

# Executive Summary

## Introduction

The goal of the North Jersey Affiliate (NJA) and the national Susan G. Komen for the Cure® is to save lives and end breast cancer forever by empowering people, ensuring quality of care for all and energizing science to find a cure. Advances in research, drug development, outreach and education to both women and men have led to substantial progress. Additionally, partnerships with the pharmaceutical industry, academia, government, and community leaders have been key to the success of the North Jersey Affiliate.

While celebrating these achievements, it is more critical now than in anytime during the NJA's thirteen year existence to respond to the service region's needs by developing new strategies and incorporating successful programs into new geographic areas.

## Demographic and Breast Cancer Statistics Overview

### Methodology

Breast cancer incidence and mortality data for the NJA's nine county service region was obtained from the New Jersey State Cancer Registry (NJSCR) website: (<http://www.nj.gov/health/ces/reports.shtml>), which is managed by the New Jersey Department of Health & Senior Services' (NJDHSS) Office of Cancer Control and Prevention (OCCP). Statistics for female breast cancer mortality were reported for the years 2001-2005, while data regarding breast cancer incidence on a county level was available through 2006. Data regarding 2007 mammography screening and the uninsured female population in the NJA service region was obtained from the Susan G. Komen for the Cure® North Jersey Affiliate Data Pack, which was prepared by Thomson Reuters in conjunction with Susan G. Komen for the Cure®.

New Jersey population demographic statistics were acquired through the 2006 U.S. Census Bureau's State & County QuickFacts on the US Census Bureau website (<http://quickfacts.census.gov/qfd/index.html>). The County Cancer Fact Sheets produced by each county's respective County Cancer Coalition (made possible by a grant from the NJDHSS OCCP) provided information regarding median household income and county ethnic/racial composition during 2006.

## Key Findings

Mortality continues to decline overall for the nine county region served by the NJA, but a significant divide continues to exist. Black women are more likely to die from breast cancer and poor women tend to present at a later stage of disease, reducing the efficacy of treatment. Despite the overall reduction in mortality in the NJA service region, Sussex County experienced an *increase* in breast cancer mortality between the NJSCR reporting periods of 1997-2001 and 2001-2005. While the overall rate of female breast cancer mortality in New Jersey *decreased* by 8.9% between the two reporting periods, female breast cancer mortality in Sussex County *increased* by 9.5%, to a rate of 11% above the state average.

An effective outreach program focused on education awareness and early diagnosis is apparent in our region. This is evidenced by a shift in the stage at diagnosis of women with breast cancer, with more women now being diagnosed at an earlier stage. Although four of our counties outpace the state in the diagnosis of early stage disease, Essex, Hudson, Passaic, and Sussex, continue to have patients diagnosed at later stages than the state average.

## Target Counties

### *Essex County*

With a population of 776,000 in 2007, Essex County is the second largest county in the NJA service region. Located in northeastern New Jersey, Essex is a diverse and densely populated county. While towns such as Montclair, Essex Fells, and Millburn are highly affluent, much of eastern Essex County has a high level of poverty (13.9%) and crime. Newark, located in the southwestern corner of Essex County, is the largest city within the county with approximately 270,000 residents. In 2007 the population was 55% African American and 31% Hispanic. Notable communities within Newark include the Ironbound district, home to many of the Brazilian and Portuguese immigrants in New Jersey. In 2007 32.1% of females aged 18-64 in Essex County were uninsured and 35% of the female population did not have a mammogram within the previous 12 months (10% didn't have time, 13.7% for other reasons)

In 2005 Essex County had the highest percentage of women under 65 diagnosed with distant (metastatic) disease. Furthermore, Essex County was below the state average for women diagnosed with cancer *in situ* and localized disease and above the state average for diagnoses

at the regional and distant stages. While Essex had the second highest female breast cancer mortality rate in 2001-2005, this position is an improvement from 1997 when the county had the highest mortality rate of the nine counties in the service area.

### *Hudson County*

Located in upper northwestern New Jersey and bordered by the Hudson River to the east and the Passaic River to the west, Hudson County is one of the most diverse and economically troubled counties in the NJA service region. In 2006, 14.4% of the population fell below the poverty level and the county had the lowest median household income in the service region. Hudson County's largest cities are Jersey City, one of the most diverse cities in the United States, and Union City, the most densely populated city in the country. Hudson County is also home to a large Hispanic community, with persons of Hispanic or Latino origin composing 41% of the population in 2006. 30.3% of Hudson County women aged 18-64 were uninsured in 2007 and 37.4% of the female population did not have a mammogram within that same timeframe (10.4% didn't have time, 14.4% for other reasons).

Hudson County not only has the highest percentage of women over the age of 65 diagnosed with distant stage disease, but also has the second highest percentage of women, regardless of age, diagnosed with regional stage disease. While mortality from breast cancer has dropped by 16.5% in Hudson County since 1997, the percentage of women who are diagnosed with later stage disease demands further attention.

### *Passaic County*

Passaic County is also located in the northwestern corner of New Jersey, bordered by Bergen and Essex counties. Similar to Essex and Hudson counties, Passaic County is also highly diverse with cities, such as Paterson and the city of Passaic, that are economically troubled. In 2006 approximately 14% of the county's population fell below the poverty level. 21.4% of Passaic County women aged 18-64 were uninsured in 2007 and 34.1% of the female population did not have a mammogram in 2007 (9.4% didn't have time, 13.4% for other reasons).

Passaic County has the third highest percentage of women diagnosed with distant stage disease in the NJA service region. It is also above the state average for women diagnosed with regional stage disease. However, Passaic County is below the state average for women under 65 diagnosed with cancer *in situ* and for women diagnosed with localized disease. Between 2001-2005 Passaic County had the highest

non-invasive breast cancer incidence and female breast cancer mortality rate among black women in the NJA service region.

### ***Sussex County***

While encompassing the largest land mass in the NJA service region, Sussex County is one of the least populated and least diverse of the nine counties. Per 2006 US Census Bureau data, Sussex County was 95.3% white, 93% (of those 25 years and older) high school graduates, and 5% below the poverty line. In 2007 9.3% of Sussex County women aged 18-64 were uninsured and 33% of the female population did not have a mammogram within the previous 12 months (9.0% didn't have time, 13.2% for other reasons).

Sussex County was the sole county in the NJA's nine county service region to show an increase in female breast cancer mortality since 1997. While the state average for mortality between 1997 and 2005 dropped by 8.5%, Sussex County showed an increase of 9.5% in that same time period. As a point of reference, the rate of breast cancer mortality in Sussex County between 2001-2005 was 20% higher than the U.S. average. Sussex County had the highest percentage of women both under and over 65 diagnosed with regional stage disease. Sussex County had the second highest percentage of women under 65 and the second lowest percentage of women over 65 diagnosed with distant stage disease. The analysis highlighted an important trend. Specifically, women in Sussex County, particularly women under 65, are consistently diagnosed with breast cancer later than the majority of other women in the NJA service region.

## **Programs and Services Overview**

### **Methodology**

Resources utilized in the preparation and analysis of the programs and services in the NJA service region include the New Jersey Primary Care Association website ([www.njpca.org](http://www.njpca.org)), the New Jersey Department of Health and Senior Services (NJDHSS) website ([www.state.nj.us/health/](http://www.state.nj.us/health/)), the December 2008 New Jersey Cancer Education and Early Detection (NJCEED) Status Report by Candido Africa, MD, Data Manager for NJCEED, the New Jersey Hospital Association's 2008 Update, the Cancer Resource guides provided by the NJDHSS' Office of Cancer Control and Prevention (OCCP), the Susan G. Komen for the Cure® website ([www.komen.org](http://www.komen.org)), as well as the NJA grant and education staff. Information collected was then organized by county, with special

attention paid to providers, organizations, and collaborative relationships in the targeted counties.

## Key Findings

There is at least one NJCEED screening site in each county with two locations in Essex County (i.e. St. Michael's Medical Center and the University of Medicine & Dentistry of New Jersey (UMDNJ) Screening Access of Value to Essex Women and Men (S.A.V.E.) Program). During the 2008 fiscal year (FY), 15% of eligible women (up to 250% of the federally designated poverty level and uninsured) in the NJA service region received a mammogram through a NJCEED screening program. The NJA does not currently have a grant or relationship with the NJCEED programs in Sussex, Warren, or Somerset counties. There are also Federally Qualified Health Centers (FQHC) in each of the four target counties; however, the NJA does not currently have established relationships with these organizations. There have been many hospital closings in northern New Jersey during the last two years; this presents the NJA with a new challenge of identifying and addressing the gaps in access and care that have resulted from these closures.

Grant distribution varies widely across the service region. While Essex County was the recipient of ten NJA grants during the 2008 grant period, there were only two grants at work in Sussex during that period. Due to the lack of available funds, there is only one active grant in Sussex County during FY 09. Since the NJA's inception in 1997, a combined total of 64% of all grants have targeted Essex, Hudson and Passaic counties.

Breast cancer services in Sussex County are relatively limited; the two acute care hospitals are located only 15 miles apart and there are only six mammography centers within the 500 square mile county. Community centers also appear to be relatively sparse and indicate to the NJA a need to build collaborative relationships between the county's existing programs, such as the Sussex County CEED program and Project Self Sufficiency.

Hudson County organizations such as Hudson Perinatal Consortium, Metropolitan Family Health Center, Save Latin America and the North Hudson Community Action Corporation, a federally qualified health center (FQHC) with eight satellite locations in Bergen, Hudson, and Passaic counties, could serve as future collaborative partners with the NJA for educational events and breast screenings. Community assets such as the Family Success Centers, whose primary purpose is to

strengthen families and neighborhoods by developing networks of family services in Essex County, could play a key role in enabling the NJA to reach new populations of women for screening and education. The abundance of ethnically oriented social services in Passaic County's largest city, Paterson, could serve as valuable assets in reaching women in the NJA service region. Finally, by collaborating with the Central South Jersey Affiliate for events such as the legislative Pink Ribbon Coffee, the NJA could more effectively promote Komen advocacy and community health initiatives.

## **Exploratory Data Overview**

### **Methodology**

To develop a better understanding of the needs and issues present in the targeted counties, the Community Profile Team reached out to key members in the NJA service region through written surveys and moderated focus groups.

Approximately twenty (20) surveys were sent to local NJCEED County Directors and members of the NJA Community Advisory Council, a group which convenes bimonthly to discuss the best practices in the service region. The Community Advisory Council is composed of local hospital outreach workers, NJCEED employees, NJA grantees, and breast health service providers in the service region. Of the twenty (20) surveys, only six (6) were returned to the Community Profile Team.

Three (3) focus groups were conducted; each was held at the NJA office and included between 5-10 participants. Outreach workers, NJCEED directors, and hospital employees were joined by local mothers, lawyers, and businesswomen who volunteer their time to serve on the NJA Grants Committee. During each focus group, moderators asked participants to share their insights into barriers preventing women from accessing care, current gaps in breast health services in their communities, and how the NJA could better serve its service region. A note taker was present at each focus group.

### **Key Findings**

Exploratory data findings indicate a continued need to build trust and confidence in the health care system within the predominant minority groups in the NJA service region. Low screening rates, late diagnosis and high mortality rates within the African American community, particularly in Passaic County, demonstrate that more education on the

critical importance of early detection through screening is needed. Focus group discussions highlighted the value of outreach with churches and local faith-based organizations as an effective means of building relationships within the African American community.

Focus group discussions also revealed that Latina women in the NJA service region tend to form closely knit communities where word of mouth and personal connections are integral in building trust in the medical establishment. Once this trust is established, it appears that Latina women are willing to utilize programs such as the NJCEED screening sites. For example, from July 2007 to July 2008, 527 of the 697 (75.6%) women screened by Passaic County's Rainbows of Hope CEED program were Hispanic. Findings also indicate a need for an educational and marketing campaign targeting monolingual Spanish speakers for whom language and cultural barriers pose considerable hurdles against the pursuit of breast health screening and treatment.

Lack of insurance remains a sizeable barrier to preventative screening as the NJCEED funding covers the screening of approximately 9-12% of eligible (up to 250% of the federally designated poverty level and uninsured) women. Other barriers revealed by the exploratory data process include uncertainty of the purpose and procedure of mammography, lack of understanding of what occurs after a positive diagnosis, and a fear of being unable to juggle work, children, family, and breast cancer. For some women, lack of transportation is prohibitive against both screening and treatment.

## **Selecting Affiliate Priorities**

Affiliate priorities were established through a series of meetings with the NJA staff including: Co-founder and Executive Director, Education Director, Advocacy Co-Chairs, Grants Co-Chairs, and the Finance and Operations Director. After having read the findings from the breast cancer statistics, demographics, programs and services, and exploratory data sections, participants came to each meeting with suggestions for appropriate priorities. The priorities chosen by the Affiliate Action plan were those that were agreed upon by each meeting member as tangible, attainable, and critical goals for the North Jersey Affiliate. After the selection of priorities, participants collaborated to generate the list of objectives that would best help the NJA achieve its priorities.

## North Jersey Affiliate Priorities

**Priority 1:** Increase collaboration with other cancer organizations, institutions, businesses, and individuals within the target communities.

**Priority 2:** Increase outreach to African American women in Essex, Hudson, and Passaic counties through a faith-based approach

**Priority 3:** Reduce the number of late diagnoses in women, with an emphasis on women under 65 in Sussex County

## North Jersey Affiliate Action Plan

### Priority 1

**Increase collaboration with other cancer organizations, institutions, businesses, and individuals within the target communities.**

*Objective 1:* By December 2009, establish a regular presence (with at least two attendees) at the County Cancer Coalitions in the four targeted counties

*Objective 2:* By September 2009, establish a Community Resource Council with members from each of the four targeted counties

*Objective 3:* Initiate a volunteer database located within each targeted county to serve as a lay group for educational events and advocacy initiatives

### Priority 2

**Increase outreach to African American women in Essex, Hudson, and Passaic counties through a faith-based approach**

*Objective 1:* Identify an African American leader within each targeted county to help with the Komen initiative

*Objective 2:* By March 2010, convene a roundtable breakfast of five faith-based leaders in each county

*Objective 3:* By October 2009, establish Circle of Promise® within the Affiliate

### Priority 3

**Reduce the number of late diagnoses in Sussex County women, with an emphasis on women under 65**

*Objective 1:* Convene county stakeholders on July 30, 2009 to discuss state of breast cancer in Sussex County

*Objective 2:* Schedule a meeting with the Sussex County CEED Director and other local health departments by December, 2009

*Objective 3:* Use stakeholder mailing list to increase Sussex County participation at the annual technical grant-writing session.

Objective 4: Develop a marketing campaign targeting Sussex County (increase Komen visibility in Sussex County and focus on team development within county for the Race)