



2011  
 COMMUNITY PROFILE  
 OF BREAST CANCER  
 IN CONNECTICUT

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EXECUTIVE SUMMARY



## INTRODUCTION

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Nancy G. Brinker promised her dying sister, Susan G. Komen, that she would do everything in her power to end breast cancer forever. In 1982 that promise became Susan G. Komen for the Cure<sup>®</sup>. Today, Komen for the Cure is the largest network of breast cancer survivors and advocates in the world.

In 1994, the first Komen Connecticut Race for the Cure<sup>®</sup> was held in New Britain, Connecticut. Six years later, on October 4, 1999 the Connecticut Affiliate of Susan G. Komen for the Cure<sup>®</sup> (Komen Connecticut) was established. Komen Connecticut works throughout Connecticut to fulfill the promise — to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find the cures. This mission is based on the promise made by Nancy to her sister when little was known about the disease. Komen Connecticut's work focuses on educating the community on breast health and breast cancer, working to ensure that screening and treatment are available to all residents of Connecticut and raising funds to fund breast cancer research. Since its inception, Komen for the Cure has invested over \$21 Million in Connecticut in these four areas of focus - education, screening, treatment and research.

Komen Connecticut's promise to save lives and end breast cancer forever relies on information obtained through the Community Profile process. Every two years, a comprehensive qualitative and quantitative analysis of the state's breast needs is completed by the Affiliate. This report intends to describe the varied breast health needs that have been identified as well as potential areas in which Komen Connecticut's programs and funding might help advance the network's promise of reducing breast cancer mortality. Potential opportunities and areas of interest have been drawn from analyses of breast cancer statistics, policies and programs in the state that may impact breast health and exploratory, primary data collection among providers and breast cancer survivors in the state. After synthesizing data from various sources, this report presents data-driven priority areas from which the Affiliate intends to develop funding decisions for the years 2012-2014.

## DEMOGRAPHICS AND STATISTICS OVERVIEW

Statistics reviewed for this Community Profile include data derived specifically for Komen Connecticut by the Department of Public Health. Additional data were obtained from the Centers for Disease Control and Prevention and the U.S. Census Bureau. Statistics were reviewed for their relevance to the current breast health situation in Connecticut as well as their applicability for targeting geographic areas smaller than the state.

Connecticut has the second highest incidence of female breast cancer in the nation<sup>i</sup> with 2,920 new cases of invasive breast cancer diagnosed in 2008<sup>ii</sup>. Connecticut ranks 35<sup>th</sup> in the nation with respect to breast cancer mortality<sup>iii</sup>, 490 women died from breast cancer in 2008<sup>iv</sup>. Table 1 summarizes key breast cancer statistics for women in Connecticut by race and Hispanic ethnicity.

*Table 1, Breast Cancer in Connecticut Women*

Breast Cancer Estimate	Race/ Ethnicity	Connecticut <sup>a</sup>	United States <sup>b</sup>
Age-adjusted incidence rate per 100,000 women (95% confidence limits)		<i>2006-2008</i>	<i>2007</i>
	All races/ ethnicities	136.1 (133.2-139.1)	120.4 (119.8-120.9)
	White	138.1 (135.0-141.2)	121.0 (120.4-121.5)
	Black	112.9 (103.6-122.8)	117.0 (115.4-118.5)
	Hispanic	120.9 (109.7-132.9)	88.2 (86.6-89.7)
Age-adjusted mortality rate per 100,000 women (95% confidence limits)		<i>2005-2007</i>	<i>2007</i>
	All races/ ethnicities	23.0 (22.0-24.3)	22.8 (22.6-23.1)
	White	23.0 (21.8-24.3)	22.2 (22.0-22.5)
	Black	28.1 (23.4-33.4)	31.4 (30.6-32.3)
	Hispanic	11.5 (8.1-15.8)	14.6 (14.0-15.3)
Percentage stage IV diagnoses		<i>2006-2008</i>	-
	All races/ ethnicities	4.5%	-
	White	4.4%	-
	Black	6.4%	-
	Hispanic	-	-
Notes:			
<ul style="list-style-type: none"> <li>Hispanic origin is not mutually exclusive from race categories (white, black).</li> <li>Statistics for other races (Asians, Pacific Islanders, and American Indians/Alaska Natives) are not presented due to small numbers leading to unreliable rate estimates.</li> </ul>			
<b>Data Sources:</b> <sup>a</sup> <i>Connecticut Tumor Registry</i> ; <sup>b</sup> <i>United States Cancer Statistics 2007</i>			

The incidence of breast cancer has varied over the past 40 years, with rates increasing steadily, and then leveling off over the past few years. Breast cancer mortality has seen a consistent decline thought to be due to early detection (mammographic screening) and improved treatment and survival. The 5-year relative survival for Connecticut women diagnosed with breast cancer is over 90%; however, the survival rates varies greatly with the stage of the cancer at diagnosis.

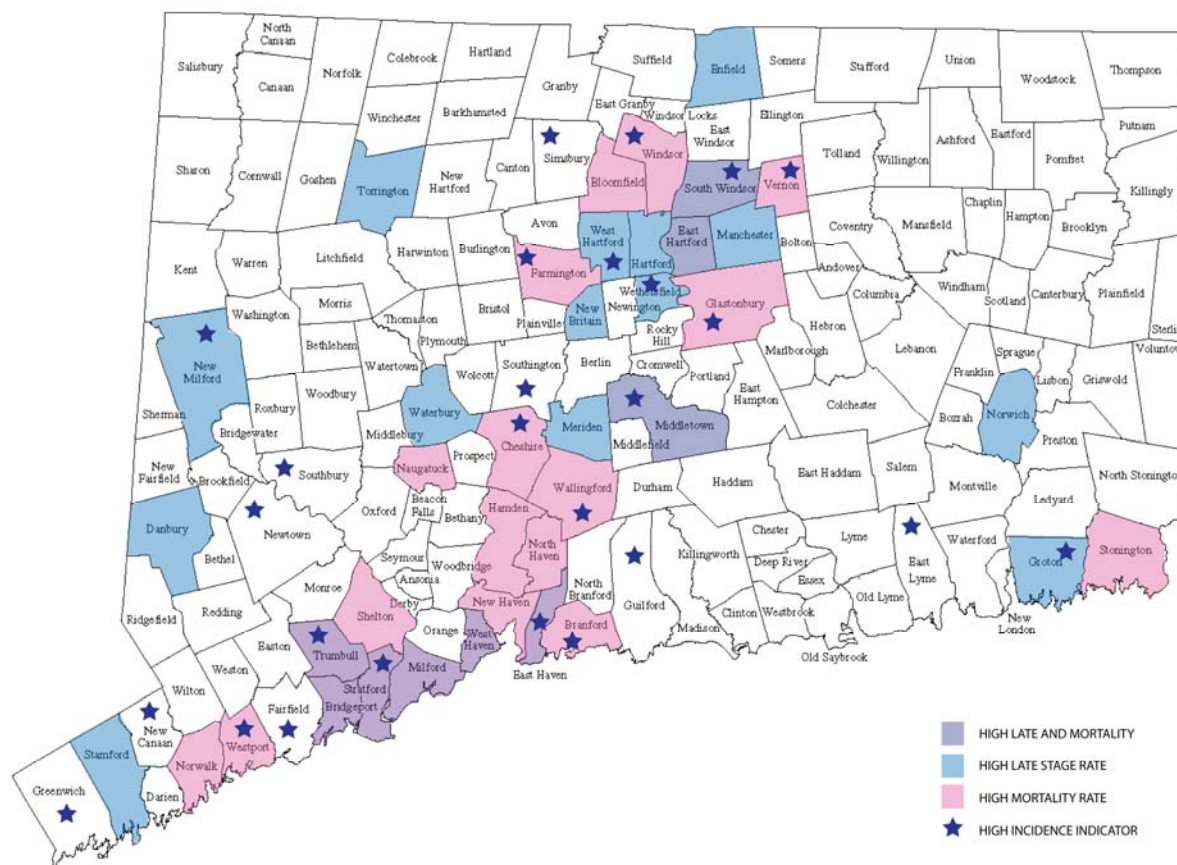
While two-year mammography rates suggest that Connecticut may be reaching many for early screening and detection, concerns remain about reducing mortality and illness severity among several populations. Data from the Behavioral Risk Factor Surveillance System

indicate that 84.1% of Connecticut women aged 40+ years have had a mammogram in the last two years compared with national averages of 76% for women 40+ years; however, racial and ethnic disparities for mammography persist.<sup>v</sup>

The Community Health Data Scan for Connecticut, commissioned by the Connecticut Health Foundation, demonstrates that African American women in the urban centers and Hispanic women in manufacturing centers are among the least likely women in the state to use mammography screening.<sup>vi</sup> The communities of interest were selected as follows, focusing on areas with high rates of breast cancer mortality and high proportions of late stage cancers where interventions will likely have most impact. Connecticut towns were ranked by age-adjusted mortality rate (2004-2008) and those towns with rates higher than the state rate, and where there were 4 or more deaths per year were selected. Similarly, the towns were ranked by the proportion of late stage (AJCC stage III and IV) breast cancers diagnosed (2004-2008) and those towns with a proportion higher than the proportion for the entire state, and where 20 or more late stage tumors were diagnosed, were selected. This method identified a total of 39 Connecticut towns. While not used in the town selection process, the age-adjusted incidence rates in the target towns were also examined. The map below shows the targeted towns.

Figure 6 shows a composite map highlighting the towns with age adjusted mortality rates higher than the state rate and percentages of late stage diagnoses higher than the state average. Towns that have incidence rates that are higher than the state incidence rate are indicated with a star.

Figure 6. Selected areas of interest.



## HEALTH SYSTEMS ANALYSIS

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In 2009, Komen Connecticut completed a comprehensive analysis of breast health programs and services throughout the state, relying on three sources of data. First, the Affiliate compiled listings of all the breast cancer organizations and organizations providing breast cancer screening, early detection and/or treatment support service. Second, an Affiliate intern developed a random list of assets using publicly available sources like the internet and the phone directory. Third, the Affiliate cross-checked these lists and then identified additional assets based on lists independently compiled by MATRIX, a local public health consultant firm.

The following clinical and non-clinical resources were mapped: Hospitals, Cancer Centers, Community Health Centers (with comprehensive cancer care services), Breast health and cancer organizations, Official Connecticut Breast and Cervical Cancer Early Detection Program (CBCCEDP) sites, Local Health Departments (with breast cancer prevention programs), Support networks or support group organizations, and The Connecticut Affiliate's grantees (2004-present).

Assets were identified based on the current availability of programs and services most relevant to breast health such as screening, diagnostic services, treatment, participation in clinical trials, community outreach programs and educational materials, complimentary therapy services, support groups and/or palliative care.

The 2009 data continue to be current and was used in our analysis for this Community Profile. Basic analysis of the asset map included considering the location of breast health assets in relation to disease burden and in relation to the state's population. Areas with surpluses and deficits of assets were considered. A second level of analyses considered the location of assets and disease burden relative to the Affiliate's recent funding (last five years).

All of the identified assets were contacted and asked to participate in the 2011 provider survey and/or provider interviews that comprise the exploratory data process of the Community Profile. Findings from this survey of clinical and non-clinical providers as well as interviews with community providers also contributed to the identification of additional assets and gaps in services for the target towns in the state.

For its size and population, Connecticut possesses a wide variety of breast health resources. In addition to a nationally designated comprehensive cancer center and a nationally designated community cancer center, there are several hospital-based cancer centers, screening services in health facilities where women are likely to present for other services such as community health centers, as well as population-specific, locally initiated support groups. Programs and services are concentrated in two of the state's largest cities and in some of the well-resourced suburban towns. Many agencies appear to provide breast health education/awareness, screening services and treatment support services i.e. counseling. Diagnostic follow up, non-medical treatment support i.e. financial, transportation, etc. and financial assistance for treatment seem limited despite the presence of federal and state funds to provide treatment for those diagnosed through the CBCCEDP.

## QUALITATIVE DATA OVERVIEW

In addition to analyzing available state data, Komen Connecticut collected exploratory community data from several sources in order to ensure that these data were reflective of recent and current experience among those diagnosed with breast cancer and the state's diversity of breast health providers. This section of the report details the exploratory data process. The Community Profile Team, tasked with collecting exploratory data, decided to supplement existing data with data from two additional data sources: a community provider survey and interviews with service providers and women diagnosed with late stage (Stage 3 and Stage 4) breast cancers. Below are summaries of both the quantitative findings from the survey and the qualitative data collected in interviews. Table 9 summarizes the data collection sources and methodology.

*Table 9: Exploratory Data Sources*

Informants	Data Sources	# included in analyses	Timeframe
Clinical and non-clinical providers of breast health services and care	35-item, self-administered, electronic survey	29	2/14/2011-4/8/2011
Social Workers, Case Managers and other non-physician providers of breast health services and care	Structured interviews (15 items)	12	3/14/2011-4/20/2011
Women diagnosed with late stage (Stage III or Stage IV) breast cancers	Structured interviews (18 items)	4	3/14/2011-4/20/2011
Case studies or examples provided by clinical providers	Oral & written case narratives	9	3/1/2011-4/8/2011

All exploratory data were analyzed to uncover common themes. Such themes may highlight potential program opportunities as well as describe potential barriers and roadblocks to reducing cancer mortality in Connecticut. These data also provide insights about elements of service delivery that could use additional refinement in order to reach and benefit more women.

Within this year's exploratory data efforts, social and cultural barriers and needs seemed most prominent. While educational and informational aspects of breast cancer service and care figured prominently, respondents sampled for both the quantitative and qualitative data collection projects were more likely to talk about social and cultural aspects of breast cancer rather than their educational/informational counterparts. In the 2009 Community Profile Report, educational and informational needs and barriers were most mentioned. As needs among providers and consumers are unlikely to change drastically over a two-year period, it makes sense that educational/informational issues were still considered important. The shift in prominence is likely a reflection of differences in the sample, as social workers, patient navigators, program managers and case managers comprised a greater proportion of providers in the 2011 study than in previous data collection. These types of providers may be more familiar with and used to responding to patients financial, social and personal concerns. Moreover, the salience of socioeconomic factors in light of the current economic crisis and the attention paid to changes in health care coverage and policies may have helped social and cultural issues rise in prominence. In addition to the shift from education/information to social/cultural barriers or challenges, these data also seem to shift away from organizational and institutional issues towards challenges with the consumers/women themselves.

## CONCLUSIONS

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The Community Profile Team created the Affiliate priorities to present to the Board of Directors. The priorities were selected after reviewing the findings in the report and comparing the findings with those of the 2009 Community Profile Report. Priorities and areas of emphasis were changed and updated in light of additional community and statistical data. The Komen Connecticut Board of Directors was presented with the priorities as recommended and ranked by the Community Profile Team and voted to approve them. The priorities and recommendations will influence Komen Connecticut's strategic plan for FY 2012 and FY 2013 requests for proposals and all other mission initiatives.

**Priority 1: Strengthen and build the capacity of existing breast health providers to identify, provide, and or refer patients to appropriate breast health and breast cancer programs and services in cities and towns demonstrating the highest burden of breast cancer morbidity and mortality.**

Objective 1: Develop and issue a request for proposals to solicit provider education grant(s) to develop and deliver a model of primary care provider breast health education including screening recommendations, clinical breast exam instruction, information about state resources (CBCCEDP and others), assessing patient risk and systems management practices to improve statewide breast health.

Objective 2: Conduct targeted outreach to solicit grant applications from providers in the following practice settings: primary care, gynecologists, medical practice directors and administrative directors of medical groups.

Objective 3: Facilitate partnerships between agencies in an affirmative fashion, i.e. between providers or provider agencies and non-traditional breast health organizations like faith-based organizations, social and cultural organizations, libraries, etc. to extend the reach and penetration of breast health messages.

**Priority 2: Promote breast health awareness and the importance of screening and early detection among women across the state.**

Objective 1: Through grant efforts, improve consumer awareness about screening programs and services in targeted communities throughout the state including increasing awareness about free or low-cost breast health programs and services since more women are eligible than are currently covered by existing programs

Objective 2: Through grant efforts, support specific patient empowerment interventions focused on improving patient-provider communication about breast health/breast cancer or improving access to useful tests (e.g. genetic) or diagnostic procedures (e.g. ultrasound or MRI for women with dense breasts).

Objective 3: Target applicants who will submit proposals that will address outreach myths about breast cancer in the state, namely, the overstated importance of family history and the importance of yearly screening and education efforts consist of more than a brochure or pamphlet

Objective 4: Target applicants who will partner with unconventional, non-clinical entities with outreach and internal evaluation efforts that reflect demographic trends that reflect critical underserved populations.

**Priority 3: Increase screening resources available to women in selected cities and towns with an emphasis on high risk women, underserved women and selected women under the age of 40.**

Objective 1: Through grant efforts, encourage screening of women over 40 years of age and over in targeted cities and towns throughout the state. Through grant efforts, encourage screening of high-risk and symptomatic women under 40 years of age in areas of the state with high rates of morbidity and late stage breast cancer diagnoses and support programs that provide assistance to women under 40 with age specific barriers to screening such as child-care.

Objective 2: Continue to work to change Connecticut from an Option 1 to an Option 3 state for Medicaid-funded breast cancer treatment and to support continued state funding for breast health services.

Objective 3: Support patient navigation and continuity of care programs that intend to increase screening and improve the quality of follow up from diagnosis through treatment and replicate other effective, evidence-based practices that engage underserved populations in breast health and breast cancer screenings.

Objective 4: Facilitate access for racial and ethnic minority populations in the identified geographic areas by supporting culturally appropriate, creative outreach strategies and partnerships.

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<sup>i</sup> U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 1999–2007 Incidence and Mortality Web-based Report*. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2010.

<sup>ii</sup> Connecticut Tumor Registry.

<sup>iii</sup> Connecticut Department of Public Health.

<sup>iv</sup> Connecticut Tumor Registry

<sup>v</sup> Centers for Disease Control and Prevention (CDC). *Behavioral Risk Factor Surveillance System Survey Data*. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, [2008].

<sup>vi</sup> Finison, Ph.D. Lorenz J., Commissioned by the Connecticut Health Foundation. Community Health Data Scan for Connecticut. March 2007. Available at <http://www.cthealth.org>

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Volunteers are the core foundation of any organization, its activities, community involvement and success. The individuals who volunteered to join the Komen Connecticut Community Profile Team demonstrated this core and we appreciate their commitment. Each volunteer brought a level of knowledge and expertise with breast cancer, breast center and data management, community hospitals and medical services available throughout the state.

A special thank you to their employers, Saint Francis and Hartford Hospital's, State of Connecticut, and Connecticut Surgical Group for allowing each to commit the hours required to tell this story. We would also like to express our appreciation to Marian Evans, M.D., CRA, Associate Professor, School of Health and Human Services for her contribution to this project.

Komen Connecticut and the Community Profile team are indebted to all the women, social workers and physicians who shared their experiences and stories. The knowledge gained allowed us to understand the challenges faced by women and families impacted by breast cancer. The recommendations in this report are a result of their story; it is our hope they will have a positive impact on breast education, screening and treatment in Connecticut.

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## DISCLAIMER

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

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