



# COMMUNITY PROFILE REPORT

©2011 Northeastern New York Affiliate of Susan G. Komen for the Cure®

The Komen Promise  
To save lives and end breast cancer  
forever by empowering people,  
ensuring quality care for all and  
energizing science to find the cures.

[www.komenneny.org](http://www.komenneny.org)

SUSAN G.  
**Komen**  
FOR THE **cure**®  
NORTHEASTERN  
NEW YORK

2011

**Disclaimer:**

The information in this Community Profile Report is based on the work of Northeastern New York 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.



**Figure 1.** 2010 Susan G. Komen Northeastern New York Race for the Cure® participants.  
Photo Courtesy of Michael Hochanadel

## Contents

<b>Executive Summary .....</b>	<b>6</b>
Introduction.....	6
Breast Cancer Impact in Affiliate Service Area .....	6
Health Systems Analysis of Target Communities .....	8
Breast Cancer Perspectives in the Target Communities .....	9
Conclusions: What We Learned, What We Will Do.....	10
<b>Introduction .....</b>	<b>12</b>
About Susan G. Komen for the Cure® .....	12
Affiliate History .....	12
Affiliate Service Area .....	12
Grant Funding.....	13
Organizational Structure .....	14
Purpose of Report .....	14
<b>Breast Cancer Impact in Affiliate Service Area.....</b>	<b>15</b>
Overview .....	15
Mortality Rates.....	15
Breast Cancer Incidence Rates .....	17
Stage of Breast Cancer Diagnosis .....	19
Insurance and Screening Rates .....	20
Area Demographic Information .....	21
Communities of Interest .....	22
<b>Health Systems Analysis of Target Communities.....</b>	<b>23</b>
Overview.....	23
Health Care Provider Survey.....	23
Breast Health Services and Rural Women .....	24
Mammography Services, Hospitals and Health Services.....	25
NYS Cancer Services Program .....	29
Conclusions.....	31
<b>Breast Cancer Perspectives in the Target Communities .....</b>	<b>33</b>
Overview.....	33
Rural Women .....	33
Young Women .....	35
African American Women .....	36
Conclusions.....	37
<b>Conclusions: What We Learned, What We Will Do.....</b>	<b>38</b>
Review of the Findings .....	38
Conclusions.....	38
Affiliate Action Plan .....	39
<b>Endnotes .....</b>	<b>41</b>

## List of Figures

Figure 1. 2010 Susan G. Komen Northeastern New York Race for the Cure® participants. _____	3
Figure 2. Affiliate service areas in New York State. _____	13
Figure 3. Komen NENY organizational structure. _____	14
Figure 4. Age adjusted breast cancer mortality rates for NYS 2003-2007. _____	16
Figure 5. Age adjusted breast cancer mortality rates from 1976-2007. _____	17
Figure 6. Age adjusted annual breast cancer incidence rates in NYS 2003-2007. _____	18
Figure 7. Age adjusted breast cancer incidence rates from 1976-2007. _____	19
Figure 8. Percent of breast cancers diagnosed at an early stage 2003-2007. _____	20
Figure 9. Certified Mammography Facilities in 11 Counties of NENY _____	26
Figure 10. Hospitals and Underserved Healthcare Areas _____	27
Figure 11. Komen Northeastern New York Grantees _____	28
Figure 12. Percent of uninsured New Yorkers not screened under Cancer Services Program, 2008 American Cancer Society estimates. _____	31

## List of Tables

Table 1. Percent of Uninsured Females _____	20
Table 2. Percent of female population over 40 with no mammogram in the last 12 months. _____	20
Table 3. Demographic information for 11 counties of NENY. _____	21
Table 4. NYS Cancer Services Program mammography and clinical breast exams provided 2009-10_	30

# Executive Summary

## Introduction

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® and the Susan G. Komen 3-Day for the Cure®, we have invested more than \$1.9 billion to fulfill our promise, becoming the largest source of nonprofit funds dedicated to the fight against breast cancer in the world. The Northeastern New York (NENY) Affiliate of Susan G. Komen for the Cure® was incorporated as a nonprofit in 2000 with a seven member board. The Albany Affiliate of Susan G. Komen for the Cure® originally served five counties: Albany, Rensselaer, Schenectady, Saratoga and Montgomery. Clinton, Essex, Franklin, Hamilton, Warren and Washington Counties were added to the Affiliate service area in 2003. In 2003, the name of the Affiliate was officially changed to the Northeastern New York Affiliate of Susan G. Komen for the Cure®. In 2011, the Northeastern New York Affiliate area will be expanded to include Fulton, Schoharie, Green and Columbia Counties. The Northeastern New York Affiliate is composed of an up to fifteen member board, functional committees and an Executive Director.

As of 2011, the Northeastern New York Affiliate has granted over \$2.4 million to breast cancer and breast health programs in its 11 county service area. Funds have been granted to over 120 projects of more than 30 nonprofit health care providers. Up to 75 percent of net proceeds generated by events like the Komen Northeastern New York Race for the Cure stay in our local area, the remaining income goes to the national Susan G. Komen Research Grants Program. In addition to raising funds for community and National Research grants, the Komen NENY Affiliate works to raise awareness of breast cancer and breast health issues in our community through speaking engagements, expos and health fairs, and state and federal advocacy efforts.

This Community Profile will help us to become more inclusive; establish focused granting priorities; fund, educate, and build awareness in the areas of greatest need; give information to policy makers to focus their work; give direction to marketing and outreach programs; and create synergy between strategic plans and operational activities.

## Breast Cancer Impact in Affiliate Service Area

Data for this section of the Community Profile is from the New York State Department of Health's Cancer Registry and U.S. Census Bureau Data estimates for 2009. Additional information was derived from the National Cancer Institutes' State Cancer Profiles 2003-2007, and Thomson Reuters Data from 2009. Breast cancer is one of the most common cancers among women in New York State. Each year, about 13,900 women are diagnosed with breast cancer and about 2,900 women die from the disease in the State. Most women in New York State are diagnosed between at 55-59 years of age; although 745 average annual cases are diagnosed in women under 40.<sup>2</sup>

Three counties in our service area are above the New York State and United States age adjusted mortality rates of 23.9 and 24 cases, respectively, per 100,000. These counties are:

- Washington County with 28.1 cases per 100,000
- Saratoga County with 24.5 cases per 100,000
- Rensselaer County with 24.1 cases per 100,000.<sup>3</sup>

Studies have shown the importance of detecting and treating cancers at early stages, for breast cancer when caught early and confined to the breast, the five year survival rate is now 98 percent for women in the United States.<sup>4</sup> The New York State average percent of breast cancers diagnosed at early stage is 62.7 percent. Rensselaer County had only 62% of breast cancers diagnosed at an early stage (below the New York State average) and Albany and Saratoga Counties were only slightly higher with only 64.6% and 65.6% cancers, respectively, diagnosed at an early stage.<sup>2</sup> Insurance coverage is an important factor in women getting screened for breast cancer and seeking any needed treatment. Clinton, Franklin, Albany and Montgomery Counties all had high rates of uninsured women—all over 10 percent uninsured. Screening rates were also examined for our area--Franklin, Hamilton, Essex and Washington County all exceed 40 percent of women over 40 who have not had a mammogram in the past year.<sup>5</sup> The population of our area is predominantly Caucasian; but in Albany, Schenectady and Rensselaer there are significant African American populations (12.4 percent, 9.6 percent and 6.1 percent, respectively). Montgomery County is notable for a large Hispanic population of 9.6 percent and Franklin County has a Native American population of 6.8 percent.

Examining the data outlined above some of counties emerge as target areas for the Northeastern New York Affiliate of Susan G. Komen for the Cure. Counties in our service area that are above the New York and United States age adjusted mortality rates (Washington, Rensselaer) are of particular importance. Washington County also has a relatively high breast cancer incidence rate, the third lowest screening rate for women over 40 in the past 12 months and the third lowest number of adults having obtained a bachelor's degree or higher. Rensselaer had the fourth highest incidence rate in our area and the largest percentage of women diagnosed at a late stage. The counties with the lowest percentage of women having had a mammogram in the past 12 months (Franklin, Essex, Washington and Hamilton) are also a concern. Albany with the second highest late stage diagnosis is also notable.

Studies also have shown ethnicity and race are factors in breast cancer outcomes. While the overall breast cancer incidence rate for African American women is about 10 percent lower than for Caucasian women, the mortality rate is 37 percent higher. Breast cancer is the most common cancer among African American women.<sup>7</sup> Among Latina women, breast cancer is the leading cause of cancer incidence (28 percent of new cancers) and deaths (15 percent).<sup>8</sup> A recent report which examined racial and ethnic disparities in health status and access to care points to factors that may contribute to later diagnosis and treatment for breast cancer in Latinas.<sup>9</sup> In addition, a 2007 study reported that Native American women have less favorable socioeconomic

status and health care access, contributing to lower rates of screening and breast cancer incidence rates, but higher late-stage diagnosis rates.<sup>10</sup>

## **Health Systems Analysis of Target Communities**

Data for this section that reviews the health care systems in our service area came from a survey of health care providers and key informant interviews using the continuum of care model; mapping of Affiliate grantees, of hospitals and health clinics from Health Resources and Services Administration (HRSA) information, of mammography facilities from the Federal Drug Administration; and an analysis of the State Cancer Services Program, which provides free cancer screening to un- and underinsured New Yorkers.

A survey was sent out to breast health and breast cancer service providers in the 11 county service area of Northeastern New York using an online survey tool. The survey addressed themes that emerged from the review of statistical information and analyzed how well the continuum of care model (screening, diagnosis, treatment and follow up care) works in our area. Best represented was Rensselaer with 14 providers responding and Essex and Albany with 10 providers each responding (these counties correspond to important target counties from the review of breast cancer and demographic statistics). Low income/working poor and those without insurance were most often cited by providers as being priority populations for breast health and breast cancer education and services (82.9 percent and 85.7 percent, respectively). The next most often cited priority population was rural women (77.1 percent). Lack of financial resources was cited most often as the critical issue that inhibited women from seeking and obtaining breast health services (40 percent). Other factors that were rated very important by providers were educational--myths and false information (42.9 percent) and lack of knowledge (45.5 percent). Transportation was also a very important factor in women seeking and obtaining services (40 percent). Financial factors (financial assistance, co-pays, access to insurance) were most often named by providers the single most important factor in improving the delivery of breast health services.

From our analysis of demographic and breast cancer statistics and the provider survey, rural women (rural counties in our area are Clinton, Essex, Franklin, Hamilton, and Montgomery) emerged as a target population for the Komen Northeastern New York Affiliate. Many barriers to screening and treatment exist in rural areas such as poorer access to health services and specialists, limited access to new therapies, limited options for transportation and limited knowledge about the importance of early detection through regular screening and prohibitive costs.<sup>11</sup> To further explore the provision of breast health care for rural women, staff of Hudson Headwaters Health Network (HHHN) was interviewed. HHHN is system of community centers providing comprehensive primary care and serves the rural target counties we identified through a review of breast cancer statistics. Staff identified primary barriers encountered to screenings in this rural area are: transportation, low literacy, and time off from work.

In our analysis of breast cancer statistics, we found that rates of breast cancer screening vary by as much as 8% in our area. To assess availability and access to screening services we mapped the mammography facilities in our target areas.<sup>13</sup> Notably the counties with the lowest screening rates, Franklin and Essex, have only three facilities over very large areas, Washington County has 1, and Hamilton County

has none. Hospitals in the target counties were mapped along with the medically underserved populations and those areas that have a shortage of health care professionals. Hamilton County has no hospital at all and many residents in our rural counties have to travel great distances to the nearest hospital. Northern rural target counties also have medically underserved areas and a shortage of health care professionals.<sup>14</sup>

New York State's Cancer Services Program is a critical component in the provision of financial assistance for cancer care for under and uninsured women in the target areas. They oversee the delivery of cancer screening services and education to underserved populations in New York. In 2004-05, through this program, over 40,000 mammograms<sup>15</sup> were provided—in 2009-10 this number was 32,947 (and 30,952 clinical breast exams). Counties with less of the eligible population screened under this program correspond to the counties identified as having low overall screening rates. Given the importance of this program, the staff of the State Cancer Services Program was interviewed for this Profile. They emphasized the importance of increasing the number of women who are screened through this Program, which only reaches 10 percent of the eligible population.

A review of community assets found most mammography services in the southern part of the Affiliate service area with few screening services in our target areas of Franklin, Washington, Essex and Hamilton County. These areas also had low overall screening rates and a low percentage of screening under the Cancer Services Program. Fewer hospital and health centers also exist in these areas. This information corresponds with health care providers' emphasis on increasing services to rural women as a priority and the need to increase financial assistance. The key informant interviews reinforced the importance of increased screening of women in our area and the need to increase accurate breast health knowledge—of risk factors, to dispel myths and to ease fears. Barriers to increased screening focused on financial issues, transportation issues, and lack of knowledge about breast health.

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

A focus group meeting of rural women from those target counties was held to address questions and service gaps and follow up on information obtained from the health systems analysis. In terms of priority populations for breast health information, the group cited low income and uninsured as the most important populations. Another population mentioned was young women—that accurate information should definitely be given out in colleges, but should start even earlier in high schools and middle schools; and that young women should be aware of their risk and that women under 40 can get breast cancer. The group was asked what barriers exist for rural women seeking breast health services. Not only the was the lack of insurance cited but also other insurance issues such as high co-pays, high deductibles, and insurance that might limit mammograms or other breast health services. Needed services for rural women included financial assistance with screening and treatment and transportation services. Most of the group cited screening as the most important use of Komen funding.

A focus group meeting of young women from target areas who were diagnosed with breast cancer under the age of 40 was also held. Likely partners to get out information

are: colleges, social networking sites, health centers, and sororities. Barriers and challenges to breast health screening focused on financial issues—high co-pays, lack of insurance or the inability to get transportation or a day off. This group also mentioned the importance of referrals, recommendations and reminders from primary care physicians and physicians need to be more aware of services, getting their patients to use them, and knowing that women under 40 can have breast cancer. To increase women's use of breast health screening and treatment services, the group thought more navigators and case workers were needed to inform women about what services are available.

Five African American women from Albany, Schenectady and Rensselaer Counties were interviewed to obtain information from a community perspective. In urban communities some thought that breast cancer is not discussed until it is too late. Some thought that in the African American community women were not as open about discussing breast cancer or their own diagnosis. In terms of barriers in the community, interviewees mentioned lack of knowledge about breast cancer and risks and lack of knowledge about what services are available. Insurance was also mentioned and that in urban communities often services were not available or the resources were subpar. Women overwhelmingly thought that area churches should be used to get information out to this community. These women also mentioned primary care physicians and clinics as important—and they need to be more proactive in breast health and screening. Education and screening were cited as priorities for Komen funding.

The qualitative data reinforced the information obtained from the review of breast cancer statistics, demographic information and the health systems analysis. The need for concrete information and knowledge, not just awareness, among young women was a common theme of all the groups. Most of the participants of the interviews and focus groups cited a need for more women to get screened and fund programs to increase screening rates and overcome barriers to screening. All the groups mentioned the role of primary care physicians or breast health navigators in this effort. Transportation services were more predominant in the focus group on rural women and the role of churches in delivering breast health messages was an integral theme of the interviews with African American women. All the groups and interviewees mentioned financial issues as critical.

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

Available demographic and breast cancer statistics, mapping of existing services and facilities, the results of health care provider interviews and surveys and community input was reviewed to develop the priorities for our Affiliate. Studies referenced in this Community Profile have shown the role that race and ethnicity play in breast health outcomes. The first priority is to increase breast health and breast cancer services to target populations that have been historically underserved in health care in those counties with significant percentages of these populations—African American women in Albany, Schenectady and Rensselaer Counties, Hispanic women in Montgomery County and Native American women in Franklin County.

- Objectives: 1. By September of 2011, revise the Affiliate request for applications to prioritize these area populations in the awarding of grants and hold grant

workshops targeted at these area populations to enable community partners to apply for Affiliate grants. 2. By 2012, identify at least one new community or faith based organization that serves these area populations and develop new partnerships with them for education and outreach. 3. By 2013, establish a partnership with one local newspaper or radio station that serves each of these area populations to provide culturally appropriate breast health information. 4. Supply 5 primary care physicians and clinics serving these populations and in these areas breast health information for their patients.

The second priority is to increase screening rates in the four counties with the lowest percentage of women over 40 who have had a mammogram in the past year—Franklin, Essex, Washington and Hamilton Counties.

- Objectives: 1. Revise the Affiliate request for applications to make this a priority in the awarding of grants by September of 2011. 2. By 2012, collaborate with the Cancer Services Program to increase the women screened through the State's uninsured breast cancer screening program in these areas by 5%. 3. Work with the Coalition to Save Cancer Screening to advocate for increased State Budget funding to 2007-2008 levels for this program by 2013. 4. By 2013, coordinate with 5 health care providers in these areas to support the use of patient navigators and other means to increase screening rates by actively identifying, recruiting and alleviating screening barriers for patients.

Many residents of Northeastern New York live in rural areas far from available services and this factor negatively impacts their health outcomes. The third priority is to increase services, and access to services, to women in rural counties (Clinton, Essex, Franklin, Hamilton, and Montgomery) of our area.

- Objectives: 1. Revise the Affiliate request for applications to prioritize breast health services in these areas in the awarding of grants by September of 2011. 2. Work with community organizations and health care providers in these areas to develop programs to increase transportation access to services and fund such programs through Affiliate grants by 2013. 3. By 2013, increase our Affiliate presence in these rural areas through educational efforts, collaborative relationships with community based organizations, donors, and volunteers. 4. Explore partnerships that provide breast cancer financial and emergency assistance and services to women in these communities by the end of 2012.

It is increasingly recognized that we need to develop evidence-based approaches to advance understanding and awareness of breast cancer among young women through education and awareness activities and emerging prevention strategies. The fourth priority is to enhance efforts to educate young women in the area about breast health.

- Objectives: 1. Provide age appropriate breast health and breast cancer information to 10 area colleges by 2012. 2. Enhance efforts through the I am the Cure Program® and using BSA (Breast Self Awareness) to provide accurate information about prevention, risk factors, and screening to young women at all Affiliate events and activities by October of 2011. 3. Revise the Affiliate request for applications to make this a priority in the awarding of grants by September of 2011.

## Introduction

### About Susan G. Komen for the Cure®

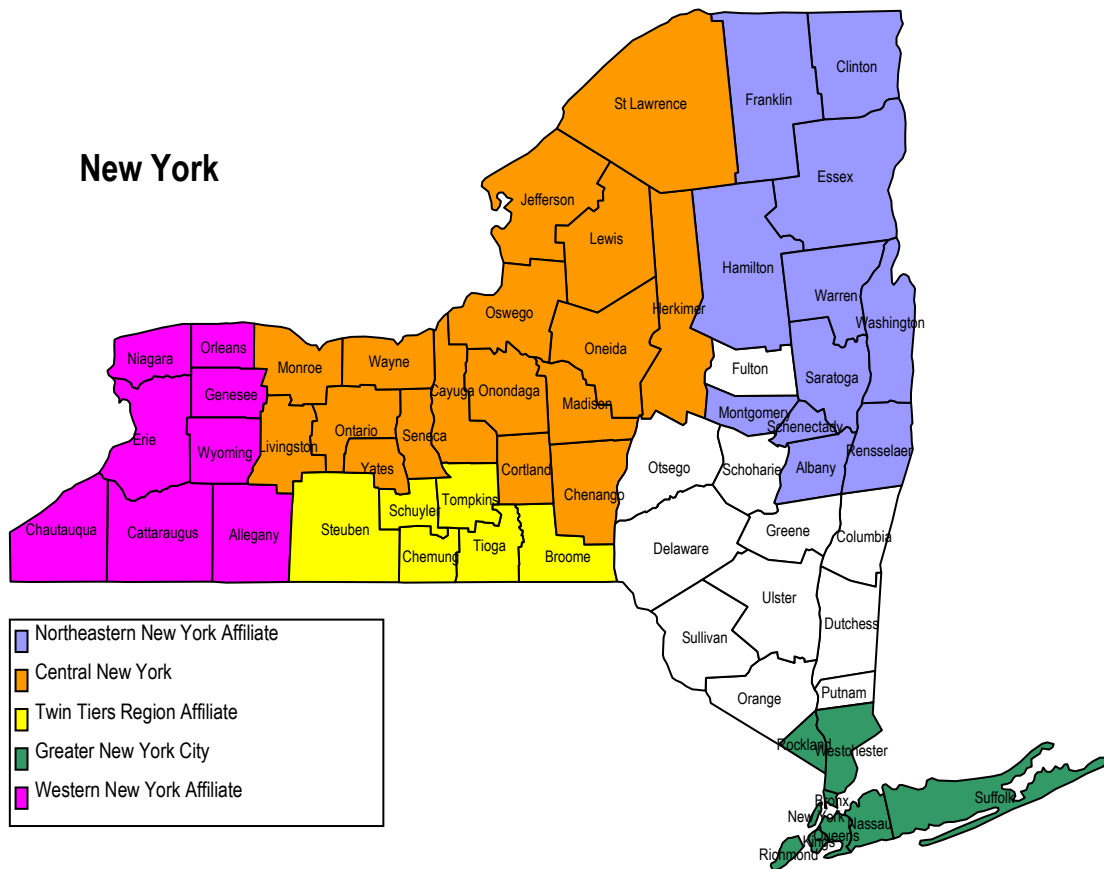
Nancy G. Brinker promised her dying sister, Susan G. Komen, she would do everything in her power to end breast cancer forever. In 1982, that promise became Susan G. Komen for the Cure® and launched the global breast cancer movement. Today, Komen for the Cure is the world's largest grassroots network 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® and the Susan G. Komen 3-Day for the Cure®, we have invested more than \$1.9 billion 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 Susan G. Komen for the Cure, breast health or breast cancer, visit [komen.org](http://komen.org) or call 1-877-GO KOMEN.

### Affiliate History

The Northeastern New York (NENY) Affiliate of Susan G. Komen for the Cure® began with conducting the organization's premier fundraising event – the Komen Race for the Cure. The Albany Race for the Cure® began in 1995 with just 900 participants and was held at Washington Park Lakehouse in Albany, New York under the auspices of the Junior League of Albany. The Komen NENY Race grew steadily and now nearly 4,500 people participate each year. In 2002, the Race was moved to the Empire State Plaza to better accommodate its growing size. Also in 2002, the historic Freihofer's Run for Women running course was first used for the 5K Race. The Affiliate was incorporated as a nonprofit in 2000 with a seven member board and 501-C3 status apart from the Junior League of Albany. The Albany Affiliate of Susan G. Komen for the Cure® originally served five counties: Albany, Rensselaer, Schenectady, Saratoga and Montgomery Counties. Clinton, Essex, Franklin, Hamilton, Warren and Washington Counties were added to the Affiliate service area in 2003. In 2003, the name of the Affiliate was officially changed to the Northeastern New York Affiliate, to better reflect this expanded service area. A map of all the Affiliates in New York State is below (*Figure 2*). In 2011, the Northeastern New York Affiliate service area will be expanded to include Fulton, Schoharie, Green and Columbia Counties.

### Affiliate Service Area

The current service area of 11 counties has a population of 1,177,954 with 49.76 percent of that population comprised of women. The region is predominantly Caucasian (91.79 percent), with 4.67 percent of the population comprised of African Americans, 3.52 percent Hispanic, and .86 percent Native American. The median household income is \$49,513, 12.14 percent of people in the region live below the poverty level and 21.16% of the adult population has a bachelor's degree or higher.<sup>1</sup> The region is marked by urban centers of Albany, Schenectady, Troy; smaller cities of Amsterdam, Plattsburgh, Malone and Glens Falls; growing suburban areas in Saratoga; and very rural and sparsely populated areas in the Northern Counties especially in the region of the Adirondack Park.



**Figure 2. Affiliate service areas in New York State.**  
*Susan G. Komen for the Cure, 2011*

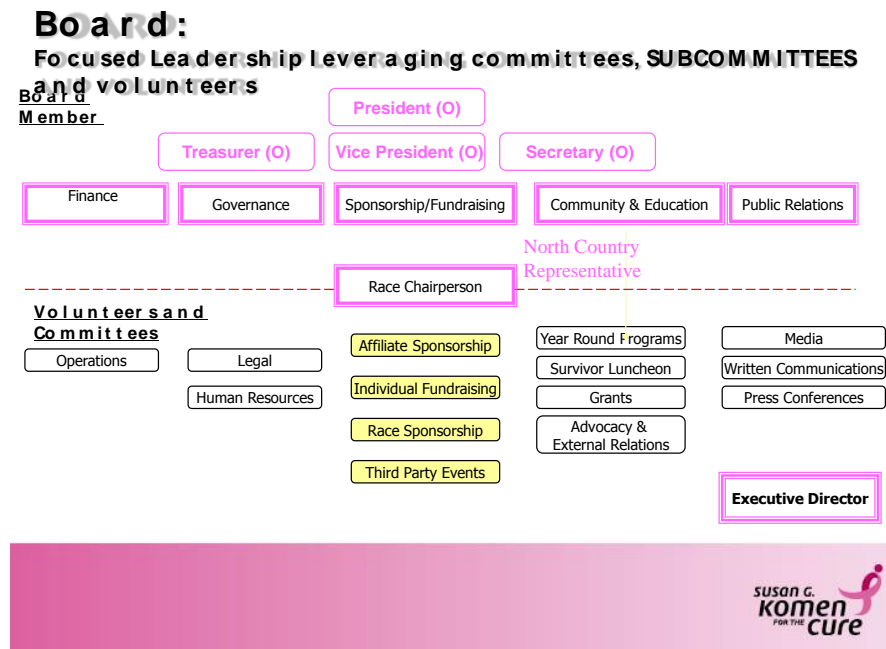
## Grant Funding

The amount of funds per year awarded in grants to our community has also increased from approximately \$30,000 in 1995 to over \$277,000 today. In 2009, the Komen Northeastern New York Affiliate added a small grants program (under \$5,000) which funds travel, educational, and conference grants to local non-profit breast health and breast cancer programs. Over the past two years, \$28,000 has been awarded under this small grants program. As of 2011, the Komen Northeastern New York Affiliate has granted out over \$2.4 million to breast cancer and breast health programs in its 11 county service area. Up to 75% of net proceeds generated by events like the Komen Northeastern New York Race for the Cure stay in our local area, the remaining income goes to the national Susan G. Komen Research Grants Program. Susan G. Komen for the Cure has funded hundreds of millions of dollars of research through this program and since 1995, over \$30 million of those research dollars have been awarded to New York State institutions, including, in Northeastern New York, to the State University of New York at Albany, the Stratton VA Medical Center and Albany Medical College.

In addition to raising funds for community and National Research grants, the Affiliate works to raise awareness of breast cancer and breast health issues in our community through speaking engagements, expos and health fairs, and state and federal advocacy efforts. In 2010, we appeared or spoke at over 50 community events. Our public policy activities included: supporting State legislation to increase utilization of cancer clinical trials, advocating for funding for the NYS State Department of Health’s Cancer Services Program, supporting legislation to inform patients about breast density issues, supporting legislation to achieve insurance rate parity between oral chemotherapy and intravenous chemotherapy and advocacy for Komen’s federal policy agenda.

## Organizational Structure

The Northeastern New York Affiliate is composed of an up to fifteen member board functional committees and an Executive Director. Volunteers and interns also are crucial in helping to carrying out the work of the Affiliate. *Figure 3* below shows the Board and Committee structure.



**Figure 3. Komen NENY organizational structure.**

**Northeastern New York Affiliate of Susan G. Komen for the Cure, 2011**

## Purpose of Report

To meet our promise, we rely on the information obtained through the Community Profile process to guide our Affiliate in the work we do. The Community Profile helps to guarantee that the work we do is targeted and does not duplicate the services of others. It will help us to become more diverse and inclusive; establish focused granting priorities; fund, educate, and build awareness in the areas of greatest need; give information to public policy makers to focus their work; give direction to marketing and outreach programs; and create synergy between strategic plans and operational activities.

# Breast Cancer Impact in Affiliate Service Area

## Overview

Breast cancer prevalence and stage of diagnosis data reported in this section of the Community Profile is from the New York State Cancer Registry. Demographic information on median household income, educational levels, and race and ethnicity is from U.S. Census Bureau Data estimates for 2009. Information on age adjusted breast cancer mortality and incidence rates for our area was derived from the National Cancer Institute's State Cancer Profiles, 2003-2007. Thomson Reuters Data for 2009 was used to obtain data on uninsured women in our area and mammography rates.

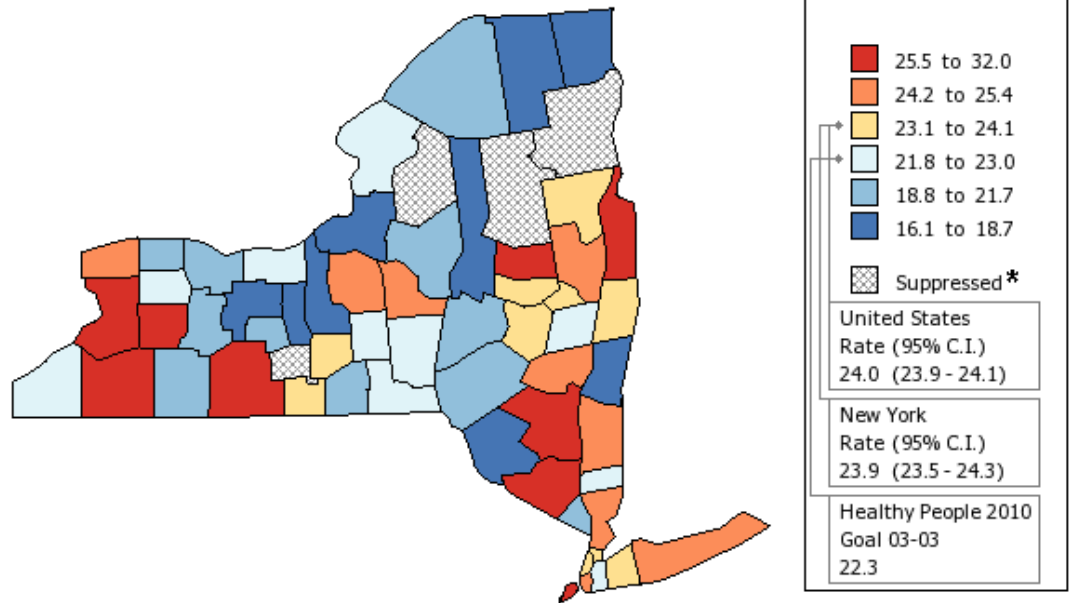
Breast cancer is one of the most common cancers among women in New York State. Each year, about 13,900 women are diagnosed with breast cancer and about 2,900 women die from the disease in the State. It is estimated that one in eight women will develop breast cancer sometime during her life. Men also get breast cancer, but it is very rare. About 150 men are diagnosed with breast cancer each year in New York State.<sup>2</sup>

Most women in New York State are diagnosed between at 55-59 years of age; although 745 average annual cases are diagnosed in women under 40.<sup>2</sup> Breast cancer is the leading cause of cancer deaths in young women under the age of 40. In the United States, each year more than 10,000 young women are diagnosed with breast cancer and for more than 1,000 of these women, the disease is fatal. Today, more than 250,000 women under age 40 are living with breast cancer; many of them found out they had cancer while they were in their 20s.<sup>4</sup> Estimated breast cancer prevalence in New York State, diagnosed in the last five years, is 53,700 cases as of 2007. Prevalence in our area ranges from a high of 870 annual cases in Albany County, 600 in Saratoga County, and 440 in Rensselaer County, to a low of 20 cases in sparsely populated Hamilton County.<sup>2</sup>

## Mortality Rates

As *Figure 4* illustrates, three counties in our service area are above the New York State and United States age adjusted mortality rates of 23.9 and 24 cases per 100,000, respectively. These counties are Washington County with 28.1 cases per 100,000 (confidence interval of 21.2-36.7), Saratoga County with 24.5 cases per 100,000 (confidence interval of 20.7-28.8), and Rensselaer County with 24.1 cases per 100,000 (confidence interval of 19.9-29). These areas are also well above the federal Healthy People goal of 22.3 cases per 100,000.<sup>3</sup>

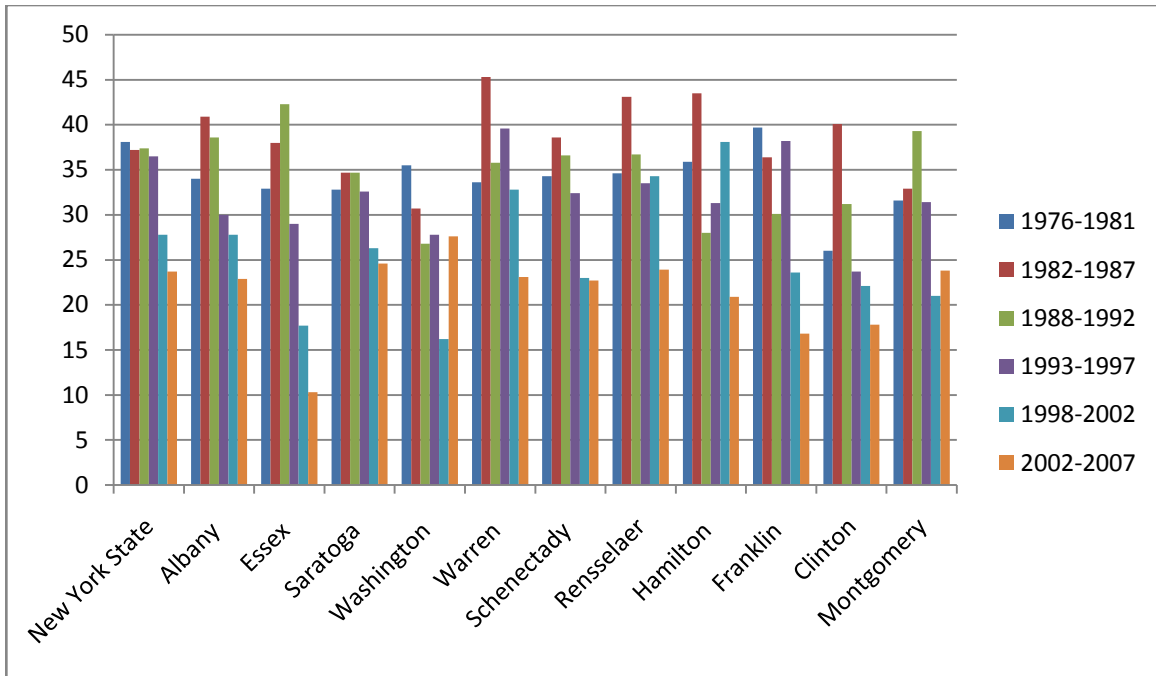
**Age-Adjusted Death Rates for New York, 2003 - 2007**  
**Breast**  
**All Races (includes Hispanic), Female, All Ages**



Created by statecancerprofiles.cancer.gov on 01/25/2011 4:32 pm.  
[State Cancer Registries](#) may provide more current or more local data.  
 Data presented on the State Cancer Profiles Web Site may differ from statistics reported by the State Cancer Registries ([for more information](#)).  
 Source: Death data provided by the [National Vital Statistics System](#) public use data file. Death rates calculated by the National Cancer Institute using [SEER\\*Stat](#). Death rates (deaths per 100,000 population per year) are age-adjusted to the [2000 US standard population](#) (19 age groups: <1, 1-4, 5-9, ..., 80-84, 85+). The Healthy People 2010 goals are based on rates adjusted using different methods but the differences should be minimal. Population counts for denominators are based on the Census 1969-2006 US Population Data File as modified by NCI. The US populations included with the data release have been adjusted for the population shifts due to hurricanes [Katrina and Rita](#) for 62 counties and parishes in Alabama, Mississippi, Louisiana, and Texas.  
 \* Data have been [suppressed](#) to ensure confidentiality and stability of rate estimates. Counts are suppressed if fewer than 16 cases were reported in a specific area-sex-race category.  
 \*\* Data have been [suppressed](#) for states with a population below 50,000 per sex for American Indian/Alaska Native or Asian/Pacific Islanders because of concerns regarding the relatively small size of these populations in some states.  
 Healthy People 2010 Goal 03-03 : Reduce the breast cancer death rate to 22.3.  
[Healthy People 2010](#) Objectives provided by the [Centers for Disease Control and Prevention](#).

**Figure 4. Age adjusted breast cancer mortality rates for NYS 2003-2007.**  
**National Cancer Institute, State Cancer Profiles, 2003-2007**

In *Figure 5* below, breast cancer mortality trends from 1976-2007, in five year increments, are illustrated.<sup>2</sup> Mortality rates in most of the counties in our service area have decreased from 1998-2002 to 2003-2007; although mortality rates in Montgomery and Washington County have increased and Schenectady and Saratoga Counties have shown only a small decline.

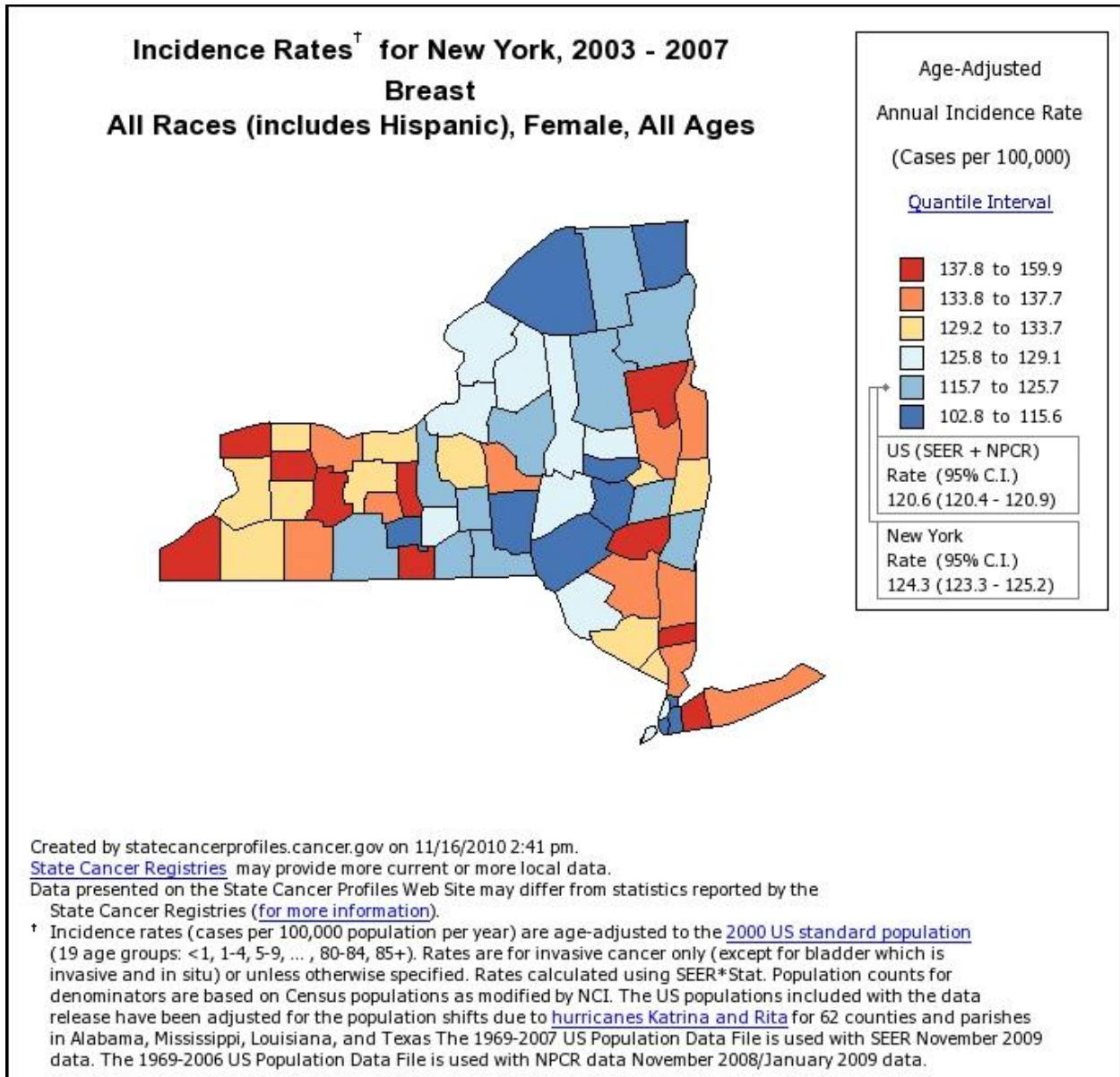


**Figure 5. Age adjusted breast cancer mortality rates from 1976-2007.**

**New York State Department of Health, State Cancer Registry, 2007**

## Breast Cancer Incidence Rates

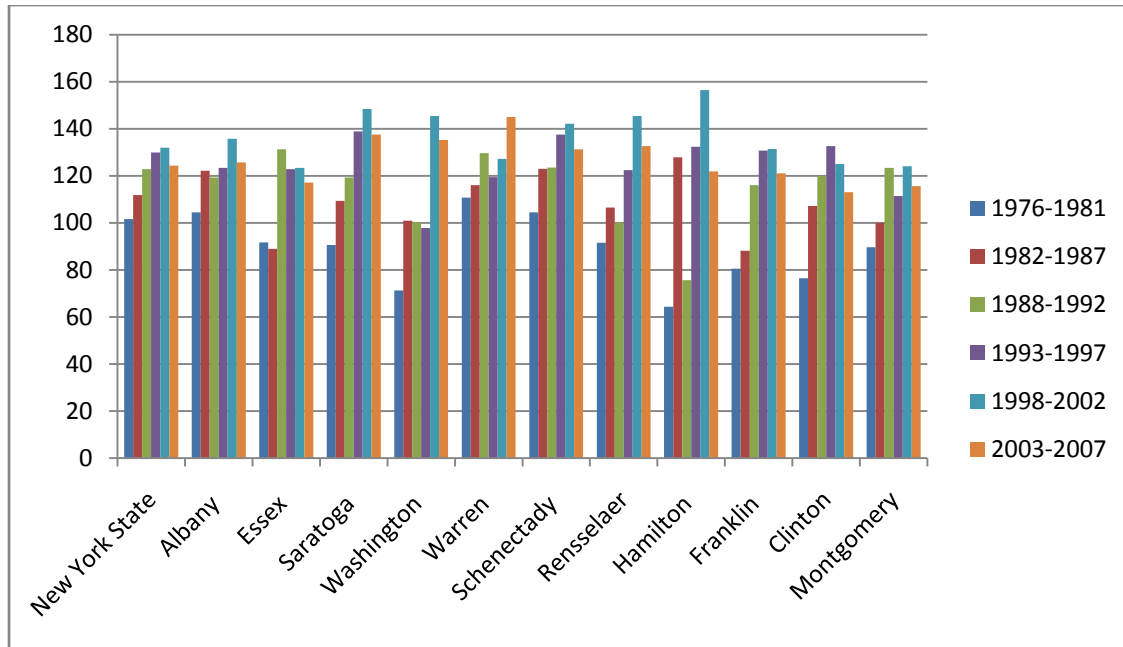
Breast cancer incidence rates were also reviewed. *Figure 6* below shows the New York State age adjusted incidence rates for breast cancer (cases per 100,000 population per year). Six counties in our area have incidence rates above the New York State rate. These counties are Warren with a rate of 145.1 cases per 100,000 population (confidence interval of 129-162.8) Saratoga with a rate of 137.6 cases (confidence interval of 128.3-147.4), Washington with a rate of 135.2 cases (confidence interval of 118.9-153.3), Rensselaer with a rate of 132.6 cases (confidence interval of 122-143.8), Schenectady with a rate of 131.3 cases (confidence interval of 120.9-142.3), and Albany with a rate of 125.7 cases (confidence interval of 118.3-133.4). The New York State rate is 124.3 cases of breast cancer per 100,000 population (confidence interval of 123.3-125.2).<sup>3</sup>



**Figure 6. Age adjusted annual breast cancer incidence rates in NYS 2003-2007.**

National Cancer Institute, State Cancer Profiles, 2003-2007

Figure 7 shows age adjusted breast cancer incidence rates in 5 year increments from 1976 to 2007.<sup>2</sup> Incidence rates in most counties from 1998-2002 to 2003-2007 have decreased but Warren County's incidence rate has increased.

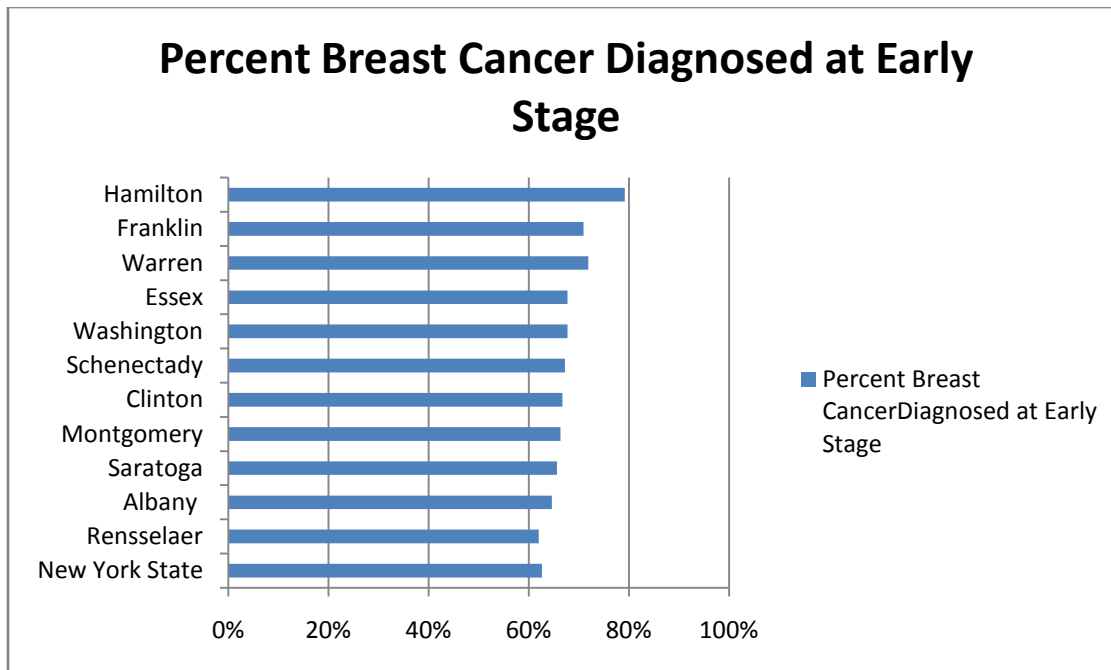


**Figure 7. Age adjusted breast cancer incidence rates from 1976-2007.**

**New York State Department of Health, State Cancer Registry, 2007**

## Stage of Breast Cancer Diagnosis

Studies have shown the importance of detecting and treating cancers at early stages, for breast cancer when caught early and confined to the breast, the five year survival rate is now 98 percent for women in the United States.<sup>4</sup> The figure below (*Figure 8*) shows the percentage of breast cancers diagnosed at an early stage in our area from 2003-2007. Early stage is defined as confined to the organ of origin at diagnosis. The New York State average percent of breast cancers diagnosed at early stage is 62.7 percent. Rensselaer County had only 62 percent of breast cancers diagnosed at an early stage (below the New York State average) and Albany and Saratoga Counties were only slightly higher with 64.6 percent and 65.6 percent cancers diagnosed at early stage.<sup>2</sup> The New York State Comprehensive Cancer Control Plan, 2003-2010 calls for an increase in the proportion of breast cancers detected at an early stage to 75%.<sup>6</sup>



**Figure 8. Percent of breast cancers diagnosed at an early stage 2003-2007.**

New York State Department of Health, State Cancer Registry, 2007

## Insurance and Screening Rates

Insurance coverage is an important factor in women getting screened for breast cancer and seeking any needed treatment. The table (*Table 1*) below shows Clinton, Franklin, Albany and Montgomery Counties all had high rates of uninsured women—all had over 10 percent of their female population uninsured.<sup>5</sup>

**Table 1. Percent of Uninsured Females in Area**

County	State	Female Population	Uninsured Females	
			Population	%
Albany	NY	144,062	14,654	10.2%
Saratoga	NY	108,577	5,573	5.1%
Schenectady	NY	87,272	7,800	8.9%
Rensselaer	NY	79,639	7,197	9.0%
Clinton	NY	40,138	4,746	11.8%
Warren	NY	33,887	2,798	8.3%
Washington	NY	31,685	2,700	8.5%
Montgomery	NY	29,010	2,906	10.0%
Franklin	NY	24,440	2,600	10.6%
Essex	NY	18,103	1,799	9.9%
Hamilton	NY	2,302	219	9.5%
		599,115	52,991	8.8%

**Table 2. Percent of female population over 40 with no mammogram in the last 12 months**

County	State	Female Population 40+	% No Mammo Last 12 Months
Albany	NY	76,423	34.2%
Saratoga	NY	55,117	34.7%
Schenectady	NY	40,319	34.7%
Rensselaer	NY	39,661	36.0%
Clinton	NY	19,605	38.8%
Warren	NY	18,162	38.0%
Washington	NY	16,208	40.1%
Montgomery	NY	13,508	39.5%
Franklin	NY	12,179	41.7%
Essex	NY	10,251	40.2%
Hamilton	NY	1,575	40.3%
		303,008	36.2%

Thompson Reuters ©2009

The table (*Table 2*) above shows the percentage of women over 40 in our region that has not had a mammogram in the past year. From this analysis we can see that Franklin, Hamilton, Essex and Washington County all exceed 40 percent of women over 40 who have not had a mammogram in the past year.<sup>5</sup> The New York State Comprehensive Cancer Control Plan, 2003-2010, calls for an increase in breast cancer screenings for women over age 40 to 75%.<sup>6</sup>

## Area Demographic Information

**Table 3. Demographic information for 11 counties of NENY**

Name	Pop.	%Female	%Cauc.	%Asian	%Hisp.	%NativeAm	% Afr.Amer.	Median Household Income*	%Poverty Level*
Albany	298,284	51.80%	81.50%	4.10%	4.20%	0.03%	12.40%	59,245	12.30%
Schenect.	152,169	51.20%	83.90%	4%	4.80%	0.30%	9.60%	53,404	11.60%
Saratoga	220,069	50.50%	95.10%	1.70%	2.20%	0.20%	1.80%	63,883	7.40%
Hamilton	4,923	50.40%	98%	0.20%	1.40%	0.30%	0.70%	41,882	10.50%
Washington	62,753	48.30%	95%	0.40%	2.40%	0.20%	3.40%	46,702	10.60%
Warren	66,021	51.10%	96.90%	0.80%	1.70%	0.20%	1%	48,376	10.50%
Essex	37,686	48%	95%	0.50%	2.40%	0.40%	3.40%	44,374	13%
Clinton	81,618	48.90%	93.90%	0.80%	2.80%	0.40%	3.80%	49,988	14.40%
Rensselaer	155,541	50.60%	89.90%	2.30%	3%	0.30%	6.10%	54,437	10.30%
Franklin	50,274	45.10%	84.90%	0.50%	4.20%	6.80%	7%	40,643	16.20%
Montgom.	48,616	51.50%	95.60%	0.70%	9.60%	0.30%	2.20%	41,708	16.70%
<b>Region</b>	<b>1,177,954</b>	<b>49.76%</b>	<b>91.79%</b>	<b>1.45%</b>	<b>3.52%</b>	<b>0.86%</b>	<b>4.67%</b>	<b>49,513</b>	<b>12.14%</b>
<b>NYS</b>	<b>18,000,000</b>	<b>51.40%</b>	<b>73.40%</b>	<b>7.10%</b>	<b>16.80%</b>	<b>6.00%</b>	<b>17.20%</b>	<b>55,980</b>	<b>13.70%</b>

U.S. Census Bureau, State and County Quickfacts, 2009 estimates

When we look at demographic information for our area (*Table 3*), we see a wide range in ethnicity, educational level, and income level. Our area is predominantly Caucasian, but in Albany, Schenectady and Rensselaer there are significant African American

populations (12.4 percent, 9.6 percent and 6.1 percent, respectively). Montgomery County is notable for a large Hispanic population of 9.6 percent and Franklin County with a Native American population of 6.8 percent. Median household income ranges from a high of \$63,883 in Saratoga County, to lows of \$41,882 and \$41,708 in Hamilton and Montgomery Counties, and the lowest median household income in Franklin County of \$40,643. Over 16 percent of households in Montgomery and Franklin Counties also live below the poverty level. In addition, Franklin, Montgomery, and Washington Counties have fewer adults with a bachelor's degree of higher.<sup>†</sup>

## **Communities of Interest**

When examining the data outlined above some counties emerge as target areas for the Northeastern New York Affiliate of Susan G. Komen for the Cure. Counties in our service area that are above the New York and United States age adjusted mortality rates (Washington, Rensselaer) are of particular importance. Washington County also has a relatively high breast cancer incidence rate, the third lowest screening rate for women over 40 in the past 12 months and the third lowest number of adults having obtained a bachelor's degree of higher. Rensselaer had the fourth highest incidence rate in our area, and the largest percentage of women diagnosed at a late stage. The counties with the lowest percentage of women having had a mammogram in the past 12 months (Franklin, Essex, Washington and Hamilton) are also a concern. Albany with the second highest percentage of late stage diagnosis in our area is also notable.

Studies also have shown race and ethnicity is a factor in breast cancer outcomes. While the overall breast cancer incidence rate for African American women is about 10 percent lower than for Caucasian women, the mortality rate is 37 percent higher. Breast cancer is the most common cancer among African American women.<sup>7</sup> Among Latina women, breast cancer is the leading cause of cancer incidence (28 percent of new cancers) and deaths (15 percent).<sup>8</sup> A recent report which examined racial and ethnic disparities in health status and access to care points to factors that may contribute to later diagnosis and treatment for breast cancer in Latinas. When compared to white women, Latinas: are less likely to have health coverage (37 percent vs. 13 percent), are less likely to have a personal doctor (37 percent vs. 13 percent), and have not had a mammogram in the past two years (29 percent vs. 25 percent).<sup>9</sup> In addition, a 2007 study reported that Native American women have less favorable socioeconomic status and health care access, contributing to lower rates of screening and breast cancer incidence rates, but higher late-stage diagnosis rates.<sup>10</sup> Consistent with this, a report examining racial and ethnic disparities in health status and access to care found that when compared to white women, Native American women were: less likely to have health coverage (34 percent for Native American women vs. 13 percent for white women), were less likely to have a personal doctor (21 percent vs. 13 percent) or a routine checkup in the past two years (19 percent vs. 17 percent).<sup>9</sup> In the next section, barriers, gaps and assets in breast health in these areas will be explored.

# Health Systems Analysis of Target Communities

## Overview

Data for this section that reviews the health care systems in our service area came from a survey of health care providers using Survey Monkey and key informant interviews using the continuum of care model; mapping of Affiliate grantees, of hospitals and health clinics from Health Resources and Services Administration (HRSA) information, of mammography facilities from the Federal Drug Administration; and an analysis of the State Cancer Services Program, which provides free cancer screening to un- and underinsured New Yorkers.

## Health Care Provider Survey

A survey was sent out to breast health and breast cancer service providers in the 11 county service area of Northeastern New York using the online survey tool, Survey Monkey. The survey contained 17 questions and included both closed and open ended questions. The survey addressed themes that emerged from the review of statistical information and analyzed how well the continuum of care model (screening, diagnosis, treatment and follow up care) works in our area. Thirty-five providers completed the survey; copies of the results can be obtained from the Affiliate. Best represented were Rensselaer with 14 providers responding and Essex and Albany with 10 each providers responding (these counties correspond to important target counties from the review of breast cancer and demographic statistics.). Most of the providers responding worked at area hospitals, but also included oncology practices, Cancer Services Program coordinators, grantees of the Affiliate and other nonprofits. Only one provider from an educational institution completed the survey and no employees of government agencies did so. Services provided by these organizations included: education/counseling—71.4 percent, some kind of patient navigator services—62.9 percent, diagnostic services—60 percent and financial assistance and screening—57.1 percent. Most of these organizations (85.7 percent) responded that they did partner with other entities in service delivery. These partners included other providers, the Cancer Services Program, physicians, shelters, schools and colleges, churches, hospitals and organizations such as the Oncology Nurses Society and Kiwanis/Rotary clubs. Providers cited that breast health and breast cancer community assets were support groups, community health nurses, imaging centers, the Cancer Services Program, the American Cancer Society, Susan G. Komen for the Cure and other nonprofits, hospitals, HMP's, obstetricians, and gynecologists.

When asked where most people in their community went for breast health and breast cancer information, the majority answered health care providers (94.3 percent). The next most used sources of information are family and friends, internet/online sources and printed material (62.9 percent). However, providers thought the most effective means for information sharing was direct presentations by organizations. Most organizations do provide breast cancer and breast health information to their clients. This material came predominantly from the American Cancer Society, Susan G. Komen for the Cure, the New York State Department of Health, the National Cancer Institute and the Lance Armstrong Foundation. This information is made available by most

providers (74.3 percent) to everyone; but women 50 years and older were targeted by 65.7 percent of providers and women 40 and older were targeted by 62.9 percent of providers. Overwhelmingly, area providers served Caucasian women (97.1 percent), with African American women and Hispanic women served by 74.3 percent of providers. Low income/working poor and those without insurance were most often cited by providers as being priority populations that should be targeted for breast health and breast cancer education and services (82.9 percent and 85.7 percent, respectively). The next most often cited priority population cited was rural women (77.1 percent).

To find out about factors that inhibit women from seeking and obtaining breast health services, lack of financial resources was cited most often as the critical issue (40 percent) and cannot take time off from work as a very important issue (47.1 percent). Other factors that were rated very important by providers were educational--myths and false information (42.9 percent) and lack of knowledge (45.5 percent). Transportation was also a very important factor in women seeking and obtaining services (40 percent). Education issues were highlighted when asking providers about their clients' awareness of breast cancer risk factors—66.7 percent of providers responded that their clients were only somewhat aware of these factors. Finally, providers were asked what the single most important factor would be in improving the delivery of breast health and breast cancer services in the area. Financial factors (financial assistance, co-pays, access to insurance) were most often named by providers. Also cited was the need for coordination of programs among providers and more information about prevention.

## **Breast Health Services and Rural Women**

From our analysis of demographic and breast cancer statistics and the provider survey, rural women (rural counties in our area are Clinton, Essex, Franklin, Hamilton, and Montgomery) emerged as a target population for the Komen Northeastern New York Affiliate. Many barriers to screening and treatment exist in rural areas such as poorer access to health services and specialists, limited access to new therapies, limited options for transportation and limited knowledge about the importance of early detection through regular screening and prohibitive costs.<sup>11</sup> In a June 2008 report on health disparities, rural women were found to be less likely to be in compliance with mammography recommendations (77.9 percent) than were urban women (82.2 percent).<sup>12</sup>

To further explore the provision of breast health care for rural women, staff of Hudson Headwaters Health Network (HHHN) was interviewed. HHHN is private, nonprofit system of community centers providing comprehensive primary care to residents of the Adirondack area and serves the rural target counties we identified through a review breast cancer statistics. HHHN is leading the Adirondack Region Medical Home Pilot, a collaborative effort by health care providers and public and private insurers to transform the health care delivery system in the region. Its goals are to improve quality, ensure access and contain costs for health care by emphasizing preventive care, enhanced management of chronic conditions, and by assuring a close relationship between patients and their primary care providers. The approach is designed to result in a strengthened patient/physician dialogue and relationship. Increased emphasis will be placed on prevention and overall health by encouraging and reminding patients

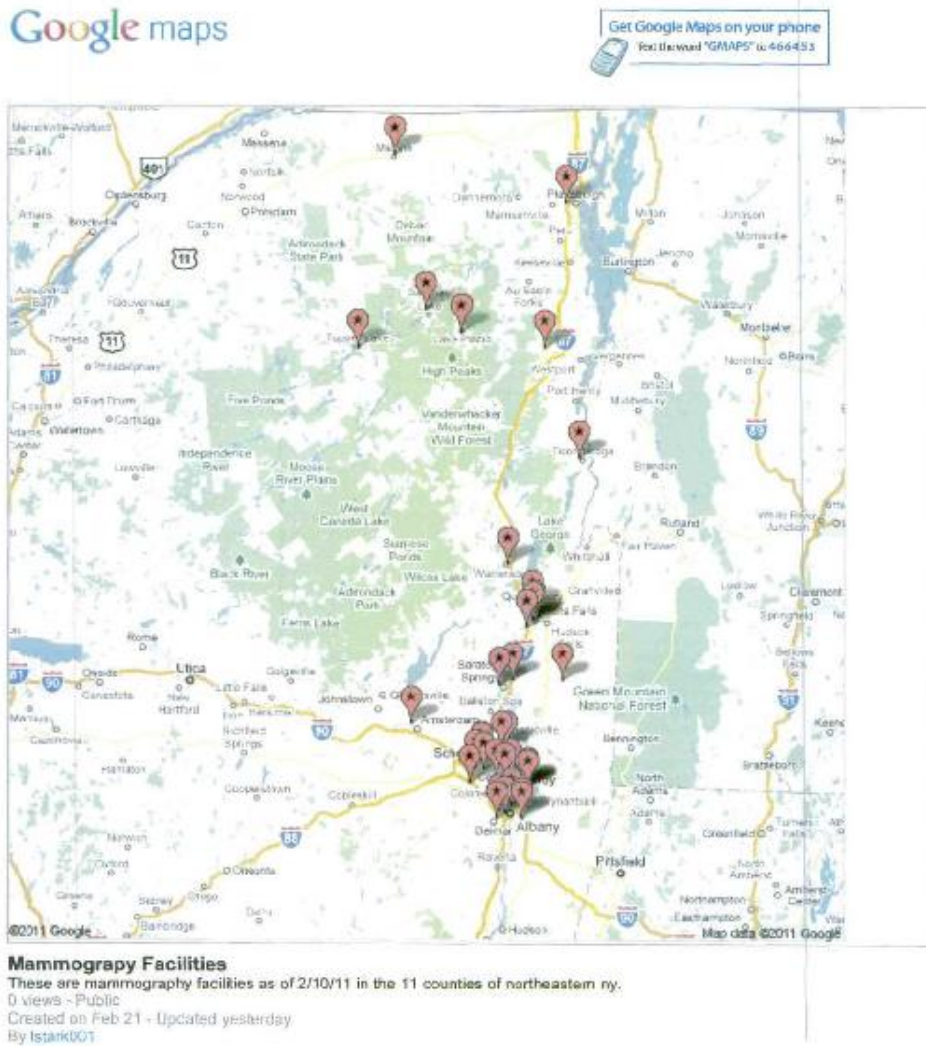
about wellness steps and practices. Patients are encouraged to schedule annual exams and stay current with age and gender-related screenings (i.e. pap smears, mammograms, prostate exams, immunizations, flu shots). Each patient will have a continuous, up-to-date partnership with a primary care doctor. The primary care doctor will be part of a team, which will take responsibility for the health of the patient and his surrounding population. The primary care doctor will provide a health care outline for the patient to lead a healthier, more productive life. The patient-centered medical home will help facilitate a partnership between the hospital, home health agencies, and the community. Patients will have enhanced access to their physicians through open scheduling, expanded hours, and new communication options. The financial cost of health care will be re-focused to avoid preventable illnesses to avoid future, more expensive treatment costs. On the patient side, increased contact with the primary care practitioner will help to enable earlier diagnosis of problems. Moreover, patients who follow primary care recommendations for diet, physical activity, smoking cessation and other behaviors associated with good health are likely to experience fewer preventable medical problems.

An important aspect of the program for women's health is screening and treatment for breast cancer. Since the program started in late 2010, staff has contacted 200 people for mammography screenings through the use of information in electronic records. Primary barriers encountered to screenings identified by staff included: transportation, low literacy, time off from work, and secondary mental health issues.

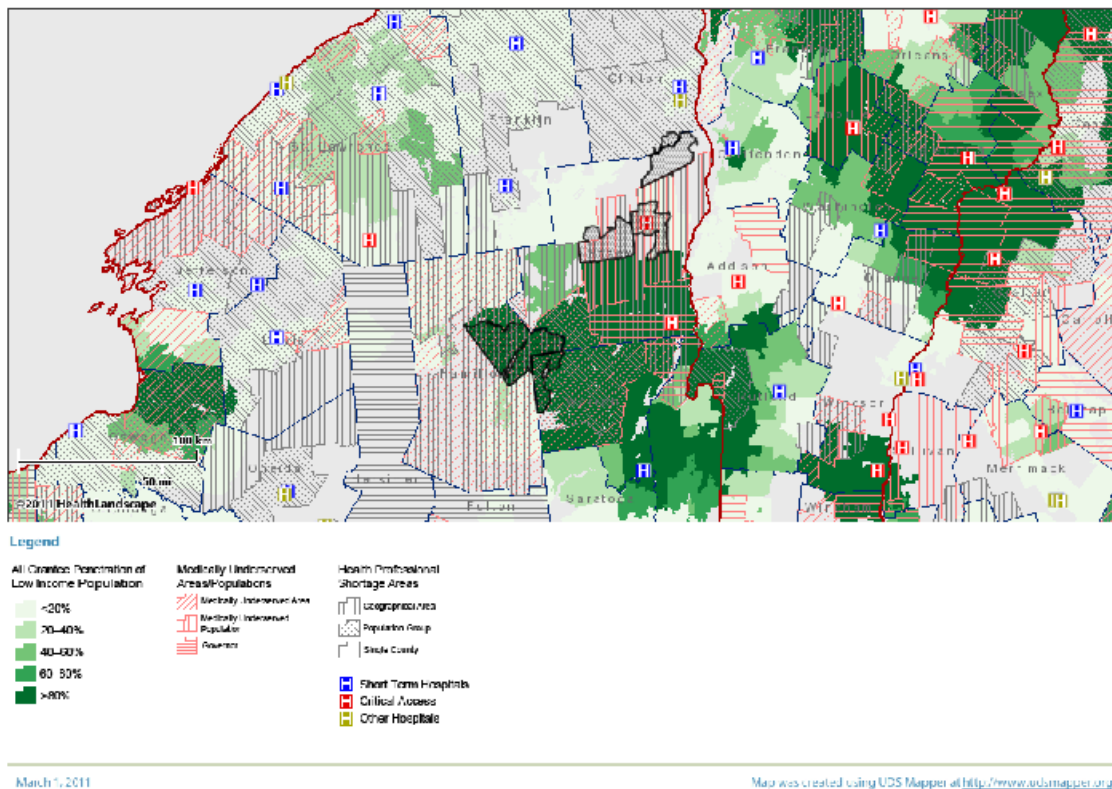
## **Mammography Services, Hospitals and Health Services**

In our analysis of breast cancer statistics in the previous section, we found the rates of screening vary by as much as 8% in our area. To assess availability and access to screening services we mapped the mammography facilities in our target areas certified as meeting baseline quality standards for equipment, personnel and practices under the Mammography Quality Standards Act of 1992 and its amendments using data from the Federal Drug Administration Mammography website.<sup>13</sup> Notably of the counties with the lowest screening rates, Franklin and Essex have only three facilities over very large areas, Washington County has 1, and Hamilton County has none (see *Figure 9*).

Using the HRSA Uniform Data System Mapper, hospitals in the target counties were mapped along with the medically underserved populations and those areas that have a shortage of health care professionals. *Figure 10* shows Hamilton County has no hospital and that residents in rural, northern counties have to travel great distances to the nearest hospital. Northern rural target counties also have medically underserved areas and areas that have a shortage of health care professionals.<sup>14</sup>

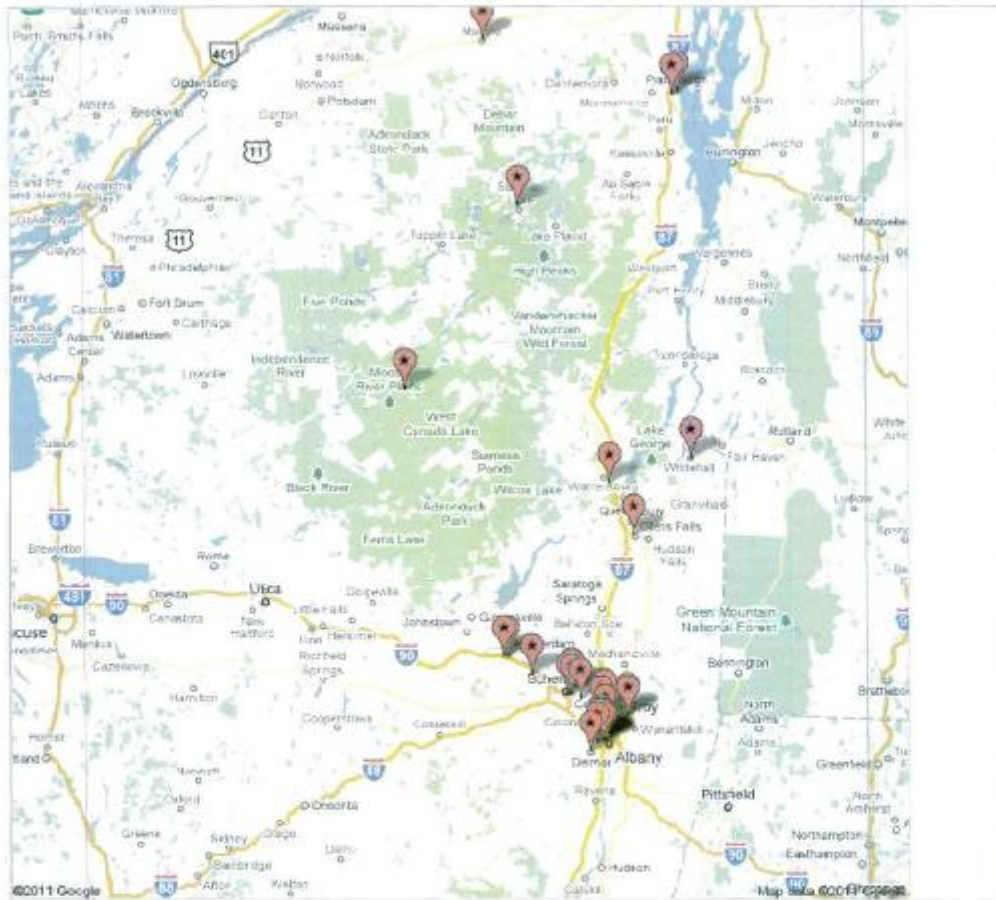
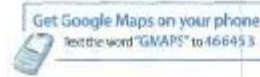


**Figure 9. Certified Mammography Facilities in 11 Counties of NENY.**  
Food and Drug Administration, Mammography Website, 2011



**Figure 10. Hospitals and Underserved Healthcare Areas.**  
**U.S. HRSA, Uniform Data System Mapper, 2011**

Figure 11 below shows the grantees of the Komen Northeastern New York Affiliate. Most grantees are in the southern part of the service area, with only eight grantees in the northern rural target counties which have been identified as underserved for health care services and having breast cancer and demographic characteristics of concern. Notably, of the counties with low screening rates, Essex County has no grantees, Franklin only has two, Hamilton County and Washington County has one grantee each. Most of the funded grants focused on education rather than assistance with screening and treatment. Few of these programs targeted historically underserved populations such as African American, Hispanic and Native American women.



**Grantees of Komen NENY**  
Grantees of the Northeastern New York  
Affiliate of Susan G. Komen for the Cure from 1995-2008.  
478 views - Public  
Created on Feb 12, 2009 - Updated 3 minutes ago  
By istark001 - 3 Collaborators

**Figure 12. Komen Northeastern New York Grantees.**  
Northeastern New York Affiliate of Susan G. Komen for the Cure, 2011

## NYS Cancer Services Program

New York State's Cancer Services Program is a critical component in the provision of financial assistance for cancer care for under and uninsured women. The Cancer Services Program oversees the delivery of comprehensive breast, cervical and colorectal cancer screening services and prostate cancer education to underserved populations in New York through contractual agreements with local community-based organizations. Eligible clients are also enrolled in the Medicaid Cancer Treatment Program for Medicaid coverage for the duration of their treatment. In addition, the program provides public and health care provider education on cancer prevention and early detection, maintains a quality improvement program to ensure the quality of clinical services provided through the program, and provides funds for community-based cancer support services for persons with cancer and their families. In 2004-05, through this program over 40,000 mammograms<sup>15</sup> were provided—in 2009-10 this number was 32,947 (and 30,952 clinical breast exams—see *Table 4*). The priority population for this program is women ages 40 and older who are at or below 250 percent of the federal poverty guideline and who have no health insurance or whose insurance does not cover screening or diagnostic services. Of special concern are ethnic and racial minority groups and women who are medically underserved because they live in isolated communities.

Given the importance of this program, the staff of the State Cancer Services Program was interviewed about the target areas for this Profile. They emphasized the importance of increasing the number of women who are screened through this program, which currently only reaches approximately 10 percent of the eligible population. They stated more advertising is needed to inform people of the program, the recent confusion caused by conflicting screening recommendations, and transportation issues as all contributing to low screening numbers. Staff recommended using the patient navigation model to identify eligible women through primary care medical practices, invite these women for screening and help them overcome barriers to screening and if necessary to diagnosis and treatment. Navigators would be culturally competent and would work within the health care system, in collaboration with providers and local community organizations. The navigators would identify resources to help patients overcome barriers to screening, communicate with providers offices to ensure patients attend appointments, and may participate in the diagnostic follow-up plan for those with abnormal findings. Staff thought this model would be more successful than more passive approaches to increasing screening efforts that have been undertaken in the past.

*Table 4* below shows the most recent numbers of mammograms and clinical breast exams funded by the NYS Cancer Services Program. *Figure 12* illustrates the percentage of eligible uninsured New Yorkers who are not being screened under the Cancer Services Program, according to American Cancer Society 2008 estimates. Counties with less of the eligible population screened under this program correspond to the counties identified as having low overall screening rates in the previous section of this Profile. The Coalition to Save Cancer Screening, made up of health care providers,

cancer survivors and advocacy organizations, including the New York Affiliates of Susan G. Komen for the Cure, have been working since 2008 to educate lawmakers and the public on the importance of this program to reduce the cancer burden in the State and to increase State budget funding for this program.

**Table 4. NYS Cancer Services Program mammography and clinical breast exams provided in 2009-10**

*2009-2010 Program Year Statistics*

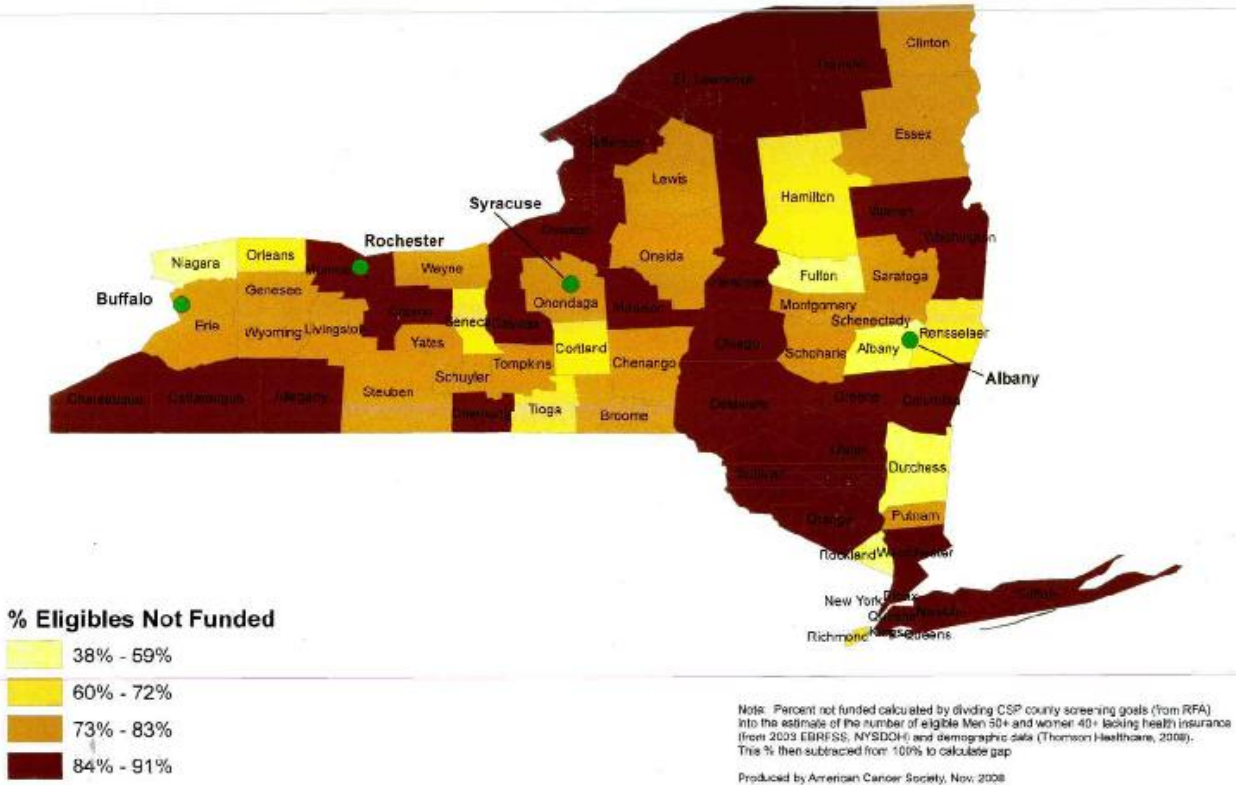
<b>Komen Region<sup>1</sup></b>	<b># Program Funded Mammograms</b>	<b>Percent</b>
Central NY Affiliate	4,493	13.6
Greater NYC Affiliate	19,082	57.9
Hudson Valley	3,056	9.3
Northeastern NY Affil	2,654	8.1
Twin Tiers Region Aff	1,355	4.1
Western NY Affiliate	2,307	7.0
<b>Total</b>	<b>32,947</b>	<b>100.0</b>

<b>Komen Region</b>	<b># Program Funded CBEs</b>	<b>Percent</b>
Central NY Affiliate	3,882	12.5
Greater NYC Affiliate	18,491	59.7
Hudson Valley	2,911	9.4
Northeastern NY Affil	2,360	7.6
Twin Tiers Region Aff	1,246	4.0
Western NY Affiliate	2,062	6.7
<b>Total</b>	<b>30,952</b>	<b>100.0</b>

<sup>1</sup> Due to Cancer Services Program partnership coverage of multiple counties in some areas, the Komen defined regions have been modified such that a) Livingston County is included under the Western NY Affiliate, b) Tompkins County is included under the Central NY Affiliate, c) Chenango County is included under the Twin Tiers Region and d) Fulton County is included under the Northeastern NY Affiliate. Data from NYS Department of Health.

**New York State Department of Health, Cancer Services Program, 2011**

**Who's not getting screened in New York?**  
 Percent of uninsured New Yorkers not funded for cancer screening under current budget for Cancer Services Program (CSP)



**Figure 12. Percent of uninsured New Yorkers not screened under Cancer Services Program. American Cancer Society, 2008 estimates**

**Conclusions**

A mapping of community assets found most certified mammography facilities in the southern part of the Affiliate service area with few screening facilities in target counties of Franklin and Essex Counties, only one in Washington, and none in Hamilton County. These target areas also had low overall screening rates and a low percentage of screening under the Cancer Services Program. A closer relationship and coordination with the NYS Cancer Services Program to remedy this will be an Affiliate priority. Maps showed fewer hospital and health centers also exist in these target areas and their populations have been identified as underserved for medical services. Existing grantees of Komen Northeastern New York Affiliate are not concentrated in the target counties and few targeted traditionally medically underserved ethnic and racial populations. This information corresponds with health care providers' emphasis on

increasing services to rural women as a priority. From key informant interviews and surveys, the importance of increased screening of women in our area was reinforced, as was the need to increase general breast health knowledge—of risk factors, to dispel myths and to ease fears. Barriers to increased screening focused on financial issues, transportation issues, and lack of knowledge about breast health. The critical role that can be played by primary care doctors and health centers in target areas in breast cancer prevention and screening also emerged and will be the focus of Komen Northeastern New York Affiliate partnerships in the future.

Provider surveys and interviews cited the importance of accurate information, and recognizing the importance of increasing breast health and breast cancer knowledge in young women, the Centers for Disease Control has convened an Advisory Committee on Breast Cancer in Young Women, a federal advisory committee established by the Education and Awareness Requires Learning Young (EARLY) Act, section 10413 of the Patient Protection and Affordable Care Act (Public Law 111-148). The EARLY Act authorizes CDC to develop initiatives to increase knowledge of breast health and breast cancer among women, particularly among those under the age of 40 and those at heightened risk for developing the disease. The Advisory Committee on Breast Cancer in Young Women will assist CDC in developing evidence-based approaches to advance understanding and awareness of breast cancer among young women through prevention research, public and health professional education and awareness activities, and emerging prevention strategies.

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

## **Overview**

Focus groups and interviews were used to gain first-hand knowledge of the communities that were found to be of concern based on the review of breast cancer statistics, demographic information and interviews and surveys of health care providers. Discussion topics were developed to address questions and gaps and follow up on information obtained from the health systems analysis. Perspectives were obtained about Susan G. Komen for the Cure, providers and services in the area, what gaps and barriers exist to seeking and obtaining services and what Komen should be doing to enhance services in the targeted areas.

## **Rural Women**

A focus group meeting of rural women from the rural northern target counties identified was held. The group included both breast cancer survivors and women who have not been diagnosed with breast cancer. They were recruited from health care providers and other nonprofit breast health organizations in these areas. Meeting notes were taken to record and identify common themes. Ten women participated for two hours and information was obtained about what challenges exist for rural women, what are the most effective ways to disseminate breast health information in rural areas, what new partnerships could be formed to improve services, and funding priorities for the Komen Northeastern New York Affiliate.

When participants were asked about Komen, the most often cited words were Inspiration, hope, the Race, research, education, and cure. Most women had heard of Komen, but a few had not had contact with Komen grantees or other activities. Rural women in this focus groups thought the most credible sources in their community for breast health information were physicians, obstetricians, gynecologists and the primary hospital/cancer center in the area—CVPH. Other primary care nonprofits were also named--Planned Parenthood and Community Link Mobile Health. In terms of priority populations for breast health information, the group cited low income and uninsured as the most important populations. There are women in the community the focus group thought that do not regularly seek out physicians and access the health care system; and information and programs should be developed for these people. Another population mentioned was young women—that accurate information should definitely be given out in colleges (SUNY Plattsburgh was mentioned), but should start even earlier in high schools and middle schools and that young women should be aware of their risk and that women under 40 can get breast cancer.

The group was asked about what barriers exist for rural women seeking breast health services. Not only the was the lack of insurance cited but also other insurance issues such as high co-pays, high deductibles, and insurance that might limit mammograms or other breast health services. Family influence was also very important, if there was not a history in the family of visiting doctors and seeking preventative screenings, it would not be important to children—they would not have role models to follow. Women in the group also said many women are afraid of screening (that procedure itself would spread

cancer or hurt) and are fearful of the potential diagnosis. Rural populations also may have lower literacy levels that make breast health education an issue. The nature of the area (in both geography and density) leads to more isolation and independence—also leading to lower use of health care services. Women also need to be knowledgeable about what services are available. Women sometimes do not seek services as they have a tendency to put their needs second to those they care for—whether it is their parents or children and hence put off their own health needs. (The focus group thought the message to these women should be that taking care of their own health is helping to provide for the care of their loved ones).

Needed services for rural women included financial assistance with screening and treatment and transportation services—even women with cars find the cost of gas has become prohibitive considering the distances that must be traveled. The American Cancer Society volunteer driver transportation program was mentioned also as a helpful and needed program. The group also discussed the importance of primary care providers—that they are integral to recommending screening and need to do a better job with following up to make sure patients schedule mammograms and any needed treatment. Survivors in the group were asked what programs they found most helpful and they most often mentioned support programs and that social networking like Facebook can be used to share experiences. Those diagnosed are inundated with information and overwhelmed by their diagnosis and often feel isolated and are busy with appointments and treatment. More information should also be available about types of breast cancer like triple negative breast cancer. One group member said even smaller support programs have a ripple effect in that they positively impact not only the survivor, but their family, friends and community. While participants thought that the areas of education, screening, treatment and survivorship were all important, most of the group cited screening as the most important use of Komen funding. Treatment assistance was also mentioned, as was survivorship programs. One participant mentioned that men in the family were important players in women's health care and should be educated as well.

In terms of getting out breast health information and new and innovative partnerships, the group thought that getting to low income populations could be best achieved through the Department of Social Services, at job fairs, the local health departments and the Cancer Services Program. The participants thought that primary care physicians, obstetricians, gynecologists and health clinics are critical in the successful delivery of breast health services. The importance of coordinating with insurance programs and the Medicaid Treatment Program in New York was cited. To help with prescription costs, one participant mentioned county prescription cards and help with the cost of prescriptions sometimes provided through pharmaceutical companies. Mass media of newspapers and radio was considered an important method of disseminating information, as are health fairs, and that in the area billboards are very effective. Mobile billboards should also be investigated.

## Young Women

A focus group meeting of young women from our service area who were diagnosed with breast cancer under the age of 40 was also held. They were recruited from nonprofit breast health organizations in the area. Meeting notes were taken to record the two hour meeting and to identify the common themes of the five women in the group. Questions focused on educational needs of young women, their unique perspective on health care systems, and screening and service gaps. These women were asked about their impressions of Susan G. Komen for the Cure. All had heard of Komen and were familiar with the organization. Phrases used to describe Komen included: the largest breast cancer group, well known, awareness, fundraising, the face of breast cancer, and advocacy. In terms of awareness, the group discussed that awareness of the pink ribbon alone does not always equate with accurate information and knowledge about breast cancer, risk factors and prevention.

When asked about credible community sources of breast information, the group mentioned other women who have gone through breast cancer as sometimes more credible to them than health care professionals. Family members and friends are very important. Many women now rely on internet sources and books. Young women do always think of breast cancer—and Komen and the Young Survivors Coalition are important sources of accurate information. This group thought that all women should get breast health services and messages and that the mass media still works well for general breast health information. Likely partners to get out information are: colleges, social networking sites, health centers, and sororities (like at Sage and RPI).

Barriers and challenges to breast health screening focused on financial issues—high co-pays, lack of insurance or the inability to get transportation or a day off and they also mentioned busy work and life schedules. This group also emphasized the importance of referrals, recommendations and reminders from primary care physicians and physicians need to be more aware of services, getting their patients to use them, and knowing that women under 40 can have breast cancer.

Needed treatment services mentioned in addition to financial assistance were child care and housecleaning. To increase women's use of breast health screening and treatment services the group thought more navigators and case workers were needed to inform women about what services are available, use team meetings of providers looking at the same person holistically, increase coordination amongst doctors, and increase the portability of health records. Participants thought ancillary services such as massage, hypnosis, nutrition, holistic and complementary therapies were helpful to them. Komen program funding should give a priority to financial assistance for treatment and screening. Participants mentioned issues that can be of particular concern to young women diagnosed with breast cancer—early menopause, potentially not working and interrupting career at that critical time in life, body image, child rearing/fertility, long term side effects of treatment, sexuality and dating. The group emphasized the need to treat women as individuals, not statistics or generalize how women will cope with the disease. Needed Komen programs mentioned by the focus groups were: more information for young women especially on risk factors, a special curriculum in high schools on breast health, mentoring programs for young survivors and better screening tools.

## **African American Women**

Five African American women from the target counties of Albany, Schenectady and Rensselaer were interviewed to obtain information from a community perspective to understand their knowledge, attitudes and beliefs about breast cancer, breast cancer resources in the target communities they live in, if education and outreach efforts are effective and what recommendations they have to enhance services. The interviews were analyzed to identify common themes. The women included breast cancer survivors and women who did not have breast cancer and were recruited from nonprofit breast health organizations. All the women had heard of Komen and associated Komen with effective fundraising; but the Komen promise and how the organization was founded also resonated with those interviewed. Credible sources for breast health information for these women included the American Cancer Society and physicians. Some found physicians, though, not to always be flexible and listen to the patients needs. In urban communities, it was thought that breast health conversation should start early, in young women, and that often breast cancer is not discussed until it is too late. Some thought that in the African American community women were not as open about discussing breast cancer or their own diagnosis.

In terms of barriers in the community, interviewees mentioned lack of knowledge about breast cancer and risks and lack of knowledge about what services are available especially those at low cost. Transportation can also be a concern if services are not on bus lines or are centered in suburban areas. Insurance was also mentioned and that in urban communities often services were not available or the resources were subpar. Women overwhelmingly thought that area churches should be used to get information out to this community, as most have health auxiliaries; community centers and organizations like the YWCA would be effective as well. Breast health and breast cancer organizations need to have a presence in the community, and attend community activities, not just expect people to come to them. Services mentioned that could help to increase use of breast health services and screening are coordinating transportation and babysitting services. These women also mentioned primary care physicians and clinics as important—and they need to be more proactive in breast health and screening—potentially using email or text reminders.

Education and screening were most often cited as priorities for Komen funding. Breast cancer survivors said that needed services in the African American community were more information and access to genetic testing and counseling, help with communicating the diagnosis and treatment and risks to family members, lymphedema services, and wigs specifically made for African American women. The women interviewed also thought that fitness, exercise and other prevention programs would be invaluable in this community. Finally, women who participated in these interviews suggested using culturally sensitive educational material—so that photos of women in the materials used looked like the women in the community and that women from the community should serve as champions and role models for breast health and breast cancer information delivery.

## **Conclusions**

The qualitative data reinforced the information obtained from the review of breast cancer statistics, demographic information and the health systems analysis. There was consistency among the themes from the various interviews and focus groups although a few important differences were noted. The need for concrete information and knowledge, not just awareness, among young women was a common theme of all the focus groups and interviews. The best method or place to get that information out varied with the community. Most of the participants of the interviews and focus groups cited a need for more women to get screened and to fund programs to increase screening rates and overcome barriers to screening. All the groups mentioned the role of primary care physicians or breast health navigators in this effort—the need for more proactive efforts, coordination and follow up to ensure women are referred and reminded about screening. Transportation services were more predominant in the focus group on rural women and the role of churches in delivering breast health messages was an integral theme of the interviews with African American women. All the focus groups and interviewees mentioned financial issues, whether it was insurance coverage, time off from work or child care, which have become acute with this economy, as being a predominant issue in breast health.

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

### **Review of the Findings**

The review of breast cancer statistics led to a further examination of those counties that had high breast cancer mortality rates (Washington, Rensselaer Counties), a high incidence for breast cancer (Warren, Washington, and Rensselaer Counties), low screening rates (Franklin, Essex, Washington and Hamilton Counties), a low percentage of insured women (Clinton, Franklin, and Albany), and a high percentage of women with late stage diagnosis of breast cancer (Rensselaer, Albany). Demographic factors of race and ethnicity, educational levels and income were also reviewed; as were studies that showed a disparity in health care outcomes for African American, Hispanic and Native American women. Census figures showed the largest populations of African American women in Albany, Schenectady and Rensselaer Counties. The largest population of Hispanic women in our area is in Montgomery County and the largest population of Native American women is in Franklin County. Insights into existing services and gaps that exist were explored through surveys of health care providers and key informant interviews. Certified mammography facilities were mapped in targeted counties, as were Affiliate grantees, hospitals and areas that had a shortage of health care professionals and health care services. The important role of the State Cancer Services Program in increasing screening rates was also assessed. Finally, community input was obtained through focus groups and interviews of key populations.

### **Conclusions**

Available demographic and breast cancer statistics, mapping of existing services and facilities, the results of health care provider interviews and surveys and community input was reviewed to develop the priorities for our Affiliate. Studies referenced in this Community Profile have shown the role that race and ethnicity play in breast health outcomes and cite disparities in healthcare for certain race and ethnic populations. The first priority is to increase breast health and breast cancer services to target populations that have been historically underserved in health care in those counties with significant percentages of these populations—African American women in Albany, Schenectady and Rensselaer Counties, Hispanic women in Montgomery County and Native American women in Franklin County. These counties also have breast cancer statistics or demographic factors of concern. For instance, Rensselaer County had the fourth highest incidence rate in our area and the largest percentage of women diagnosed at a late stage. Albany County had the second highest percentage of late stage diagnosis in our area. Franklin County had the lowest percentage of women having had a mammogram in the past 12 months.

We know that early detection is the key to breast cancer survival. The next priority is to increase screening rates in the four counties with the lowest percentage of women over 40 who have had a mammogram in the past year—Franklin, Essex, Washington and Hamilton Counties. As shown from our mapping of facilities, these counties also have the least mammography facilities, a low percentage of women being screened through the State Cancer Services Program and are underserved for health care services and

have areas that have shortages of health care professionals. Key informant interviews from health care professionals reinforced the need to increase screening rates in these areas.

Many residents of Northeastern New York live in rural areas far from available services and this factor negatively impacts their health outcomes. HRSA's Office of Rural Health Policy has designated Clinton, Essex, Franklin, Hamilton and Montgomery as rural counties. These negative impacts are evidenced by the demographic and breast cancer statistical information in this Community Profile--Franklin, Hamilton, Essex and Washington County all exceed 40 percent of women over 40 who have not had a mammogram in the past year and Clinton, Franklin, and Montgomery Counties all had high rates of uninsured women—all had over 10 percent of their female population uninsured. Information provided by health care professionals through our key informant interviews and surveys and shown in mapping of mammography facilities, hospitals and healthcare facilities and services also reinforces this statement. Rural women in our focus group from these counties emphasized the need for transportation to services and financial assistance programs. The third priority is to increase services, and access to services, to women in rural counties of our area.

Information from the provider survey, interviews and focus groups focused on the need for accurate information to be disseminated to young women to dispel myths and discuss risk factors and prevention. They emphasized the need to move from awareness to understanding and action. The CDC recognized this need in establishing the Advisory Committee on Breast Cancer in Young Women. The fourth Affiliate priority is to enhance efforts to educate young women in the area about breast health risks, prevention, and screening.

## **Affiliate Action Plan**

The first priority is to increase breast health and breast cancer services to target populations that have been historically underserved in health care in those counties with significant percentages of these populations—African American women in Albany, Schenectady and Rensselaer Counties, Hispanic women in Montgomery County and Native American women in Franklin County.

- Objectives: 1. By September of 2011, revise the Affiliate request for applications to prioritize these area populations in the awarding of grants and hold grant workshops targeted at these area populations to enable community partners to apply for Affiliate grants. 2. By 2012, identify at least one new community or faith based organization that serves these area populations and develop new partnerships with them for education and outreach. 3. By 2013, establish a partnership with one local newspaper or radio station that serves each of these area populations to provide culturally appropriate breast health information. 4. Supply 5 primary care physicians and clinics serving these populations in these areas breast health information for their patients.

The second priority is to increase screening rates in the four counties with the lowest percentage of women over 40 who have had a mammogram in the past year—Franklin, Essex, Washington and Hamilton Counties.

- Objectives: 1. Revise the Affiliate request for applications to make this a priority in the awarding of grants by September of 2011. 2. By 2012, collaborate with the Cancer Services Program to increase the women screened through the State's uninsured breast cancer screening program in these areas by 5%. 3. Work with the Coalition to Save Cancer Screening to advocate for increased State Budget funding to 2007-2008 levels for this program by 2013. 4. By 2013, coordinate with 5 health care providers in these areas to support the use of patient navigators and other means to increase screening rates by actively identifying, recruiting and alleviating screening barriers for patients.

Many residents of Northeastern New York live in rural areas far from available services and this factor negatively impacts their health outcomes. The third priority is to increase services, and access to services, to women in rural counties (Clinton, Essex, Franklin, Hamilton, and Montgomery) of our area.

- Objectives: 1. Revise the Affiliate request for applications to prioritize breast health services in these areas in the awarding of grants by September of 2011. 2. Work with community organizations and health care providers in these areas to develop programs to increase transportation access to services and fund such programs through Affiliate grants by 2013. 3. By 2013, increase our Affiliate presence in these rural areas through educational efforts, collaborative relationships with community based organizations, donors, and volunteers. 4. Explore partnerships with organizations that provide breast cancer financial and emergency assistance and services to women in these communities by the end of 2012.

It is increasingly recognized that we need to develop evidence-based approaches to advance understanding and awareness of breast cancer among young women through education and awareness activities and emerging prevention strategies. The fourth priority is to enhance efforts to educate young women in the area about breast health.

- Objectives: 1. Provide age appropriate breast health and breast cancer information to 10 area colleges by 2012. 2. Enhance efforts through the I am the Cure Program® and using BSA (Breast Self Awareness) to provide accurate information about prevention, risk factors, and screening to young women at all Affiliate events and activities by October of 2011. 3. Revise the Affiliate request for applications to make this a priority in the awarding of grants by September of 2011.

## Endnotes

- <sup>1</sup> U.S. Census Bureau. 2009 Estimates. State and County Quickfacts. Available at: [www.quickfacts.census.gov](http://www.quickfacts.census.gov) .
- <sup>2</sup> New York State Department of Health. (2007). New York State Cancer Registry. Available at: [www.health.state.ny.us](http://www.health.state.ny.us) .
- <sup>3</sup> National Cancer Institute. State Cancer Profiles. Available at: [www.statecancerprofiles.cancer.gov](http://www.statecancerprofiles.cancer.gov) .
- <sup>4</sup> Susan G. Komen for the Cure®. Available at: [www.komen.org](http://www.komen.org) .
- <sup>5</sup> Thomson Reuters ©2009. Northeastern New York Demographic and Breast Cancer Data.
- <sup>6</sup> New York State Department of Health. New York State Comprehensive Cancer Control Plan, 2003.
- <sup>7</sup> American Cancer Society. (2009). Cancer Facts & Figures for African Americans 2009-2010. Atlanta: American Cancer Society.
- <sup>8</sup> American Cancer Society. (2009). Cancer Facts & Figures for Hispanics/Latinos 2009-2011. Atlanta: American Cancer Society.
- <sup>9</sup> Kaiser Family Foundation. (2009, June). Putting Women's Health Care Disparities on the Map: Examining Racial and Ethnic Disparities at the State Level. Henry J. Kaiser Family Foundation.
- <sup>10</sup> Espey, D.K., Wu, X.C., Swan, J., Wiggins, & C, Jim, M.A. et al. (2007). Annual Report to the Nation on the Status of Cancer, 1975-2004, Featuring Cancer in American Indians and Alaska Natives, Cancer, 110 (10), 2119-2152.
- <sup>11</sup> Gamm, L.D., Hutchison, L.L., Dabney, B.J., Dorsey, A.M. eds. (2003). Rural Healthy People 2010: A Companion Document to Healthy People 2010, Volume 1. College Station, Texas: The Texas A&M University System Health Science Center, School of Rural Public Health, Southwest Rural Health Research Center.
- <sup>12</sup> Bennett, K.J., Olatosi B., Probst J.C. (June 2008). Health Disparities: A Rural-Urban Chartbook. *Technical report provided to Health Resources and Services Administration/Office of Rural Health Policy*. Retrieved on 3/4/2010 from <http://rhr.sph.sc.edu>.
- <sup>13</sup> Food and Drug Administration. 2011 Mammography website at: [www.accessdata.fda.gov/scripts.cdrh/cfdocs/cfMQSA/mqsa.cfm](http://www.accessdata.fda.gov/scripts.cdrh/cfdocs/cfMQSA/mqsa.cfm) .
- <sup>14</sup> Uniform Data System Mapper. HRSA funded project by the Robert Graham Center. Available at: [www.udsmapper.org](http://www.udsmapper.org) .
- <sup>15</sup> New York State Department of Health, Cancer Services Program. 2005. Breast and Cervical Cancer Screening (Healthy Women Partnerships), Program Report.