammogram and if not, that service is automatically provided. If this procedure could be employed at other facilities, like University Medical Center, many more high risk individuals would enter the continuum of care.

Breast Cancer Perspectives in the Target Communities

Methodology

Multiple sources were used to collect and compare data including the use of surveys, personal interviews and focus groups. Surveys were sent out throughout the community soliciting responses from African-American women throughout all six parishes. Special efforts were made to reach African-American women in Lafayette Parish, in particular the 70501 zip code. Surveys were received from fifty-six (56) individuals. Three focus groups were conducted. The participants in all three focus groups were African-American women between the ages of 25-65 and one focus group was limited to residents of Lafayette Parish. Interviews with breast cancer survivors were also conducted.

Review of Qualitative Findings

When attempting to answer the question of why African-American women get regular preventative screenings less frequently than other races, there is clearly no single answer. This issue is not limited to our community but serves as a challenge across the nation. The answers given to this general question ranged from culture, to awareness, to lack of income. Numerous respondents indicated a general culture, particularly with older African-American women, to not go to the doctor unless something is wrong. These women will often take steps to make sure that their children and spouses receive appropriate medical care but they do not make their own health a priority. This is even more common where income is so limited that putting food on the table is a struggle and will always take priority over preventative health care. Time can also be an issue where working mothers do not have the option to take off of work to go get a mammogram and do not have childcare or transportation available to take advantage of screenings which may be available during the evenings.

There were several recurring themes in both the focus groups and surveys as to the specific reasons that African-American women may not take advantage of services which are available.

Lack of Income

Numerous individuals in the focus groups indicated that they simply could not afford either to pay for a mammogram, or more frequently to take off of work to go get a free mammogram which might be available.

Quotes from focus groups:

“If I have to choose between getting shots for my kids and going to get a mammogram, I’m not going to spend money on a mammogram.”

“I know that I can go get a mammogram at UMC (University Medical Center), but I would have to sit there all day long and if I take a day off of work, I will get fired.”

Awareness/Education

The majority of the individuals surveyed and the participants in the focus groups were unaware of (1) the increased risk of African-American women and (2) the number of free screening services available.

In both the surveys and the focus groups, participants were asked whether they regularly encouraged their friends and family member to get mammograms. The respondents then were advised of the statistics relative to the increased risk of African-American women. The respondents were then asked if, after becoming aware of those risks, whether they would then make it a regular practice to encourage their friends and family members to get screened. When asked the first question, approximately 50% of the respondents in both the surveys and the focus groups indicated that they did NOT regularly encourage friends and family members to get screened. However, after being advised of the increased risks facing African-American women, 100% of the respondents stated that they would begin making it a practice to encourage the women they knew to get screened.

Additionally, only about 1/3 of the survey respondents were aware that there were several programs available in our area where individuals could get free mammograms if they could not afford them. Likewise, almost all of the members of the focus groups were unaware of these services.

Several providers as well as participants in the focus groups stated that it would be helpful to have “champions” or “ambassadors,” trusted and influential members of the African-American community who would promote education and awareness.

Quotes from focus groups:

“If I had known there was somewhere I could go at night to get a free screening, I would have already had me and my daughters there getting one. I have never seen those advertised and I never heard anyone talk about that.”

“I always thought that you could only get a mammogram if you went to UMC after you found a lump or something. I didn’t know you could get one just to make sure there wasn’t anything there.”

Lack of Treatment Options/Lack of Awareness of Treatment Options

Several focus group participants indicated that they did not bother getting preventative screenings because they could not afford treatment if they were diagnosed with breast cancer. They took the approach that they would simply rather not know about it since

there was nothing they could do about it. When advised that there were programs available to cover their treatment costs, their perspective changed.

Quotes from focus groups:

“I can’t afford to have breast cancer so why would I want to find out if I have it.”

“If more women knew they could get treatment if they had breast cancer, more women would go get checked. No one tells us about these options. Someone needs to start letting our community know that there’s help out there.”

There were also several recurring issues raised as to other gaps in the continuum of care.

Patient Follow Up/Tracking Patients

Several of the providers interviewed in the key informant interviews indicated that often women fail to follow through with screenings if they get an abnormal result from a mammogram or fail to follow through with treatment once they are diagnosed. The providers indicated that this gap can sometimes be avoided if the provider that initially gets the patient into the continuum of care creates a process whereby patients are tracked throughout the process. Some of the providers who provide free screenings indicated that after a woman is screened, that providers’ role is complete and the women are on their own. The problem is that if an individual does not know what the next step in the process is, they will simply fail to take another step. One of the survivors interviewed also indicated this was a problem. She stated that she had no idea where she was supposed to go after she got her diagnosis. She indicated that it was only because she took it upon herself to start making phone calls and finding treatment options that she got treatment. She stated “it would have been nice if there had been someone there telling me what the process was going to be and making sure I did what I needed to do. It probably would have been a lot less scary.”

Lack of Income

Several providers indicated that a lack of income often caused women not to get the treatment they needed. They stated that women would find ways to try to cut costs during their treatment, such as taking a pill every other day rather than every day or cutting their chemotherapy or radiation treatments short of the recommendations.

Conclusions

Community awareness and education must be made a priority. Individuals in the targeted areas need to be made aware not only of the increased risk which they face based upon the failure to get regular mammograms but also of the services which currently exist in the community. Survey respondents and focus group participants indicated the significance that this knowledge has on their actions. If people are more

aware of the risks AND aware that there are services available, they are more likely to get screened. Finding “champions” or “ambassadors” within the community to help promote education and awareness is vital.

Providers of services need to take steps to get individuals in the targeted communities into the continuum of care. Innovative methods can be undertaken to include preventative breast health treatment along with other medical treatment which individuals may already be receiving. Providers also need to be aware of how their role fits into the entire continuum of care. If a provider is providing free screenings, they should have a process in place to direct women to the next stage in the continuum of care.

Conclusions: What We Learned, What We Will Do

Review of the Findings

In the Acadiana area, African-American women throughout all six parishes are at a higher risk based upon late stage diagnosis than other races in this area. In addition, African-American women in the 70501 zip code of Lafayette Parish have the highest breast cancer mortality rate of any race in any of our six parishes. As there are currently numerous free screening programs available to women in this area, the gap seems to be in education and awareness.

The Acadiana Affiliate has been very successful in implementing fundraising efforts that assist local community based organizations with financial support. However, as evidenced in our qualitative research process, there remains a need to further inform and educate individuals in the targeted communities not only of the risks of preventative breast health but also of the availability of services. Perception among respondents in our focus groups and interviews indicate a general lack of awareness of what services are out there.

Conclusions

As a grant making organization, the Acadiana Affiliate can make a tremendous impact in addressing the concerns outlined in the Community Profile. This can be achieved by making a concerted effort to fund partner organizations that can provide solutions to the issues addressed here and by implementing key partnerships with local resources as described in the following Action Plan.

Action Plan

After analyzing the statistics and survey data, and evaluating the programs and services in the Komen Acadiana service area, there is no doubt that the need for increased awareness and funding for programs and services is great.

Priority 1: Expand awareness and educational outreach programs to African-American women throughout Acadiana.

Without knowledge of their increased risks and awareness of the existing programs, African-American women are failing to get screened and therefore failing to increase their chances of survival in the event they are diagnosed with breast cancer.

- *Objective 1:* Partner with the public health units, community health clinics, and other key resources to provide greater breast health educational materials to the targeted communities.

- *Objective 2:* Develop partnerships with groups within the African-American communities such as churches and sororities to increase education and awareness.
- *Objective 3:* Implement a “Pink Sunday” educational program in churches.

Priority 2: Increase awareness and educational outreach programs to African-American women in Lafayette Parish.

There are more services available in this area than in any other area of our service area, yet African-American women are still dying at a higher rate here. Getting these women screened has to be a priority.

- *Objective 1:* Develop an advertising campaign targeting African-American women to insure (1) awareness of the increased risk; and (2) awareness of available services.
- *Objective 2:* Compile a list of all breast health services available in Lafayette Parish and distribute that list throughout targeted communities.
- *Objective 3:* Work with providers to determine the best ways to get African-American women into the continuum of care.
- *Objective 4:* Identify “champions” or “ambassadors” within the African-American community to help promote education and awareness.

Priority 3: Educate providers as to the services available

Providers need to be aware of all of the services available in our service area and how they can work together to insure the best quality of care.

- *Objective 1:* Educate the public health units and community health clinics, as well as existing and past grantees, on all of the services provided by current Komen Acadiana grantees.
- *Objective 2:* Starting in 2011, conduct annual meetings of Komen Acadiana grantees to raise awareness of each other’s programs, to foster collaboration, and to build a stronger relationship with our affiliate.
- *Objective 3:* Continue to hold grant writing workshops to which all hospitals, community health clinics and public health units in all six parishes will be invited.

Priority 4: Establish a public policy committee to create and to implement a plan to maintain relationships with state and national legislators.

As we move forward as a community that is working to lessen the number of women dying from breast cancer each year it is critical that we develop relationships with our legislators so that we may have a voice toward positive change of programs that serve our under and uninsured women – a group of women who are most at risk.

- *Objective 1:* Proactively contact state and national officials that represent our service area to introduce Komen Acadiana to them and to maintain year round communications.
- *Objective 2:* Collaborate with the state officials who can be influential in addressing increases in funding for the LBCHP program and moving Louisiana from an option two state to an option three state.
- *Objective 3:* Recruit public policy committee members to investigate the LBCHP program and find ways to get more of our providers qualified under the program.