



# COMMUNITY PROFILE REPORT

Susan G. Komen for the Cure®  
**Central Wisconsin Affiliate**



2009

## **Acknowledgements**

We would like to extend our thanks to the organizations and community members who assisted with this effort. Their enthusiasm and dedication to this project is appreciated.

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### **Special Thanks to the Following Partners:**

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Mary Kluz and Eric Giordano, Ph.D, Wisconsin Institute for Public Policy and Service

Peter Yang, Executive Director, Wausau Area Hmong Association

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## **Executive Summary**

The Central Wisconsin Affiliate of Susan G. Komen for the Cure embraced the mission to end breast cancer forever more than two years ago. At that time, the Affiliate set goals in the area of education, screening, diagnosis, treatment, and support services.

Since then, the Central Wisconsin Affiliate has moved steadily towards its goals, awarding its first grant in the fiscal year 2006-2007. Because the Affiliate operates with a working board, it relies on the volunteered time and effort of a dedicated group of people and the contacts and partnerships that they develop in the community to achieve its goals.

Our present Community Profile Committee has found that although inroads have been made and visibility of the Affiliate has improved in the community, there is still a great deal to be accomplished. Therefore, the Committee has built on the previous goals and objectives, refined them with recent research, and laid out realistic expectations for the next two years. These goals and objectives will be expanded and adjusted by the Board of Directors and committees, and action plans will be created around them.

The present state of the economy and recent changes in demographics in the Central Wisconsin Affiliate's seven-county area have complicated the research and made the Community Profile Committee aware that we must proceed with these goals, objectives, and resulting action plans with flexibility. The needs of our community might change rapidly.

Regarding statistical findings in our service area, the Community Profile Committee determined that the populations of most need have remained the same – rural women and minority groups. However, anecdotal research and information gained through the community forum, Harvesting Our Collective Wisdom World Café (sponsored by our Central Wisconsin Affiliate) have given us a more detailed understanding of the issues having to do with breast health care in Central Wisconsin. This deeper understanding will help us to be more focused in our approach to reaching our goals, especially in the area of programs and services.

With the community forum information as a starting point, the Community Profile Committee developed questions related to its findings. These questions were asked of a group of key informants: people in the community who are directly involved in breast care health as a provider, a public health official, or a survivor.

As a result, we have determined that our two main priorities are access to care for rural women and minority breast health care. The following goals and objectives were developed to guide the Central Wisconsin Affiliate in its planning for the next two years and beyond. The SMART Goals format was used (Specific, Measurable, Attainable, Realistic and Timely).

**Goal One:**

Improve access to Care for Rural Women (rural defined as greater than 20 mile distance from a mammography).

Objective One:

We will improve screening and treatment tools for rural women by assisting health care providers in finding gaps in service areas for rural women. We will contact all providers invited to the September 2008 Forum, give them the Forum report, Community Profile Report and information on the Request for Proposal process. Follow up with this group will be in fall 2009 and we will send them a new grant Request for Proposal. The Community Profile Report will be shared with area hospital boards in a personal meeting by the President and Vice President of the Board of Directors.

Objective Two:

We will provide funding to grantees that support rural services.

Objective Three:

We will provide educational outreach for breast health care at community health fairs and events that target rural women, including county fairs. Additional partnerships will be explored with Curves for Women in Marathon, Lincoln and Portage counties and Adventure 212 in Portage County. A subcommittee will be put together to develop a list of health care events sponsored by area hospital and clinic systems, so that we can participate in these events. We will also provide educational outreach at non-traditional settings, such as shopping centers and grocery stores.

Objective Four:

We will work to remove the identified barriers to screening and treatment, by working with the local chapters of the American Cancer Society and to continue in collaboration with Komen National's Advocacy efforts. We will continue to promote awareness of the mobile mammography unit through the grantee.

Objective Five:

We will build greater awareness of what Central Wisconsin can offer in resources, by having our first Race for the Cure in August 2010, and by becoming more proactive with media. Greater use of e-mail, Convio and enhanced use of our Website will support efforts at greater awareness. Non-race fund-raising efforts through third parties will continue.

**Goal Two:**

We will work to improve minority breast health care, by gaining a greater cultural awareness of the key minority populations in our service area.

Objective One:

We will create opportunities and alliances that result in more conversations with our minority populations, especially the Hmong and Hispanic groups, establishing a committee within the Hmong community. This will include clan leaders, Peter Yang, local Hmong celebrities, and key members of the Board of Directors. Once this committee is developed, we will use it as a model with the Hispanic community.

Objective Two:

We will provide outreach to meet the breast health needs of diverse cultures, by providing targeted health education to Hmong and Hispanic groups. We will determine which media best works with these groups and develop material accordingly. Educational materials in Hmong (both white and green languages) have already been collected from Websites and the American Cancer Society.

**Goal Three:**

We will build our Central Wisconsin Affiliate's community partnerships.

Objective One:

We will develop partnerships with the NTC Nursing Program and with the University of Wisconsin/Stevens Point Communications Program for potential volunteers.

## **Introduction**

### ***Central Wisconsin Affiliate of Susan G Komen for the Cure: Affiliate History***

The Central Wisconsin Affiliate was granted affiliation by Susan G. Komen for the Cure in December 2006 and announced to the public Jan. 3, 2007. This followed a thorough application process that began in 2004. The planning committee was dedicated to bringing the foundation's mission to end breast cancer through the advancement of research, education, screening and treatment to seven counties—Langlade, Lincoln, Marathon, Portage, Taylor, Wood and western Shawano—in Central Wisconsin.

The planning committee and eventual board members are a group of women and men who have been touched by breast cancer. They have grieved for family and friends who lost their battle and celebrated life with survivors. They know the loss of life can be greatly reduced with increased survival through early detection and are dedicated to making that happen.

During the application process, the planning committee submitted a Community Profile to identify the gaps in breast health services, which, in turn, helped determine future goals and objectives by the Board of Directors. Those gaps led to goals in four areas:

- Education
  - Increase breast health education to people who currently do not have a health care provider.
  - Improve effective communication with Hmong and Hispanic women.
  - Provide more education on available services to resource outlets in the service area.
- Screening
  - Bring screening services to rural locations.
  - Help women unable to access screening because of transportation issues.
- Diagnosis and Treatment
  - Need for breast health navigators to help newly diagnosed women.
  - Help with transportation to and from treatment.
- Support Services
  - Better access to support services in rural areas.
  - Assure support services are available to minority populations.

Upon affiliation, Central Wisconsin moved quickly to award its first grant for fiscal year 2006-2007. A program offering free mammograms for 50 women in the Central Wisconsin Affiliate service area was granted \$11,000. The money came in large part from our portion of the National 3-Day Walk for the Cure program in 2006.

In the next fiscal year, the Affiliate awarded almost \$65,000 to a mobile mammogram and screening program aimed at reaching women in rural communities.

### ***Organizational Structure***

The Central Wisconsin Affiliate is currently an all-volunteer organization, composed of a Board of Directors and a number of Committees chaired by Board members.

#### *Board of Directors*

President	Susan Ford-Hoffert
Vice President/Board Development Chair	Dr. Pamela Galloway
Secretary	Gretchen Thuot
Treasurer	Maria Bruggink
Grants Committee Chair	Kris McGarigle
Events Committee Chair	Beverly Sartori
Volunteer Committee Chair	Karla Kurtz
Race Committee Chair	Barb Kliner
Public Relations Chair	Sally Gartmann
Education Committee Co-Chair	Julianne Fondell
Education Committee Co-Chair	Susan Coleman
Advocacy Committee Chair	Jennifer Smith
Information Technology Chair	Gerry Klein
Fund Raising Committee Chair	Open

### ***Description of Service Area***

The Central Wisconsin Affiliate serves six counties and part of a seventh in Central Wisconsin. These are:

- Langlade
- Lincoln
- Marathon
- Portage
- Taylor
- Wood
- Western portion of Shawano

### ***Purpose of Report***

The Community Profile is used to determine the demographics of the seven-county area served by the Central Wisconsin Affiliate of Susan G. Komen for the Cure, review the current breast health programs, institutions and services in those areas and reveal the gaps in breast health services. This profile assists the Central Wisconsin Affiliate with determining our future goals and objectives as well as the types of grants awarded by the Affiliate in line with the overall mission of Susan G. Komen for the Cure.

# **Demographic and Breast Cancer Statistics**

## **Data Source and Methodology Overview**

Some of the initial 2007 demographic estimates for this report came from Thomson Reuters. The information on population, income and aging is from the U.S. Census bureau as of December 2007 with adjusted numbers projected from the 2000 census. Other information concerning poverty levels, the labor force and those speaking languages other than English also came from the U.S. Census Bureau. Other sources of data were The Wisconsin Department of Health Services, Wisconsin Cancer Reporting System, and State Cancer Profiles from the Center for Disease Control. Additional information came from the Division of Public Health, Wisconsin Department of Health and Family Services. The county unemployment information was derived from the Wisconsin Department of Workforce Development as of December 2008.

Health insurance data sources reported on insurance coverage from 2004-2006. Trends in both ethnicity and economic status have changed dramatically in just recent months. The data we have will not reflect current layoffs and resulting changes in insurance coverage. Not only are more people uninsured, but also more are underinsured, paying higher deductibles or large co-pays.

In addition, minorities are not showing up in health care data, especially the Hispanic and Asian (Hmong) populations. Therefore, some of our conclusions and recommendations will be based not only on collected data but also anecdotal information from health care providers and public health officials.

## **Overview of Key Demographic & Breast Cancer Statistics at State and County Level**

The following charts outline the key demographic and breast cancer statistics at the county and state level. It is to be noted that Marathon County has the largest population of counties in our Affiliate area. It also has the largest number of Hispanic, African-American, and Hmong citizens, although Lincoln and Portage Counties are reporting recent increases in Hispanic populations.

**Langlade County, Wisconsin**

Prepared by Matthew Bargander, CW Affiliate Community Profile Committee

Total Population:	20,360	Female	10,197	50.10%
		Male	10,163	49.90%
Median Household Income:	\$ 38,546	Median Age	42.7	
Median Family Income:	\$ 50,104	Under 5 Yrs	1,051	5.20%
Per Capita Income:	\$ 21,960	18 Years +	15,981	78.50%
Pop. Percent Change from 2000:	1.70%	65 Years +	3,909	19.20%

**Ethnicity**

White	19,749	97.00%
Black	47	0.20%
American Indian	148	0.70%
Asian	84	0.40%
Pacific Islander	0	0.00%
Hispanic (Non White)	223	1.10%
Two or More	185	0.90%
Other	147	0.70%

**Poverty**

Families Below	8.60%
Individuals Below	11.60%

**Economic**

In Labor Force	10,565	63.90%
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**Unemployment Rate**

Last Rate	7.70%	Dec. '08
Last State Rank	6.50%	Nov. '08
Yr Ago Rate	14	
State Rank (of 72)	6.10%	Dec. '07
	15	

**Language**

Speaking Language other than English	N/A
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**Breast Cancer Statistics**

Incidence	Annual Incidence Rate over rate period(95% Confidence Interval)	Average Annual Count	Rate Period
	113.2 /100,000	24	2001-2004
Death Rate	Met Healthy of 22.3	N/A	
	Annual Death Rate	N/A	
	Average Deaths per Year	3 or Fewer	
	Rate Period	2001-2005	
	Recent Trend	N/A	
	Recent Annual Percent Change	N/A	
	Recent Trend Period	1981-2005	

Income: US Census Bureau. <http://quickfacts.census.gov/qfd/states/55000.html> - As of 2007  
 Population: US Census Bureau. <http://quickfacts.census.gov/qfd/states/55000.html> - As of 2007  
 Unemployment: Wis. Department of Workforce Development, <http://worknet.wisconsin.gov/worknet/Cntysnap.aspx?menuselection=wdb> - Dec. '08  
 Cancer: Wis. Dpt. of Health Services, Wis. Cancer Reporting Sys <http://dhs.wisconsin.gov/wcrs/pubs.htm> - Death and Incidence - 2000-2004  
 State Cancer Profiles, Center for Disease Control, <http://www.statecancerprofiles.cancer.gov/> -Trend Data - 2001-2005

**Lincoln County, Wisconsin**

Prepared by Matthew Bargander, CW Affiliate Community Profile Committee

Total Population:	29,771	Female	15,046	50.80%
		Male	14,725	49.20%
Median Household Income:	\$ 45,953			
Median Family Income:	\$ 57,450	Median Age	41.3	
Per Capita Income:	\$ 23,126	Under 5 Yrs	1,495	5%
		18 Years +	26,156	77.80%
Pop. Percent Change from 2000:	1.70%	65 Years +	5,168	17.40%

**Ethnicity**

White	28,919	97.10%
Black	0	0%
American Indian	251	0.80%
Asian	178	0.60%
Pacific Islander	18	0.10%
Hispanic (Non White)	318	1.10%
Two or More	291	1.00%
Other	114	0.40%

**Poverty**

Families Below	7.10%
Individuals Below	9.90%

**Economic**

In Labor Force	15,797	65.50%
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**Unemployment Rate**

Last Rate	7.40%	Dec. '08
Last State Rank	6.30%	Nov. '08
Yr Ago Rate	14	
State Rank (of 72)	5.30%	Dec. '07
	22	

**Language**

Speaking Language other than English	N/A	N/A
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**Breast Cancer Statistics**

<b>Incidence</b>	Annual Incidence Rate over rate period(95% Confidence Interval) 124.0 /100,000	Average Annual Count 24	Rate Period 2001-2004
<b>Death Rate</b>	Met Healthy of 22.3 Annual Death Rate Average Deaths per Year Rate Period Recent Trend Recent Annual Percent Change Recent Trend Period	Yes 18.7 (11.2, 22.9) 4 2001-2005 Falling < -2.8 (-5.0, -0.5) 1981-2005	

Income: US Census Bureau. <http://quickfacts.census.gov/qfd/states/55000.html> - As of 2007  
 Population: US Census Bureau. <http://quickfacts.census.gov/qfd/states/55000.html> - As of 2007  
 Unemployment: Wis. Department of Workforce Development, <http://worknet.wisconsin.gov/worknet/Cntysnap.aspx?menuselection=wdb> - Dec. '08  
 Cancer: Wis. Dpt. of Health Services, Wis. Cancer Reporting Sys <http://dhs.wisconsin.gov/wcrs/pubs.htm> - Death and Incidence - 2000-2004  
 State Cancer Profiles, Center for Disease Control, <http://www.statecancerprofiles.cancer.gov/> -Trend Data - 2001-2005

**Marathon County, Wisconsin**

Prepared by Matthew Bargander, CW Affiliate Community Profile Committee

Total Population:	128,952	Female	64,364	49.90%
		Male	64,588	50.10%
Median Household Income:	\$ 52,241	Median Age	38.7	
Median Family Income:	\$ 63,310	Under 5 Yrs	7,792	6.00%
Per Capita Income:	\$ 25,853	18 Years +	97,748	75.80%
Pop. Percent Change from 2000:	1.70%	65 Years +	17,136	13.30%

**Ethnicity**

White	120,581	93.50%
Black	597	0.50%
American Indian	341	0.30%
Asian	5,809	4.50%
Pacific Islander	0	0.00%
Hispanic (Non White)	1,492	1.20%
Two or More	1,151	0.90%
Other	473	0.40%

**Poverty**

Families Below	4.70%
Individuals Below	6.90%

**Economic**

In Labor Force	74,087	72.70%
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**Unemployment Rate**

Last Rate	5.30%	Dec. '08
Last State Rank	4.80%	Nov. '08
Yr Ago Rate	47	
State Rank (of 72)	3.90%	Dec. '07
	50	

**Language**

Speaking Language other than English	9,105	7.50%
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**Breast Cancer Statistics**

<b>Incidence</b>	Annual Incidence Rate over rate period(95% Confidence Interval) 128.0/100,000	Average Annual Count 92	Rate Period 2001-2004
<b>Death Rate</b>	Met Healthy of 22.3 Annual Death Rate Average Deaths per Year Rate Period Recent Trend Recent Annual Percent Change Recent Trend Period	No 22.9 (18.3, 28.5) 17 2001-2005 Falling < -1.9 (-3.0, -0.7) 1981-2005	

Income: US Census Bureau. <http://quickfacts.census.gov/qfd/states/55000.html> - As of 2007  
 Population: US Census Bureau. <http://quickfacts.census.gov/qfd/states/55000.html> - As of 2007  
 Unemployment: Wis. Department of Workforce Development, <http://worknet.wisconsin.gov/worknet/Cntysnap.aspx?menuselection=wdb> - Dec. '08  
 Cancer: Wis. Dpt. of Health Services, Wis. Cancer Reporting Sys <http://dhs.wisconsin.gov/wcrs/pubs.htm> - Death and Incidence - 2000-2004  
 State Cancer Profiles, Center for Disease Control, <http://www.statecancerprofiles.cancer.gov/> -Trend Data - 2001-2005

**Portage County, Wisconsin**

Prepared by Matthew Bargander, CW Affiliate Community Profile Committee

Total Population:	67,898	Female	34,010	50.10%
		Male	33,888	49.90%
Median Household Income:	\$ 50,465	Median Age	34.6	
Median Family Income:	\$ 63,879	Under 5 Yrs	3,642	5.40%
Per Capita Income:	\$ 23,947	18 Years +	53,386	78.60%
Pop. Percent Change from 2000:	1.70%	65 Years +	7,619	11.20%

**Ethnicity**

White	64,596	95.10%
Black	270	0.40%
American Indian	212	0.30%
Asian	1,717	2.50%
Pacific Islander	39	0.10%
Hispanic (Non White)	1,167	1.70%
Two or More	523	0.80%
Other	541	0.80%

**Language**

Speaking Language other than English	3,683	5.70%
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**Poverty**

Families Below	5.70%
Individuals Below	13.50%

**Economic**

In Labor Force	38,543	69.70%
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**Unemployment Rate**

Last Rate	4.70%	Dec. '08
Last State Rank	4.10%	Nov. '08
Yr Ago Rate	62	
State Rank (of 72)	3.90%	Dec. '07
	67	

**Breast Cancer Statistics**

<b>Incidence</b>	Annual Incidence Rate over rate period(95% Confidence Interval) 120.0 /100,000	Average Annual Count 40	Rate Period 2001-2004
<b>Death Rate</b>	Met Healthy of 22.3 Annual Death Rate Average Deaths per Year Rate Period Recent Trend Recent Annual Percent Change Recent Trend Period	No 25.2 (18.3, 34.0) 9 2001-2005 Falling < -2.1 (-4.1, -0.1) 1981-2005	

Income: US Census Bureau. <http://quickfacts.census.gov/qfd/states/55000.html> - As of 2007  
 Population: US Census Bureau. <http://quickfacts.census.gov/qfd/states/55000.html> - As of 2007  
 Unemployment: Wis. Department of Workforce Development, <http://worknet.wisconsin.gov/worknet/Cntysnap.aspx?menuselection=wdb> - Dec. '08  
 Cancer: Wis. Dpt. of Health Services, Wis. Cancer Reporting Sys <http://dhs.wisconsin.gov/wcrs/pubs.htm> - Death and Incidence - 2000-2004  
 State Cancer Profiles, Center for Disease Control, <http://www.statecancerprofiles.cancer.gov/> -Trend Data - 2001-2005

**Shawano County, Wisconsin**

Prepared by Matthew Bargander, CW Affiliate Community Profile Committee

Total Population:	41,072	Female	20,340	49.80%
		Male	20,668	50.40%
Median Household Income:	\$ 44,141	Median Age	40.8	
Median Family Income:	\$ 50,563	Under 5 Yrs	2,359	5.80%
Per Capita Income:	\$ 22,015	18 Years +	31,598	77.10%
Pop. Percent Change from 2000:	1.70%	65 Years +	7,022	17.00%

**Ethnicity**

White	37,527	90.20%
Black	158	0.40%
American Indian	2,420	6.60%
Asian	185	0.50%
Pacific Islander	37	0.00%
Hispanic (Non White)	629	1.60%
Two or More	563	1.00%
Other	118	0.30%

**Language**

Speaking Language other than English	1,473	3.80%
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**Poverty**

Families Below	10.00%
Individuals Below	11.80%

**Economic**

In Labor Force	21,699	65.90%
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**Unemployment Rate**

Last Rate	6.10%	Dec. '08
Last State Rank	5.50%	Nov. '08
Yr Ago Rate	27	
State Rank (of 72)	4.60%	Dec. '07
	35	

**Breast Cancer Statistics**

<b>Incidence</b>	Annual Incidence Rate over rate period(95% Confidence Interval)	Average Annual Count	Rate Period
	119.8/100,000	30	2001-2004
<b>Death Rate</b>	Met Healthy of 22.3 Annual Death Rate Average Deaths per Year Rate Period	No 23.2 (15.6, 33.4) 6 2001-2005	
	Recent Trend Recent Annual Percent Change Recent Trend Period	Falling < -1.4 (-3.4, 0.7) 1981-2005	

Income: US Census Bureau. <http://quickfacts.census.gov/qfd/states/55000.html> - As of 2007  
 Population: US Census Bureau. <http://quickfacts.census.gov/qfd/states/55000.html> - As of 2007  
 Unemployment: Wis. Department of Workforce Development, <http://worknet.wisconsin.gov/worknet/Cntysnap.aspx?menuselection=wdb> - Dec. '08  
 Cancer: Wis. Dpt. of Health Services, Wis. Cancer Reporting Sys <http://dhs.wisconsin.gov/wcrs/pubs.htm> - Death and Incidence - 2000-2004  
 State Cancer Profiles, Center for Disease Control, <http://www.statecancerprofiles.cancer.gov/> -Trend Data - 2001-2005

**Taylor County, Wisconsin**

Prepared by Matthew Bargander, CW Affiliate Community Profile Committee

Total Population:	19,680	Female	9,714	49.60%
		Male	9,966	50.40%
Median Household Income:	\$ 38,502	Median Age	37.4	
Median Family Income:	\$ 46,176	Under 5 Yrs	1,148	5.80%
Per Capita Income:	\$ 17,570	18 Years +	14,348	72.90%
Pop. Percent Change from 2000:	1.70%	65 Years +	2,992	15.20%

**Ethnicity**

White	19,427	98.70%
Black	17	0.10%
American Indian	37	0.20%
Asian	46	0.20%
Pacific Islander	0	0.00%
Hispanic (Non White)	127	0.60%
Two or More	116	0.60%
Other	37	0.20%

**Language**

Speaking Language other than English	780	3.80%
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**Poverty**

Families Below	334	6.20%
Individuals Below	1,894	9.80%

**Economic**

In Labor Force	10,378	68.90%
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**Unemployment Rate**

Last Rate	8.20%	Dec. '08
Last State Rank	6.40%	Nov. '08
Yr Ago Rate	30	
State Rank (of 72)	5.60%	Dec. '07
	17	

**Breast Cancer Statistics**

Incidence	Annual Incidence Rate over rate period(95% Confidence Interval)	Average Annual Count	Rate Period
	93.0/100,000	11	2001-2004
<b>Death Rate</b>	Met Healthy of 22.3 Annual Death Rate Average Deaths per Year	* * 3 or fewer	2001-2005
	Rate Period		
	Recent Trend	*	
	Recent Annual Percent Change	*	
	Recent Trend Period		1981-2005

Income: US Census Bureau. <http://quickfacts.census.gov/qfd/states/55000.html> - As of 2007  
 Population: US Census Bureau. <http://quickfacts.census.gov/qfd/states/55000.html> - As of 2007  
 Unemployment: Wis. Department of Workforce Development, <http://worknet.wisconsin.gov/worknet/Cntysnap.aspx?menuselection=wdb> - Dec. '08  
 Cancer: Wis. Dpt. of Health Services, Wis. Cancer Reporting Sys <http://dhs.wisconsin.gov/wcrs/pubs.htm> - Death and Incidence - 2000-2004  
 State Cancer Profiles, Center for Disease Control, <http://www.statecancerprofiles.cancer.gov/> -Trend Data - 2001-2005

**Wood County, Wisconsin**

Prepared by Matthew Bargander, CW Affiliate Community Profile Committee

Total Population:	74,196	Female	37,762	50.90%
		Male	36,434	49.10%
Median Household Income:	\$ 47,879	Median Age	41.4	
Median Family Income:	\$ 58,765	Under 5 Yrs	4,233	5.70%
Per Capita Income:	\$ 23,705	18 Years +	57,233	77.10%
Pop. Percent Change from 2000:	1.70%	65 Years +	12,533	16.90%

**Ethnicity**

White	72,855	96.40%
Black	201	0.30%
American Indian	528	0.70%
Asian	1,220	1.60%
Pacific Islander	7	0.00%
Hispanic (Non White)	709	0.90%
Two or More	521	0.70%
Other	223	0.30%

**Poverty**

Families Below	5.40%
Individuals Below	7.70%

**Economic**

In Labor Force	39,339	67.10%
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**Unemployment Rate**

Last Rate	6.50%	Dec. '08
Last State Rank	6.10%	Nov. '08
Yr Ago Rate	16	
State Rank (of 72)	4.90%	Dec. '07
	25	

**Language**

Speaking Language other than English	2,930	4.20%
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**Breast Cancer Statistics**

<b>Incidence</b>	Annual Incidence Rate	Average Annual Count	Rate Period
	over rate period(95% Confidence Interval)		
	147.2/100,000	69	2001-2004
<b>Death Rate</b>	Met Healthy of 22.3	Yes	
	Annual Death Rate	20.1 (14.9, 26.7)	
	Average Deaths per Year	11	
	Rate	2001-2005	
	Period		
	Recent Trend	Falling	
	Recent Annual Percent Change	< -2.1 (-3.7, -0.6)	
	Recent Trend Period	1981-2005	

Income: US Census Bureau. <http://quickfacts.census.gov/qfd/states/55000.html> - As of 2007  
 Population: US Census Bureau. <http://quickfacts.census.gov/qfd/states/55000.html> - As of 2007  
 Unemployment: Wis. Department of Workforce Development, <http://worknet.wisconsin.gov/worknet/Cntysnap.aspx?menuselection=wdb> - Dec. '08  
 Cancer: Wis. Dpt. of Health Services, Wis. Cancer Reporting Sys <http://dhs.wisconsin.gov/wcrs/pubs.htm> - Death and Incidence - 2000-2004  
 State Cancer Profiles, Center for Disease Control, <http://www.statecancerprofiles.cancer.gov/> -Trend Data - 2001-2005

**Local Data on Poverty Status and Health Insurance Coverage in Wisconsin  
Lincoln County, 2004-2006**

Estimated Number		95% Confidence Interval	Estimated Percent	95% Confidence Interval
<b>Lincoln County Total</b>	30,000		100%	
<b>Poverty Status</b>				
Less than 100% of FPL	3,000	+/- 2,000	10%	+/- 6%
100%-199% of FPL	1,000	+/- 1,000	5%	+/- 4%
200% or more of FPL	24,000	+/- 5,000	82%	+/- 7%
Unknown	1,000	+/- 1,000	3%	+/- 3%
<b>Insurance Status</b>				
Insured all of the past year	25,000	+/- 5,000	85%	+/- 7%
Insured part of the past year	2,000	+/- 1,000	7%	+/- 5%
Uninsured all of the past year	3,000	+/- 2,000	9%	+/- 5%
<b>Insurance Type</b>				
Currently uninsured	4,000	+/- 2,000	13%	+/- 6%
Employer-sponsored	20,000	+/- 5,000	68%	+/- 9%
Private	3,000	+/- 2,000	9%	+/- 6%
Medicaid	--	+/- --	1%	+/- 1%
Medicare	3,000	+/- 2,000	9%	+/- 6%
Others	--	+/- --	1%	+/- 1%

**Source:** 2004-2006 Wisconsin Family Health Survey, Bureau of Health Information and Policy, Division of Public Health, Wisconsin Department of Health and Family Services. Sample size for Lincoln County: 118.

**Notes:**

Estimated numbers have been rounded to nearest 1,000 to avoid unwarranted precision. Estimated percentages have been rounded to nearest whole percentage. A dash (--) indicates 0.5% or less, or fewer than 1,000 persons.

*Poverty status* is expressed as a percentage of the Federal Poverty Level (FPL), and is based on responses to questions about household size and income.

*Insured all of the past year, insured part of the past year or uninsured all year* measures health insurance status during the 12 consecutive months prior to the survey interview.

*Insurance type* is a measure of persons insured and uninsured at one point in time. It is a "snapshot" of insurance coverage at the time of the survey interview. Some people have multiple types of insurance, but each person is counted only once in this table. Those with multiple types of insurance are tabulated according to the order of categories in the third panel of this table. For example, someone with both Medicare and private insurance would be counted in the private category. This substantially reduces the estimated number and percent with Medicare coverage, and also slightly reduces estimates of private and Medicaid coverage.

The Wisconsin Family Health Survey is a random-sample telephone survey conducted each year by DHFS. An adult in each sampled household answers the survey questions on behalf of all people living in that household. Survey data represent all household residents. Persons living in group quarters such as nursing homes, dormitories, and jails are not represented by survey results. More information about the survey is on the Web: <http://dhfs.wisconsin.gov/stats/healthinsurance.htm>

**For more information:**

Eleanor Cautley, Research Analyst, Bureau of Health Information and Policy, (608) 267-9545, or e-mail the Bureau of Health Information and Policy, [bhip@dhfs.state.wi.us](mailto:bhip@dhfs.state.wi.us)

**Local Data on Poverty Status and Health Insurance Coverage in Wisconsin  
Marathon County, 2004-2006**

Estimated Number		95% Confidence Interval	Estimated Percent	95% Confidence Interval
<b>Marathon County Total</b>	128,000	100%		
<b>Poverty Status</b>				
Less than 100% of FPL	5,000	+/- 3,000	4%	+/- 2%
100%-199% of FPL	31,000	+/- 7,000	25%	+/- 5%
200% or more of FPL	84,000	+/- 10,000	65%	+/- 5%
Unknown	8,000	+/- 3,000	6%	+/- 2%
<b>Insurance Status</b>				
Insured all of the past year	120,000	+/- 12,000	94%	+/- 2%
Insured part of the past year	7,000	+/- 3,000	6%	+/- 2%
Uninsured all of the past year	--	+/- --	--%	+/- --%
<b>Insurance Type</b>				
Currently uninsured	2,000	+/- 2,000	2%	+/- 1%
Employer-sponsored	99,000	+/- 11,000	77%	+/- 4%
Private	6,000	+/- 3,000	5%	+/- 2%
Medicaid	12,000	+/- 4,000	10%	+/- 3%
Medicare	6,000	+/- 2,000	4%	+/- 2%
Others	3,000	+/- 2,000	2%	+/- 2%

**Source:** 2004-2006 Wisconsin Family Health Survey, Bureau of Health Information and Policy, Division of Public Health, Wisconsin Department of Health and Family Services. Sample size for Marathon County: 435.

**Notes:**

Estimated numbers have been rounded to nearest 1,000 to avoid unwarranted precision. Estimated percentages have been rounded to nearest whole percentage. A dash (--) indicates 0.5% or less, or fewer than 1,000 persons.

*Poverty status* is expressed as a percentage of the Federal Poverty Level (FPL), and is based on responses to questions about household size and income.

*Insured all of the past year, insured part of the past year or uninsured all year* measures health insurance status during the 12 consecutive months prior to the survey interview.

*Insurance type* is a measure of persons insured and uninsured at one point in time. It is a "snapshot" of insurance coverage at the time of the survey interview. Some people have multiple types of insurance, but each person is counted only once in this table. Those with multiple types of insurance are tabulated according to the order of categories in the third panel of this table. For example, someone with both Medicare and private insurance would be counted in the private category. This substantially reduces the estimated number and percent with Medicare coverage, and also slightly reduces estimates of private and Medicaid coverage.

The Wisconsin Family Health Survey is a random-sample telephone survey conducted each year by DHFS. An adult in each sampled household answers the survey questions on behalf of all people living in that household. Survey data represent all household residents. Persons living in group quarters such as nursing homes, dormitories, and jails are not represented by survey results. More information about the survey is on the Web: <http://dhfs.wisconsin.gov/stats/healthinsurance.htm>

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**Local Data on Poverty Status and Health Insurance Coverage in Wisconsin  
Portage County, 2004-2006**

Estimated Number		95% Confidence Interval	Estimated Percent	95% Confidence Interval
<b>Portage County Total</b>	65,000		100%	
<b>Poverty Status</b>				
Less than 100% of FPL	4,000	+/- 2,000	7%	+/- 3%
100%-199% of FPL	12,000	+/- 3,000	18%	+/- 5%
200% or more of FPL	47,000	+/- 7,000	72%	+/- 6%
Unknown	2,000	+/- 1,000	3%	+/- 2%
<b>Insurance Status</b>				
Insured all of the past year	60,000	+/- 8,000	92%	+/- 4%
Insured part of the past year	1,000	+/- 1,000	2%	+/- 2%
Uninsured all of the past year	3,000	+/- 2,000	5%	+/- 3%
<b>Insurance Type</b>				
Currently uninsured	4,000	+/- 2,000	6%	+/- 3%
Employer-sponsored	52,000	+/- 7,000	80%	+/- 5%
Private	1,000	+/- 1,000	2%	+/- 2%
Medicaid	3,000	+/- 2,000	5%	+/- 3%
Medicare	4,000	+/- 2,000	6%	+/- 3%
Others	1,000	+/- 1,000	1%	+/- 1%

**Source:** 2004-2006 Wisconsin Family Health Survey, Bureau of Health Information and Policy, Division of Public Health, Wisconsin Department of Health and Family Services. Sample size for Portage County: 277.

**Notes:**

Estimated numbers have been rounded to nearest 1,000 to avoid unwarranted precision. Estimated percentages have been rounded to nearest whole percentage. A dash (--) indicates 0.5% or less, or fewer than 1,000 persons.

*Poverty status* is expressed as a percentage of the Federal Poverty Level (FPL), and is based on responses to questions about household size and income.

*Insured all of the past year, insured part of the past year or uninsured all year* measures health insurance status during the 12 consecutive months prior to the survey interview.

*Insurance type* is a measure of persons insured and uninsured at one point in time. It is a "snapshot" of insurance coverage at the time of the survey interview. Some people have multiple types of insurance, but each person is counted only once in this table. Those with multiple types of insurance are tabulated according to the order of categories in the third panel of this table. For example, someone with both Medicare and private insurance would be counted in the private category. This substantially reduces the estimated number and percent with Medicare coverage, and also slightly reduces estimates of private and Medicaid coverage.

The Wisconsin Family Health Survey is a random-sample telephone survey conducted each year by DHFS. An adult in each sampled household answers the survey questions on behalf of all people living in that household. Survey data represent all household residents. Persons living in group quarters such as nursing homes, dormitories, and jails are not represented by survey results. More information about the survey is on the Web: <http://dhfs.wisconsin.gov/stats/healthinsurance.htm>

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**Local Data on Poverty Status and Health Insurance Coverage in Wisconsin  
Shawano County, 2004-2006**

Estimated Number		95% Confidence Interval	Estimated Percent	95% Confidence Interval
<b>Shawano County Total</b>	41,000		100%	
<b>Poverty Status</b>				
Less than 100% of FPL	6,000	+/- 3,000	15%	+/- 6%
100%-199% of FPL	7,000	+/- 3,000	18%	+/- 7%
200% or more of FPL	26,000	+/- 6,000	63%	+/- 8%
Unknown	2,000	+/- 1,000	4%	+/- 3%
<b>Insurance Status</b>				
Insured all of the past year	31,000	+/- 7,000	76%	+/- 7%
Insured part of the past year	3,000	+/- 2,000	8%	+/- 4%
Uninsured all of the past year	6,000	+/- 3,000	16%	+/- 6%
<b>Insurance Type</b>				
Currently uninsured	8,000	+/- 3,000	19%	+/- 7%
Employer-sponsored	22,000	+/- 6,000	54%	+/- 9%
Private	2,000	+/- 2,000	5%	+/- 4%
Medicaid	5,000	+/- 2,000	11%	+/- 5%
Medicare	3,000	+/- 2,000	7%	+/- 4%
Others	1,000	+/- 1,000	3%	+/- 3%

**Source:** 2004-2006 Wisconsin Family Health Survey, Bureau of Health Information and Policy, Division of Public Health, Wisconsin Department of Health and Family Services. Sample size for Shawano County: 144.

**Notes:**

Estimated numbers have been rounded to nearest 1,000 to avoid unwarranted precision. Estimated percentages have been rounded to nearest whole percentage. A dash (--) indicates 0.5% or less, or fewer than 1,000 persons.

*Poverty status* is expressed as a percentage of the Federal Poverty Level (FPL), and is based on responses to questions about household size and income.

*Insured all of the past year, insured part of the past year or uninsured all year* measures health insurance status during the 12 consecutive months prior to the survey interview.

*Insurance type* is a measure of persons insured and uninsured at one point in time. It is a "snapshot" of insurance coverage at the time of the survey interview. Some people have multiple types of insurance, but each person is counted only once in this table. Those with multiple types of insurance are tabulated according to the order of categories in the third panel of this table. For example, someone with both Medicare and private insurance would be counted in the private category. This substantially reduces the estimated number and percent with Medicare coverage, and also slightly reduces estimates of private and Medicaid coverage.

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**Local Data on Poverty Status and Health Insurance Coverage in Wisconsin  
Wood County, 2004-2006**

	<b>Estimated Number</b>	<b>95% Confidence Interval</b>	<b>Estimated Percent</b>	<b>95% Confidence Interval</b>
<b>Wood County Total</b>	75,000		100%	
<b>Poverty Status</b>				
Less than 100% of FPL	1,000	+/- 1,000	Less than 100% of FPL	1,000
100%-199% of FPL	16,000	+/- 5,000	100%-199% of FPL	16,000
200% or more of FPL	56,000	+/- 8,000	200% or more of FPL	56,000
Unknown	2,000	+/- 1,000	Unknown	2,000
<b>Insurance Status</b>				
Insured all of the past year	66,000	+/- 9,000	Insured all of the past year	66,000
Insured part of the past year	3,000	+/- 2,000	Insured part of the past year	3,000
Uninsured all of the past year	6,000	+/- 3,000	Uninsured all of the past year	6,000
<b>Insurance Type</b>				
Currently uninsured	6,000	+/- 3,000	Currently uninsured	6,000
Employer-sponsored	50,000	+/- 8,000	Employer-sponsored	50,000
Private	3,000	+/- 2,000	Private	3,000
Medicaid	7,000	+/- 3,000	Medicaid	7,000
Medicare	8,000	+/- 3,000	Medicare	8,000
Others	1,000	+/- 1,000	Others	1,000

**Source:** 2004-2006 Wisconsin Family Health Survey, Bureau of Health Information and Policy, Division of Public Health, Wisconsin Department of Health and Family Services. Sample size for Wood County: 268.

**Notes:**

Estimated numbers have been rounded to nearest 1,000 to avoid unwarranted precision. Estimated percentages have been rounded to nearest whole percentage. A dash (--) indicates 0.5% or less, or fewer than 1,000 persons.

*Poverty status* is expressed as a percentage of the Federal Poverty Level (FPL), and is based on responses to questions about household size and income.

*Insured all of the past year, insured part of the past year or uninsured all year* measures health insurance status during the 12 consecutive months prior to the survey interview.

*Insurance type* is a measure of persons insured and uninsured at one point in time. It is a "snapshot" of insurance coverage at the time of the survey interview. Some people have multiple types of insurance, but each person is counted only once in this table. Those with multiple types of insurance are tabulated according to the order of categories in the third panel of this table. For example, someone with both Medicare and private insurance would be counted in the private category. This substantially reduces the estimated number and percent with Medicare coverage, and also slightly reduces estimates of private and Medicaid coverage.

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### At a glance data comparisons : Breast Cancer Incidence and Mortality

	U.S.	Wisconsin	Langlade	Lincoln	Marathon	Portage	Shawano	Taylor	Wood
<b>Mammography rates</b> (State Cancer Profiles, 2006 Had a Mammo in past 2yrs All races, 40+)	2010 Goal 70%	77.9%	<i>Not available at the county level</i>						
<b>BC incidence</b> Cases per 100,000, age adjusted (State Cancer Profiles Incidence Rate Report by County, All races, 2001-2004)	123.9	126.8	113.2	124.7	128.0	120.2	119.8	93.0	147.2
<b>BC mortality</b> Deaths per 100,000, age adjusted (State Cancer Profiles Mortality rate by County, All Races, 1990-2004)	25.5  2010 Goal 22.3%	24.5	18.6	18.0	22.6	23.2	21.6	(3 or fewer cases)	22.2
<b>Percent of individuals below poverty level</b> (US Census Bureau 2000 / 2005-06 estimates )	12.4 / 13.3	8.7 / 11	10.1 / 11.6	6.9 / 9.9	6.6 / 6.9	9.5 / 13.5	7.9 / 11.8	9.8 / na	6.5 / 7.7
<b>%White</b> (US Census Bureau 2000 / 2005-06 estimates )	75.1 / 74.1	88.9/ 87.5	97.7 / 97.0	97.8 / 97.1	93.8 / 93.5	95.7 / 95.1	91.6 / 91.5	98.7 / na	96.4 / 96.0
<b>%AA</b> (US Census Bureau 2000 / 2005-06 estimates )	12.3 / 12.4	5.7 / 5.9	0.1 / 0.2	0.4 / 0.0	0.3 / 0.5	0.3 / 0.4	0.2 / 0.4	0.1 / na	0.3 / 0.5
<b>%AI/AN</b> (US Census Bureau 2000 / 2005-06 estimates )	0.9 / 0.8	0.8 / 0.8	0.5 / 0.7	0.4 / 0.8	0.3 / 0.3	0.4 / 0.3	6.3 / 5.9	.2 / na	0.7 / 0.5
<b>%Asian</b> (US Census Bureau 2000 / 2005-06 estimates )	3.6 / 4.3	1.7 / 2	0.3 / 0.4	0.4 / 0.6	4.5 / 4.5	.2 / 2.5	0.3 / 0.5	0.2 / na	1.6 / 1.6
<b>%Hispanic</b> (US Census Bureau 2000 / 2005-06 estimates )	12.5 / 14.7	3.6 / 4.7	0.8 / 1.1	0.8 / 1.1	0.8 / 1.2	1.4 / 1.7	1.0 / 1.5	0.6 / na	0.9 / 1.2

This is an overview of the incidence/mortality statistics and sociodemographic data for the seven counties served by the Affiliate. It is derived from updates to the 2000 census based on the American Community Survey.

The chart was provided by Griselle Sanchez from NCI's Cancer Information Service.

## **County/Counties of Interest: What the Data Shows**

A number of themes and questions were revealed during the data analysis. Some of these involve gaps found in services, though more research is needed as the Affiliate's action plan evolves. Because much data is not available for some of the rural areas, we needed to rely on health care providers to provide anecdotal information upon which to base portions of this report.

One conclusion from the data is that the mammography rates for Wisconsin in all races, 40 years or older, are approximately 7.9% higher than the national average. Unfortunately, we do not have the data broken out by county in our service area. Wisconsin has a higher reported breast cancer incidence rate (126.8%) than the national average (123.9%) likely due to a higher percentage of screenings. Wood County's breast cancer incidence rate is the highest of the seven counties in the Affiliate's service area (147.2%) with a 22.2% mortality rate. It is possible that the incidence rate in Wood County is due to an increased screening rate. The second highest is Marathon County. All counties' mortality rate is lower than the state and national percentages. Portage and Marathon County have the highest mortality in our region. Although these counties' rates are lower than the state and national percentage, they still exceed the 2010 U. S. goal of 22.3%.

From 2005-2006 U. S. Census Bureau estimates, Portage County has the highest percent of individuals below the poverty line, followed by Shawano and Langlade. The Portage County poverty level is the only county's poverty level in our area higher than national poverty levels. It is likely there is an increase in poverty levels in all counties due to the current economic times.

Other observations:

- Portage County has the highest mortality rate and the highest Hispanic population.
- Marathon County has the highest Asian population.
- Portage County has the highest percent below poverty level.

One of the biggest conclusions is that the demographics of the region are changing. After comparing 2000 U.S. Census Bureau rates to the 2005-2006 estimates, there is an increase in Hispanic population in all counties except Taylor county for which information is not available. An area of concern is the increase in the Hispanic population in western Marathon County, southern Lincoln County and southeast/south central Portage County. In addition, unemployment rates continue to climb, causing a growth in low socioeconomic status and homelessness in our region.

Another major concern is that screening rates are lower in rural areas. The Marshfield Clinic Mobile Mammography unit has been trying to address the needs in these rural areas. It does approximately 4,800 screenings, as recorded by the mobile mammography unit managers, per year at 22 rural Marshfield Clinic sites, 16 additional community outreach sites and 25 worksites. (Some of these sites are outside our Affiliate area, but separated data is not available at this time.) However, there is a need for more outreach by the mobile mammography units, particularly in rural areas of the counties.

Although data is incomplete, many in our service area are uninsured or underinsured.

### **Demographic and Breast Cancer Findings**

Based on the data study, the Community Profile Committee concluded that as a small and slowly growing Affiliate, we will continue to concentrate our efforts on Marathon County, the largest county in our service area with many rural and underserved populations. Once we have learned how to best attack the problems of these areas of Marathon County, we will then expand our attention to other rural counties that have high percentages of need. At this time, we do not have enough resources to effectively reach all areas.

## **Programs and Services**



### **Data Source and Methodology Overview**

In September, 2008, the Susan G. Komen Central Wisconsin Affiliate brought together in a forum a group of stakeholders in the Central Wisconsin region to investigate breast health care in the region. A committee consisting of representatives from our Affiliate, the American Cancer Society, Marathon County Health Department, Aspirus Wausau Hospital, Ministry Health Care, Marshfield Clinic, Breast Center of Central Wisconsin, UnitedHealthcare and Integrity First Bank formed to identify the people who represented those affected by or impacting breast cancer screening and treatment.

While preparing for the forum, the committee worked to develop a directory or list of breast cancer programs and services in our Affiliate area. That information was pulled from previous Affiliate surveys which used the Yellow Pages, United Way's First Call, Public Health Departments for each county, Tribal Health Centers, and area Websites.

### **Programs and Services Overview**

For the purposes of this report, we are focusing primarily on Marathon County because it has the largest population and the largest incidence of breast cancer without looking at rate. Although some of the other counties have a higher incidence rate, the numbers are much smaller. Once again, our Affiliate has

limited resources, and until we have practices and procedures, goals and objectives for this area well underway, we will not be equipped to branch out into other needy counties.

Our research has indicated that the rural areas in all counties are in most need. Marathon County's more densely populated areas are served by a number of medical care facilities and providers, but there is a need in rural areas for screening and supportive services such as transportation, care and education.

Major medical and support services in the Central Wisconsin Area are listed below.

### **Langlade County**

Aspirus General Clinic, Antigo

Family Planning Health Service, Antigo

Langlade Health Care Center, Antigo

Langlade Memorial Hospital, Antigo

### **Lincoln County**

Ministry Medical Group, Tomahawk

Aspirus Clinic, Merrill

Family Planning Health Services, Tomahawk

Sacred Heart Hospital, Tomahawk

Good Samaritan Hospital, Merrill

Marshfield Clinic, Merrill

St. Vincent de Paul Free Clinic, Merrill

## **Marathon County**

Afterreach – Aspirus Cancer Center , Wausau

American Cancer Society Marathon Unit, Wausau

Aspirus Wausau Hospital, Wausau

Breast Cancer Center of Central Wisconsin, Wausau

Bridge Community Health Clinic, Wausau

Cancer Support Group, Weston

Family Planning Health Service, Inc, Wausau

Look Good...Feel Better - Aspirus Cancer Center, Wausau

Reach to Recovery, American Cancer Society, Wausau

St. Clare's Hospital, Weston

Wisconsin Well Women Program

Women Living With Hope, Weston

## **Portage County**

Living With Cancer Support Group, Stevens Point

Look Good, Feel Better, Stevens Point

Saint Michael's Hospital, Stevens Point

Wisconsin Well Women Program, Stevens Point

Portage County Medical Society, Stevens Point

Marshfield Clinic, Stevens Point

Family Planning Health Services, Stevens Point

## **Taylor County**

Memorial Health Center, Medford

Our Lady Victory Hospital, Stanley (Note: it's in Clark County but definitely has coverage to Taylor county)

St. Joseph's Home Health Agency, Medford

Family Planning Health Services, Medford

Aspirus Regional Cancer Center, Medford

Memorial Medical Clinic, Rib Lake

Rib Lake Clinic, Rib Lake

## **Shawano County**

Aurora Health Center, Shawano

Shawano Medical Center Riverside, Shawano

WIC Clinic, Shawano

Baycare Clinic, Shawano

## **Wood County**

St. Joseph's Hospital (Ministry Health Care), Marshfield

Look Good, Feel Better, Marshfield

Marshfield Clinic, Marshfield

Women Living With Hope, Hope Lodge, Marshfield

Reach to Recovery, Marshfield

Riverview Hospital, Wisconsin Rapids

Riverview Hospital U.W. Cancer Center, Wisconsin Rapids

Women Living With Hope, Marshfield

The seven county area is also served by clinics provided by the three major systems in our region, including Aspirus (15 clinics), Marshfield Clinic (10 clinics) and Ministry Health Care (6 clinics).

The Central Wisconsin Affiliate's service area includes additional assets, such as churches and religious groups, public schools, charities and non-profits (e.g. parent resource centers and thrift stores), chambers of commerce, media, and childcare centers. We believe these assets are being underutilized. Our plan is to collaborate with these entities by providing educational materials at events and throughout the year.

### **Partnerships and Grant Opportunities**

The Wisconsin Well Woman Program (WWWP) Cancer Screening Program is a breast and cervical cancer-screening program for women funded by the Centers for Disease Control (CDC) and the State of Wisconsin. The program provides limited health care screening services, referral, follow up, and patient education for women meeting the following criteria: ages 45-64; at or below 250% of the federal poverty level; no health insurance or insurance which does not cover routine screening, or unable to pay high deductibles or co-payments.

The Marathon County Health Department coordinates this program for women in Marathon County. Each of the counties in the Affiliate service area has a Well Woman Coordinator in its respective Public Health Department. The coordinator's role is to determine eligibility and enrollment, provide case management, assist with billing and reimbursement, and report local activity to WWWP. Well Woman Coordinators from the region have actively participated in Susan G. Komen Events, surveys, and committees.

Aspirus Women's Health is a current grantee of the Affiliate. The grant supports Aspirus Women's Health Mobile mammography outreach within our service area, providing for screening services and in some cases, diagnostic services for qualifying women who are uninsured or underinsured but do not qualify for governmental services.

Our plan to further partnerships and grant opportunities is for the Board President and Vice-President to meet with all of the seven county hospital Board of Trustees. This personal contact will enable us to explain the Komen mission, and increase awareness of grant opportunities and potential collaborations.

## Public Policy Perspectives

The legislative branch of the Wisconsin State government is made up of the senate with 33 members and the assembly with 99 members. Each senate district is divided into three assembly districts. The Senators serve four-year terms and the Assembly members serve two-year terms. To a large extent the legislature does its work in committees. In the 2009 Legislature, the senate has 19 standing committees, the assembly has 37, and there are 10 joint committees. These committees consist of legislators only.

The Central Wisconsin Affiliate area consists of six and a half counties. The legislative district borders are not contiguous with the county borders. The Affiliate area includes all or part of five senate districts and 10 assembly districts. A detailed summary is below.

Senate District	Assembly District	Last name	Counties served	Party	Relevant committee membership
24		Lassa	Portage, Wood	D	Joint Finance Committee, Senate Committee on Health
	70	Vruwink	Portage, Wood	D	Assembly Committee on Health and Health Reform
	71	Molepske	Portage	D	
	72	Schneider	Portage, Wood	D	
23		Kreitlow	Wood Marathon, Taylor	D	
	69	Suder	Marathon, Taylor	R	Assembly Committee on Insurance
29		Decker	Marathon, Taylor, Portage, Shawano	D	Senate Majority Chair
	85	Siedel	Marathon	D	Assembly Committee on Health, Assembly Committee on Children and Families
	86	Petrowski	Marathon, Shawano	R	
	87	Williams	Taylor	R	
12		Holperin	Lincoln, Langlade, Shawano	D	
	35	Friske	Lincoln, Langlade	R	
	36	Mursau	Langlade, Shawano	R	
2		Cowles	Shawano	R	
	6	Tauchen	Shawano	R	

Retrieved from: <http://www.legis.state.wi.us/> on February 27, 2009.

## **Programs and Service Findings**

One of our best summaries of programs and services needs was the report from the World Café Forum (Addendum II). One of the outcomes of the September 2008 forum hosted by our Susan G. Komen Central Wisconsin Affiliate was a report written by the Wisconsin Institute for Public Policy and Service (WIPPS). That report (Addendum II) summarizes the interactive dialogue process among its various participants: a collection of cancer survivors, doctors, nurses, and health advocates. Over 60 such people participated in the forum, and some of the feedback reflected upon area programs and services. In particular, the question, “How does our community currently embrace and support breast care?” addressed this issue.

Following are some of the main points gathered from the report, relative to programs and services:

- Programs and services need to be centered on whole community education on breast health. Although hospitals and clinics need to take a significant role, education must flow from other settings and providers too.
- Organizations that provide programs and services should utilize effective communication and marketing in order to bring people’s time and attention to breast cancer and other health issues.
- People who administer the programs and services need to better understand the barriers to effective screening, treatment, and support so that resources may be better allocated.
- Programs and services need to reach all women and families, especially including the growing minority populations and the rural poor.
- Strong and consistent advocacy for women is necessary both locally through coordinated health care programs and at the state level through lobbying efforts for funding of wellness programs and insurance coverage.
- Breast health care delivery needs to be improved by thoroughly overhauling the navigation system of routing patients through breast centers by finding ways to empower women to take control of their breast health.

Although the mobile mammography units are a potentially effective strategy to target remote underserved areas, our findings from the Forum indicate their services are not optimally utilized. We believe that the barriers to access include the lack of knowledge about where and when the mobile units are available, limited access to treatment if the mammography results would warrant follow-up care, (preventing women from initiating contact), limited auxiliary services such as transportation and childcare for appointments, and lack of education on preventive care. Our Affiliate will need to address these concerns as we plan for the future.

As far as legislative resources and efforts at advocacy, we have determined that our Affiliate needs to develop broader community connections and a broader area of active service in order to really address public policy effort. It will be part of our long-range planning to share this report with our legislators, and having follow up meeting with them to discuss our priorities.

We have a strong health care system in our counties. We believe as awareness of our organization grows, health care providers will be more aware of what we have to offer the community.

## Exploratory Data



### Data Sources and Methodology Overview

The Affiliate used the report from the Harvesting Our Collective Wisdom World Café, an Affiliate-sponsored forum, to identify important questions that emerged from the event. These were rewritten and used for the Key Informant surveys. Key Informants included local health care providers, Wisconsin Well Woman Coordinators, and other public health officials. The interviews were conducted face to face, over the phone, and via e-mail. All of those surveyed were from the more populated areas of the Komen Affiliate area.

Additional, anecdotal information related to health care utilization and cultural barriers was supplied by Peter Yang, Executive Director, Wausau Area Hmong Association and Sarah Jaeger, PA-C, Outreach Coordinator for Aspirus Women's Health. The information was transcribed from interview notes. Wisconsin and county Hmong population, employment status, English proficiency, and income data was derived from the University of Wisconsin Extension Hmong Educational Needs Assessment, prepared by the University of Wisconsin Extension and Applied Population Laboratory, 1450 Linden Drive, Madison, WI 53705 and is based on 2000 U.S. census data.

## **Exploratory Data Findings**

Improving outreach to women is a significant need, especially in our targeted rural areas and with targeted populations. Key informants identified the following barriers to that outreach:

### *Financial Barriers*

Several health care providers surveyed indicated that financial barriers needed to be addressed. For example, insurance premiums are rising, causing a higher number of uninsured or underinsured people. Often, deductibles are high, causing reluctance for office visits. Thus, as one provider indicated, we need better preventative care coverage.

### *Transportation*

Another barrier to comprehensive outreach to women is the issue of inadequate transportation for many populations. The Marshfield Clinic Mobile Units regularly provide screenings at their outreach sites, but according to another health care provider, additional efforts need to be made to provide community-based screening in rural locations.

### *Fear*

During the other key informant interviews, many interviewed brought up fear as a barrier to adequate breast health care. One provider indicated that many women in the rural areas are “not so global. They are not in facilities, have no family support. Fear is a huge barrier.”

In addition, another provider indicated that women need to be comfortable in assessing their breasts. Some are simply afraid of the pain or perception that pain is associated with screening. A third provider suggested, “taking opportunities by utilizing the ‘stories’ of high profile people in the community... normalizing it.” One public health official stated, “Many women are afraid of what they are going to find out if they go to the screening. Statistics of incidence and prevalence are widely used and are often used as a tactic to encourage women to go to their screening. However, it can be a scare tactic,” and that can work negatively in the case of women who intensely fear cancer. “Instead of just giving the rates of how many women are diagnosed with breast cancer, perhaps the follow up should be a statistic about the survival rate with early detection.” Another public health official agreed that fear was a powerful force working against proper breast health outreach, but felt that education about prevention could help reduce that fear. However, the official stated, it would not address their inability to pay for screening or their fear of not being able to pay. Even in a situation where screening is free, people are unlikely to get screened if they know they cannot pay for any necessary follow-up treatment.

### *Consistent Use of Practice Guidelines*

Many of the comments from the interviewed health care providers, public health officials and survivors indicated that inconsistent use of practice guidelines was another barrier to outreach. One of the providers shared that there is “a lack of consensus in the medical community regarding effectiveness and how often a clinical exam should occur. Different physician organizations are recommending different things, and this causes confusion/problems.” Another provider indicated that not all providers do a good job of making a breast exam and the coaching that goes with it a part of any health exam. One provider added that they had determined that one of the barriers to outreach and screening was, “as simple as providers not recommending the screening.”

### *Insufficient Focus on Integrated Support*

The providers interviewed all agreed that support for breast cancer patients is not adequately integrated into their treatment. They believe that a great deal of information is given to the patients but that a more “whole person” approach is necessary. For example, one provider shared that he or she did not necessarily make an effort to integrate support and felt he or she could not do so during an office visit. Another provider indicated that any support for breast health given is done once a woman is diagnosed because “we are an illness-based society, not a wellness-based society.” In addition, providers felt that what support is given is a “one-size fits all.” Public health officials agreed with this general lack of integrated support from the health care system. One stated that “each woman has a complex web of appointments, different doctors, pharmaceuticals, insurance and billing issues, medical leave issues with work, family to take care of and the list goes on...she need serious help!!!” Another health care official observes that most of the support comes from family and friends.

### *Need for Self-Advocacy*

All persons interviewed believed that more education is necessary to help women become their own advocates. One provider stated, “Education, education, education. We need to help women understand that health care is a right. They should not leave the office with unanswered questions.” Another said that women often have faith that the “clinic” will take care of everything and that they are at the mercy of everyone else. Instead, they need to see themselves as the key player in their care, feel comfortable asking questions and expecting answers. One of the public health officials indicated that “many women believe everything they are told by health care professionals – even if they are not satisfied with the answer or instinctively feel that something else is wrong...It’s important for women to realize that they CAN ask the doctor questions...that they can call his/her office.”

### *Language and Culture - Hmong*

Because language and culture can be a huge barrier to outreach, and because the Central Wisconsin Affiliate of Susan G. Komen for the Cure identifies our region's Hmong females as an at-risk population, two interviewers met with our local Hmong Association officials to gain insight on the way breast health care is perceived by the community.

The Hmong settlers came from their native Southeast Asian countries to Wisconsin in the mid-1980s, largely sponsored through various religious organizations. Despite being established in and supported by their communities, there remain significant barriers to health care access and utilization for our area's Hmong.

Although the overall incidence of breast cancer in Hmong women is lower than the average population, low screening mammography utilization rates, a higher rate of "no shows" for scheduled mammography appointments, and failure to access information and assistance until a problem arises, all contribute to their risk for late stage diagnosis.

US Census Bureau statistics indicate that over 6,084 Hmong live in counties served by the Affiliate, with all counties experiencing steady growth in their Hmong populations.

Based on interviews with leaders from the Wausau Area Hmong Association and health care providers from the Bridge Community Clinic and area hospitals, the following barriers have been identified as significant for this group:

- Wellness and prevention is not part of the traditional Hmong health care focus. In many cases, Shamans, traditional Hmong healers, are still consulted by some elders.
- As a rule, older Hmong women do not necessarily seek medical attention until there is a problem that cannot be ignored.
- Cultural barriers impact access to mammography and clinical breast exams. Many older Hmong women do not wish to be seen by another person, much less a male, and many older Hmong husbands do not want their wives to be viewed by another male.
- Language barriers still present a problem for older Hmong women. In fact, there is no clear word for "breast cancer" in Hmong dialects. Cancer would be described as a "sickness" in that area. In addition, 25.5% of Hmong persons who speak an Asian and Pacific Island language at home do not speak English well or at all.

- Hmong is a largely verbal language with white and green dialects. It is not a widely read language, which negates many forms of printed educational materials and screening program advertising.
- In terms of educational attainment, 60% of Hmong females in Wisconsin have not completed any schooling, 13% have some schooling, but no high school diploma, and 14% have completed only high school.
- Employment, and access to employee-offered benefits is also a barrier. In 2000, 49% of Hmong women in Wisconsin were either unemployed or not in the labor force at all.

While the Affiliate has uncovered the above anecdotal information, the Affiliate's Board has designated an ongoing sub-committee to uncover more concrete statistical data, foster collaboration between identified community groups, and improve outreach and educational efforts.

It is important to continue efforts to reach our region's older Hmong females by uncovering the best means to reach them within their culture. At the same time, a focus must remain on reaching the younger female Hmong population, who are much more "westernized" in their approach to personal health and medicine. Current avenues for reaching the Hmong population are:

- Bridge Community Clinic (about 30% Hmong clients)
- The Hmong radio show (coordinated through the Wausau Area Hmong Association)
- The Wausau Daily Herald Hmong Connection newspaper
- Area Hmong churches and leadership groups

## Conclusions

### Target Area Findings

Based on the research and data analysis, several concerns came to the foreground:

- The mobile mammography unit is underutilized in some areas.
- Residents need to be educated on the importance of screening.
- Other barriers to access or use of the mammography units need to be addressed (understanding the need for preventative care, providing transportation for medical appointments, understanding where and when mobile units are available).
- The growing minority populations provide unique issues
- Although our rural areas in Langlade and Taylor Counties, especially, need to be addressed, the sheer numbers of people in Marathon County rural areas absorb most of our time and resources.
- The national state of the economy is rapidly changing. Our data has become outdated, and we need to be flexibly responsive to changes in needs in our Affiliate area.

Some recommendations based on data gathered were:

1. Improve outreach to women by:
  - Supporting grant applications that include both clinical and medical exams. Both imaging and clinical exams are important for screening for breast cancer.
  - Normalizing the practice of self-breast exams and clinical breast exams through education.
  - Make additional efforts to reach more women with the mobile mammography units, especially in rural locations.
  - Provide the community with ongoing education on the importance and availability of screening.
2. Empower women to make good choices about treatment by:
  - Giving positive messages rather than negative ones. Get rid of the scare tactics.
  - Finding new and creative ways to reach and educate women about breast health care. Take advantage of unique locations, venues, and events and using them as opportunities to educate women (child care centers, hair salons, grocery stores, and

community events), meeting women where they work, eat, and shop.

- Teaching women to take ownership of their options and not just to rely on the doctor or nurse to make decisions for them.
- Promoting holistic care methods such as massage and spa treatments.
- Beginning education at an early age; targeting high school and college age young adults for outreach.
- Working on solutions for people who cannot pay for treatment. Some women will not even be screened because they know they cannot pay for treatment even if they need it.
- Educating women to be strong communicators and strong self-advocates.

3. Reducing barriers that prevent women from seeking screening:

- Lobbying for more and better insurance coverage.
- Educating and empowering women.
- Improving accessibility and availability of screening and treatment.
- Improving health care organizations' understanding of barriers to care so that we can collaborate to eradicate them.
- Improving cultural sensitivity among our health care and support service providers.

4. Integrating support into treatment:

- Expanding the role of navigators to broaden their assistance across the entire spectrum of care. Patients often need advocates to “translate” for them when a diagnosis is made. Their families and children also need assistance and support through diagnosis and treatment.
- Recognizing complementary treatments such as yoga and mental health support.
- Supporting a “whole person” approach.
- Providing support groups for women and their families (cost free and in all geographical regions). This could include a network of survivors.

5. Improving women's ability to advocate for themselves.

- Empowering women as they go through the system of health care; give them a voice in their communities.
- Lobby public policy makers for legislation that supports women's health.
- Promote new and more effective models for personalized medicine and care.

## **Selecting Affiliate Priorities**

Based on all the information gathered, statistical and anecdotally, the Community Profile Committee developed two priorities for the Komen Affiliate to begin to build our goals and action plan. Because we are a working board with no staff, we need to be sure our priorities are tightly focused and achievable, yet able to be expanded at a reasonable pace as our Affiliate grows.

The first priority the committee identified was to address the issue of access to care for rural women. It is a priority that has evolved with our Affiliate over the past two years and is reflected in our community partnerships and grants. However, the issue is so large and prevalent in more than one of our service area counties, and there is a great deal that we must still do.

The second priority is to concentrate more on minority breast health care. This priority is closely related to the first priority, yet needs a more specific focus on establishing partnerships that will help us with cultural understanding and outreach.

### ***Priority One:***

#### ***Access to Care for Rural Women***

- Goal One: Improve screening and treatment opportunities for rural women.
  - Objectives:
    - Assist health care providers in finding the gaps in service areas for rural women.
    - Provide funding to grantees that support rural services.
    - Provide educational outreach for breast health care at community health fairs and events that target rural women.
    - Provide educational outreach at some non-traditional settings such as fitness centers, grocery stores, and shopping centers.
    - Increase participation and awareness of mobile mammography unit screenings.
- Goal Two: Remove the identified barriers to screening and treatment.
  - Objectives:
    - Eradicate the fear and confusion associated with breast health.
    - Educate women on the positive nature of regular screening.

- Empower women to manage their own breast health care.
  - Lobby for better health insurance and funding for women's health care.
  - Provide better navigator services to women with breast cancer.
- Goal Three: Build our Susan G. Komen Central Wisconsin Affiliate's community partnerships so that we become better known in the community and thus, better able to attract and distribute more resources for breast health.
    - Objectives:
      - Be a positive force in the communities we serve.
      - Increase the number and scope of our events, including those that involve education, fundraising, and advocacy.
      - Improve our marketing approaches.
      - Reach out to diverse populations and minorities.

***Priority Two:***

***Minority Breast Health Care***

- Goal One: Gain a greater cultural awareness of the major minority groups in our Affiliate area so that barriers and solutions can be properly addressed.
  - Objectives:
    - Create opportunities and alliances that result in more conversations with our minority populations, especially the Hmong and Hispanic.
    - Discover the avenues that will lead to better understanding of minority groups.
- Goal Two: Provide outreach to meet the breast health needs of diverse cultures.
  - Objectives:
    - Provide targeted health care education to Hmong and Hispanic groups.
    - Once they are identified (Goal One), address the cultural barriers that prevent minorities from accessing breast health care.

In order to meet these suggested goals, the Susan G. Komen Central Wisconsin Affiliate needs to develop an action plan based on the stated goals and objectives. First of all, to reach rural and minority populations, our Affiliate needs to improve and expand on our community partnerships. One way might be to simply gain visibility. This can be done through increased participation in

health fairs, more educational outreach, and expanded fundraising events. An event such as a Race for the Cure would be an exceptional way to bring more attention to the Komen mission. By increasing our visibility, we will be able to increase our impact on the community, raising more money and sharing our resources with grantees who share our goals and objectives.

**ADDENDUM I**

**Key informant interview script**

CW Komen Affiliate  
2009 Assessment

Name of interviewer: \_\_\_\_\_

Name of interviewee: \_\_\_\_\_

Affiliation/Organization: \_\_\_\_\_

—

Address/  
Phone: \_\_\_\_\_

Date of interview: \_\_\_\_\_

Hello,

My name is \_\_\_\_\_ and I'm a (volunteer/Board member/other) for the Central Wisconsin Affiliate of Susan G. Komen for the Cure. We are currently working on our community profile project and an important first step in our effort is to better understand the status of breast health and breast health services in our service area. To do that, we are conducting interviews with key community leaders (or partners).

The themes that emerge from the interviews will be used to set priorities and inform the efforts of the Susan G Komen for the Cure local office. The priorities that we establish will help us determine where to target our grant making, as well help us build community relationships and partners, learn about evidenced based work taking place in our community and address outreach and policy needs. While we use the themes from the interviews, the interviews themselves are strictly confidential.

Your knowledge is invaluable and we appreciate you making yourself available for an interview. The interview will take about an hour. I will be taking notes during the

interview (discuss recording interviews if that is an option) and trying to take down as much information as possible. If during the interview you have any questions please feel free to ask those at any time.

**Note:** If using sample script for initial contact end with the following statement — Your knowledge would be very valuable and we hope you could make yourself available for an interview. The interview will take about an hour. Could we schedule a time to meet?

In regards to screening, how do we improve outreach to women?

How can we empower women with knowledge to make good choices about screening? And treatment?

What is the most important thing that can be done to reduce the barriers to seeking screening? And treatment?

How is support being integrated into treatment? How could it be further integrated?

How do we improve women's ability to advocate for themselves in the medical system?

What other care and management models exist that could be utilized for breast cancer treatment?

***Sample Closing Statement***

Thank you very much for your time. Your knowledge and insights will be very helpful to us. We expect to complete this phase of our work in months and we hope to issue a report by\_\_\_\_\_. Would you like to receive a copy of the report?

Thank you again.

**ADDENDUM II**

**Harvesting Our Collective Wisdom World Café**

**A Report to the**

**Susan G. Komen for the Cure  
Central Wisconsin Affiliate**

**From the**

**Wisconsin Institute for Public Policy & Service**

**Authored by**

**Mary Kluz and Eric Giordano, Ph.D.**

**December 5, 2008**

## **Harvesting Our Collective Wisdom World Café Report to the Susan G. Komen for the Cure Central Wisconsin Affiliate**

### **INTRODUCTION**

Formed in October 2007, Susan G. Komen for the Cure Central Wisconsin (SGK-CWA) is a new Affiliate of the Susan G Komen for the Cure national organization “dedicated to curing breast cancer at every stage—from the causes to the cures to the pain and anxiety of every moment in between” (<http://www.komencentralwisconsin.org/>). SGK-CWA is particularly interested in uncovering gaps in breast health care and providing community grants to address these gaps in seven counties of North Central Wisconsin: Langlade, Lincoln, Marathon, Portage, Taylor, Wood and a portion of West Shawano County.

SGK-CWA recently created a Public Forum Planning Committee to investigate ways that stakeholders interested in breast health issues in the Central Wisconsin region could be brought together in a forum to begin a process of improving knowledge and collaboration centered on breast cancer issues. The Committee consisted of representatives from SGK-CWA, the American Cancer Society, Marathon County Health Department, Aspirus, Ministry Health Care, Marshfield Clinic, Breast Center of Central Wisconsin, UMR, and Integrity First Bank. (Lists of Board and Committee members are found in **Addendum One**.)

The Committee decided to hold the “Harvesting Our Collective Wisdom” World Café event on September 16, 2008 in Wausau, Wisconsin. Over sixty stakeholders connected with issues of breast health in Central Wisconsin attended the event.

### **PURPOSE**

Planning Committee members communicated the SGK-CWA Board’s desire to host a gathering to foster collaboration on topics relevant to breast cancer and to raise awareness that the foundation was actively functioning in the North Central Wisconsin region. The purpose statement of the forum is as follows:

*To bring together people representing those affected by or impacting breast cancer, to learn, engage, inform and connect, and become a catalyst for action in our seven county region.*

## PROCESS

As the Planning Committee members defined desired outcomes, they considered potential structures for the meeting, ultimately deciding to use the World Café methodology, an interactive dialogue process that engages all participants. World Café is often described as a methodology for hosting conversations that matter. (For more information on the World Café model, visit [www.theworldcafe.com](http://www.theworldcafe.com); a list of sample references for the model can also be found in **Addendum Two**). Principles behind the methodology are as follows:

- Set the context
- Create hospitable space
- Explore questions that matter
- Encourage contribution
- Connect diverse perspectives
- Listen together for insights
- Share collective discoveries

Planning Committee members became active participants in the design of the forum using these principles. Prior to the event, the Committee set the context of the event through discussion that defined the boundaries of the topic. The topic boundaries aided Committee members to develop key questions that were used at the Café. Committee members also took charge of creating hospitable space in a conceptual sense by focusing on a theme of “harvest,” which linked the Café to the principles of contribution, connecting perspectives, and sharing collective discoveries.

Committee members sent save the date postcards followed by mailed invitations to over 250 persons, targeting representation from a wide variety of groups and individuals, including breast cancer survivors, doctors, nurses, and health advocates. The invitation described the gathering, informing invitees of the expectation that they would be actively engage at the event. Over sixty attendees participated in the Forum.

World Café is designed as a fluid conversation that connects all participants, guiding them through a series of questions and shared reflections. Participants explore the questions together in groups of five to eight per table. One person stays at each table for the entire process, acting as the table host, with specific responsibilities of welcoming, summarizing and connecting people and ideas. After each question and related discussion, participants move to a new table and create a new conversation group based on the new question. But the model encourages participants to carry ideas over from the preceding table conversation, thus allowing a “cross-fertilization” of ideas.

The questions that the Planning Committee developed followed a progression that took people from their personal stake in breast cancer to possible action. The questions, in order, were:

- 1) Why am I here at this forum?
- 2) If we had the best community for breast care, what would that look like?
- 3) How does our community currently embrace and support breast care?
- 4) What do we need to build together to fight breast cancer in our backyard?

Participants were able to express their thoughts verbally and through drawing and writing on “tablecloths”, literally large pieces of paper in the center of each table. If time did not allow all ideas to be expressed, participants were given yet another mechanism for sharing their thoughts. Specifically, at any point during the event, participants were invited to share thoughts about what pieces of the larger breast care system were missing, the resources they already had available and their wishes for the future, by posting small sticky notes on several posters hanging on a side wall. All of these notes were recorded as part of the overall harvest of ideas.

To wrap up the table conversations and share collective discoveries, the meeting facilitator asked several harvest questions to encourage all participants to explore where their conversation had taken them, as a group. The harvest comments from the large group were collected on flipcharts. Participants were asked:

- What has been your “aha” moment so far?
- What is emerging?
- What can you already anticipate sprouting?
- What question, if answered, would shift us to the next level?

The final activity at the event was a request that each participant record a personal answer to the question, “Based on your experience today, what is the promise that you will make that contributes to the cure?” Individuals wrote their response on pink paper on which the question had been printed.

## **HARVEST THEMES**

A number of important themes emerged from the World Café event. The following list represents an attempt to organize ideas into major themes. (Readers of this report may wish to read the original harvest notes for additional insights.)

### **1. Increase Awareness through Education**

Participants strongly suggested the need for greater education, not only for survivors and their families, but also for whole communities. The group agreed that health education for girls—with emphasis on breast health—needed to begin early, with programs continuing into adolescence and adulthood. For example, one individual commented on the need for education and awareness of breast health from “babies at the breast” to infinity. Because more women in their twenties and thirties are facing risk of breast cancer than ever before, participants agreed that breast health must be a critical part of health curricula in public education at all levels. It was suggested that such education be directed towards men as well to raise overall awareness of the disease to promote opportunities for detection and treatment.

Education must extend beyond the classroom into the community. One participant suggested creating mother-daughter education and awareness programs, beginning in public schools, then branching out to other community settings. Another participant pointed to the success of the Kids Voting USA model, which teaches youth healthy voting habits by creating parallel “mock” polling stations side-by-side with actual polling stations to encourage parents and children to “vote” together. It was suggested that a similar program could be designed for women and their daughters, creating inter-generational learning and promotion of healthy

habits beginning in childhood that would carry into adulthood. Many agreed that effective breast health education should be frequent and varied in form, ranging from dissemination of personal testimonials to innovative community-centered activities. Specific suggestions included exercise groups, cooking classes, and a walking club at the mall for breast cancer survivors. Such programs could be goal-oriented (with goal attainment rewards such as mall coupons) to promote better overall health.

Finally, while it is natural—even expected—that hospitals and clinics take a significant role in educating women in breast health, participants emphasized that education must expand to other venues, settings and providers to achieve maximum coverage.

## **2. Change How We Communicate**

To increase awareness of breast health, education must be coupled with effective communication and marketing. According to World Café participants, there is a need to dramatically improve channels of communication among all stakeholders, and particularly in patient-provider and patient-insurer interactions. Participants agreed that the issue is systemic and that to improve communication, awareness of the problem must extend across professional and geographic communities. It is important, for example, that providers and advocacy organizations expand notions of community to reach out to those who are less visible or underserved, including the poor, ethnic minorities, and families in rural areas. Better communication and marketing to increase awareness of existing services and resources is paramount. One participant noted that groups such as the American Cancer Society or Susan G. Komen Affiliates have knowledge and resources, but that more must be done to help individuals and communities become aware of what these organizations can offer.

We must also find ways to communicate that can be as accurate as possible while empowering survivors. Survivors reported wanting “real answers and facts” in a timely way, which mirrored provider sentiments that “getting information to the cancer patient is really important.” Effective communication may also require the communities connected with breast cancer to address how we speak about the problem. One participant labeled the terminology of breast cancer as “too scary.” Positive language and vocabulary related to breast health and health in general might overcome fears that otherwise prohibit investment of people’s time and attention to their own health and well-being.

## **3. Improve Access to Diagnosis, Treatment and Cure**

It is tempting to sum up the issue of improving access as a resource deficiency problem. But to improve access, the group concluded, one must first be aware of the barriers that prevent effective screening, treatment and support and then understand *how* to apply *which* resources *where*. Participants identified examples of barriers as follows:

- *Transportation.* To get the help women need, they often need to travel significant distances for wellness checkups, screening, and treatment. Geographic barriers can create secondary problems, most obviously acquiring and paying for transportation;
- *Child Care.* Managing absence from home, including finding and paying for day care is sometimes prohibitive;

- *Low Income.* Lack of money or lack of awareness of opportunities for no- or low-cost screening and treatment is a barrier to breast health for some women. Free screenings are helpful, but some participants asked, “What happens when they have a positive diagnosis and need treatment? Who will pay then?” The problem of low income also magnifies other barriers such as transportation and child care;
- *Lack of Insurance.* The uninsured are among the most vulnerable, foremost because they are the least likely to seek screening and testing;
- *Navigating the System.* Understanding and navigating both the health delivery and insurance systems is a longstanding difficulty for many survivors. Even those with adequate resources report frustration in trying to receive answers to both medical and non-medical questions. Frustration can be amplified for those who lack resources;
- *Paying Bills.* Closely linked to the difficulty of navigating the system is the stressful matter of paying for health care. As one participant shared, imagine the frustration of receiving a bill which says “right off the bat I’m 45 days overdue and it was the first one I ever got!”
- *Cultural Factors.* The current models of health education and delivery do not necessarily appeal to women of different cultures in our communities. Better efforts must be made to appeal to women and families from a variety of backgrounds;
- *Stress.* Emotional stress and trauma often accompany women trying to access screening, undergo treatment, make medical and insurance and payments, and manage a household—let alone having to re-imagine one’s life after a positive diagnosis of breast cancer. As one survivor remarked, “I have had to work out issues between [the] medical system and insurance company myself and it is *very stressful* to deal with while currently going through treatment” [original emphasis]. Emotional support is not only paramount for women, but also in many cases for family members of survivors.

World Café participants were in agreement that resources *do* exist for diagnosis, treatment, and support, including through hospitals, clinics, advocacy organizations such as the American Cancer Society, and government agencies. Some suggested that more information about barriers to access would be helpful to understanding where and how resources could be applied most effectively. Accordingly, an important concern is how to empower people to take advantage of existing resources while simultaneously determining gaps in coverage where additional resources can be directed. Participants suggested during the large group discussion that a comprehensive survey of existing models, programs, and services was overdue.

#### **4. Expand Outreach**

Improving access goes hand in hand with effective outreach. The current network of breast health delivery systems, while improving, still does not reach all women and families. Some communities, or groups within communities, are underserved; examples in Central Wisconsin include Southeast Asian, Native American, and Latino/Latina populations as well as poorer and rural populations. Greater and more effective outreach to these populations is necessary. Participants agreed that the breast health community must develop programs that reach out to these and other underserved populations in culturally sensitive and appropriate ways. Hispanic and Hmong radio public service announcements were suggested. Whatever

the medium, education and awareness programs must find ways to bridge cultural divides by linking with culturally accepted practices in innovative ways. Rather than teaching people of other cultures the mainstream perspective, perhaps more effective coverage could be achieved by adjusting *our* understanding and expectations to meet the needs of underserved populations.

Effective outreach models and programs do exist. Mobile mammography clinics, such as those offered by Marshfield Clinic, have improved accessibility to screening across a large portion of Wisconsin. Experience suggests that women will accept screening if it can be conveniently available to them at their place of work or other location. New and better efforts at marketing are also needed. For instance, women in low-income families may not have easy computer access, but they may shop at Dollar Stores and Walmart, and sooner or later will fill their tanks at the gas station. Outreach efforts must leverage such opportunities to reach women wherever they are. The potential multiplying impact of outreach cannot be overstated. As one participant noted, “if one woman has a positive experience she will tell her co-workers” and friends. More efforts along these lines are needed because some women are clearly slipping through the cracks and participants agreed that they would like to see resources devoted to new and innovative ways to increase outreach.

## **5. Strengthen Advocacy**

Both during the table and large group discussions, participants spent considerable energy discussing the importance of strengthening advocacy for breast health generally and for survivors of breast cancer and their families specifically. Poignant personal stories from survivors were shared, leading to a persistent theme: even the most resolute survivors are overwhelmed at times on their paths to recovery, whether trying to navigate the complex medical or insurance systems or handling the pressures of supporting family while undergoing taxing treatment. As one table group observed, “doctors and nurses are forced to increase their productivity . . . but not patient support and information.”

The missing ingredient, many concluded, is strong and consistent advocacy for a woman and her family after diagnosis. Participants agreed that more resources are needed to create and/or energize advocacy organizations and health professionals to enhance support-related services. Most suggestions focused on the need for dependable one-on-one support. One participant poignantly stated, what is needed is “One person to ask, ‘What do you need?’” Beneficiaries of effective advocacy fervently agree. A survivor praised the help she received from a breast cancer “coordinator” for undertaking the seemingly mundane task of making appointments, emphasizing, “I couldn’t have done it without her!”

There was consensus that to be most effective, advocacy must attend women not just in the treatment phase, but must follow them through the long term healing process as well. To this end, several participants discussed the value of mentorship programs and other support models. Some lamented that an assortment of past programs had not endured. Others noted the success of current programs such as “Reach to Recovery” sponsored by the American Cancer Society. Participants noted that needs are also variable. A younger survivor expressed strong interest in connecting with younger women to whom she could more closely relate. Another noted that she wanted “to connect to cancer survivors who are 5 years out and are getting on with their lives. I don’t want to focus on the cancer, but on healthy living and connecting with women who are doing the same.”

Participants also acknowledged that there are many advocacy programs and resources currently available and warned that it would be a mistake to duplicate current efforts. The Well Woman program was cited as an example of successful advocacy through coordination.

But there was recognition that the program had gaps in some areas. To fill gaps in knowledge and in actual coverage, a powerful suggestion emerged that communities would benefit from a “warehouse” or database of organizations and resources, including listings of individuals who were willing to contribute time and services for all aspects of survivors’ (and their families’) needs, from carpentry skills to transportation and daycare help. As one participant put it, the community needs a similar concept to the “211 Directory” of community assistance for breast cancer survivors. Others recommended investment in a brick and mortar facility that would serve as a one-stop-shop, working in tandem with an online and telephone 211 program. Participants also wondered about creating a drug recycling program or donation center for unused prescriptions or chemo drugs that could be shared with those in need.

One final component of advocacy suggested by participants was to provide stronger lobbying to the state legislature to fund wellness programs. Although one participant helped educate the group by informing them of existing lobbying activities (specifically, by the Wisconsin Breast Care and National Breast Care Coalitions), another pointed out that more intense lobbying might be effective, especially in lean budget years.

**6. Improve Health Delivery through Simplification, Transparency, and Systems Thinking**

World Café participants recognized inconsistencies in effective breast health treatment and coverage for women. They also expressed the need for some rationalization and simplification of health care delivery and coverage for survivors. Some suggested the creation of community guidelines or standards for breast health, including screening, treatment, abatement of treatment, and so forth. These guidelines would require some standardization and would have to be made widely available online and through other accessible formats. To ensure that community needs are accurately accounted for, a needs assessment should be undertaken periodically (it was noted that SGK conducted such an assessment, but it is out of date). In addition, participants suggested that greater transparency about all phases of breast health care and costs would be helpful. For example, some wished that hospitals would make clearer the costs of a mammogram. It is confusing for some patients to delineate value between health care “specials” such as free mammograms on a designated day versus programs that provide discount mammograms during an entire month. Although the former might sound appealing, for example, the latter tends to generate better access to overall breast health and is likely to capture more working single mothers and others because of its flexibility. An even more daunting challenge is how to help women gain access to treatment *after* free or discounted screenings. There must be some kind of system response or mechanism in cases of positive diagnoses; otherwise, free or discounted screening programs are wasted

Considerable discussion centered on the need for better and timely information for survivors to help foster reasonable expectations. First and foremost, women need to understand treatment options. Closely following is the need to understand what to expect in terms of insurance coverage, return to work policies, and a variety of interrelated issues from transportation to household management. Advocacy is one answer, but even advocacy can be stymied by a system that is not structured to meet the real needs of individuals.

Café participants spent a great deal of energy discussing the need for a systems approach to better breast health and survivor care. They concluded that greater attention must be placed on improving understanding of the various components and systems that make up the breast health community. Only by examining screening, treatment, and recovery from a systemic perspective can lead to lasting improvement. Similarly, issues such as choosing appropriate and qualified providers, accessing required medications, and receiving appropriate treatment can only be understood by examining the relationship between health insurance programs, providers, and drug companies. These organizations provide services essential to women with breast cancer, but most retain agendas that are organization-centric. What is needed, some suggest, is some neutral entity—perhaps the Susan G. Komen Foundation and other advocacy groups—to moderate the inherent biases and proclivities of a system focused more on organizational competition than patient care.

World Café attendees suggested that serious efforts should be made to bring the system in line with the desires of most women: to effectively treat those diagnosed with breast cancer, support their recovery, and find a cure. To this end, many highlighted the need for integrated holistic care—not only to address the physical, but also the psychological and spiritual needs of breast cancer survivors. The key is to put survivors at the center of the system. Some specific suggestions emerged in light of this sentiment. First, map out existing assets and services along a comprehensive continuum of care. This service map could then be overlaid onto a map of who requires services and where they reside. Second, bring health care professionals, service-providers, and advocates together to discuss what services are available and how they might be networked or linked in rational ways to benefit survivors. Such a process would itself serve two purposes: a) encourage professional networking; and b) help professionals understand what services are available where and to use this knowledge to help patients. Third, design a system of systems, or at least promote greater integration of services, to create a survivor-centered model in which women are able to choose from within a variety of networked groups to receive treatment and other valuable support. In this manner, from a patient’s perspective, there might be a more seamless approach to screening, diagnosis, treatment and recovery. To be most effective, such a system would also allow non-medical entities to carry out vital roles in supporting breast cancer survivors, integrating medical and non-medical services in efficient and effective ways.

The UW-Madison Paul Carbone Center was mentioned by several participants as a model worthy of study. The care at this facility is recognized as exceptional, in part because employees (from doctors to maintenance staff) take a holistic, integrative approach to their work and to overall patient care. Structurally, the center serves as a one-stop-shop for women’s breast health and related needs. The Center also networks with survivor groups and takes a personal approach with “hugs and human contact.” In short, they encourage a caring team approach to meet the needs of the individual.

## 7. **Build Supportive Communities**

World Café participants reflected on the importance of building and strengthening community in at least two important ways: 1) improve communities of support for cancer survivors and their families; and 2) construct a broader community of breast cancer providers, advocates, and survivors that can improve overall diagnosis, treatment and long term care. The difference is a matter of degree. First, participants unanimously agreed that for the individual cancer survivor and her family, a support community is absolutely essential. One participant suggested that while the notion of community remains fundamental to effective long-term care, breast cancer survivors need a community independent of the medical realm: a community “for daughters, sisters, nieces, friends and survivors . . . people to bond with.” Family and friends often fill this role—sometimes to great effect. But even within supportive families, there are times when expectations are incompatible with reality. As one participant noted, “sometimes survivors are overwhelmed with reassuring their family . . . [they] need support from outside the family at certain trying times.” Unfortunately, inadequate or non-existent personal support networks remain an identified gap for many survivors. Several participants suggested that mentor programs and personal support from fellow survivors could fill an important void. Most acknowledged that existing programs remain underdeveloped and require more attention and resources.

Participants were united in their desire to form broader notions of community, or in other words, to “[b]uild opportunities for dialogue and collaboration.” A significant number of participants, for example, either wrote or made statements expressing their appreciation for the SGK-sponsored forum and their desire to continue building a breast cancer community of providers, advocates, and survivors. As one participant wrote, we should “[c]reate a society of practitioners, survivors, etc., that can meet periodically for best practices and that can continue beyond this meeting.” The best outcome of this type of broad community, observed one participant, would be a community that recognizes the gaps in effective screening, treatment and care, and then provides the resources and impetus to bring “people and agencies . . . together to solve” existing problems. But as bridges are built and community ties strengthened, some insist it is important not to duplicate existing efforts.

## REFLECTIONS

### **How Well Were Objectives Met?**

- 1) **Bring Stakeholders Together.** The purpose statement of the forum was to bring together people representing those affected by or impacting breast cancer, to learn, engage, inform and connect, and become a catalyst for action in the seven county Central Wisconsin region. The forum attracted 60 persons from across a wide spectrum of those affected by or impacting breast cancer, from survivors to advocates to health care practitioners. Attendees were identified as younger and older survivors, family members of survivors, doctors, nurses, educators, and advocates.
- 2) **Learn, Engage, Inform, and Connect.** Learning, engaging, informing and connecting were simultaneous and overlapping happenings at the World Café. Before, during and after the event, attendees were observed sharing personal stories and experiences,

networking, exchanging information, and engaging in joint problem solving. Structured and informal conversation frequently centered on improving the care and support of those diagnosed with breast cancer.

- 3) **Catalyzing for Action.** Catalyzing for action was an outcome important to the event Planning Committee. Evidence for such an outcome was indicated by the written responses to the final question at the forum: “Based on your experience today, what is the promise you will make that contributes to the cure?” In some cases, participants echoed the word “promise” by communicating a personal commitment such as, “I promise to create more programs . . . .” Though not requested, a number of participants volunteered their contact information to reinforce the connection and commitment they had made. There was also a promise of financial resources.

### **What Lessons Were Learned from the Process?**

- 1) **Creating Community.** The World Café methodology provided a framework for people to connect and engage. The carefully considered invitation process led to the convergence of diverse stakeholders in the breast cancer community in one room for several hours to address pressing breast health and survivor care. Attendees represented a microcosm of people who use, advocate or work within the larger breast health system. The Café questions, also carefully crafted by the Planning Committee, allowed the participant stakeholders to work together and envision options for collective action. Paramount to this process was that the attendees clearly viewed themselves as part of a community, a concept reinforced by the nature of the World Café event. Notes and comments from attendees clearly indicate that not only did they view themselves as part of a community, but they desired to *continue engaging* as a community.
- 2) **Achieving Common Ground.** A unique characteristic of the World Café is its tendency to cede control to participants and empower them through a minimally managed process. The model requires trust and faith that the people who attend are willing to act responsibly and collectively. More important, the model holds that the collective outcome will be greater than the sum of its parts. It is recognized that while World Café results are not necessarily predictable, they can nevertheless unify and inspire because they reflect the will of the whole as shared by the whole. True to form, the SGK-CWA event, culminating in the “harvest” of ideas, generated clear themes reported herein. These themes are remarkable in the sense that there was an enormous degree of consensus as to their importance.
- 3) **Continuing the Conversation.** There exist tangible outcomes from this event. These tangibles, in the form of tablecloth notes, post-it notes, and verbal expressions during the harvest (as recorded by note-takers), written promises, and even this report, express an anticipation and expectation that, at minimum, the conversation about treating and curing breast cancer in Central will continue. For this reason, as important as the World Café meeting and its immediate outcomes might be, it is perhaps even more important that a follow-up meeting be convened in the near future to fulfill participant expectations that the process of engagement will continue. Forum facilitators suggest that to strengthen the

tangible results of the meeting, future forums should be photographed to help communicate the vibrancy of the event as well as to help the conversation move to the next level.

- 4) **Engagement through Shared Experience.** After the event, several members of the Planning Committee expressed their surprise at how the event had affected them personally and had generated a range of emotions. Committee members who served as table hosts during the event also reported a high level of emotional interaction among participants. Event observers also noted the emotional content of many of the table discussions. Some table conversations began with powerful personal stories from breast cancers survivors. These stories created immediate bonds among table participants and provided fruitful avenues of discussion as health providers and advocates connected their knowledge and experience to the shared personal stories.

At one table, for example, a survivor shared her difficulties in receiving proper care and support after diagnosis. In fact, she reported still having questions for which she was seeking answers. Table participants listened respectfully, asked clarifying questions, and offered suggestions for future treatment (and other assistance). The initial story served as a springboard for broader discussion of what was working and not working in our health system. Health providers and advocates were able to sympathize while at the same time provide immediate information and feedback that helped the story-teller. Survivors felt supported and empowered by being listened to, while providers and advocates had opportunities to share knowledge in response to real personal challenges. Remarkably survivors, providers, and advocates could each tell a version of the same story, thus adding value to the whole.

Attending health providers expressed real gratitude at the opportunity to hear the unvarnished concerns of survivors, recognizing that professional roles often do not promote deep discussion or sharing of profoundly personal experiences. The personal nature of the conversations also added a sense of urgency to uncover barriers to effective breast health and to share ideas for improvement. In short, emotion was channeled towards a renewed purpose and vigor to share ideas on improving diagnosis, treatment and cure of breast cancer.

### **What Important Questions Emerged from the Event?**

- What specific barriers are preventing access to resources, diagnosis, treatment, and support?
- How do we better empower women with knowledge and access to resources to make wise and responsible choices?
- How do we encourage a systems approach to address the whole health of the individual?
- How do we continue to entreat health communities to come together to network and rationalize health delivery and care?
- How do we seamlessly integrate non-medical support into the treatment and long-term recovery programs of survivors?

- What models of effective treatment and care are worth emulating and where are new models needed?
- How do we improve outreach and advocacy to women in terms of screening, treatment, and long-term recovery care?

## CONCLUSIONS

Participants in the Susan G. Komen for the Cure Central Wisconsin forum held on September 16, 2008 created a significant shared experience. The group identified ideas for action and topics of relevance, grouped into seven emerging themes reflected in this report:

1. Increase Awareness through Education
2. Change How We Communicate
3. Improve Access to Diagnosis, Treatment and Cure
4. Expand Outreach
5. Strengthen Advocacy
6. Improve Health Delivery through Simplification, Transparency, and Systems Thinking
7. Build Supportive Communities

There is one additional theme that prevailed at the World Café and which pervaded the small and large group discussions. One participant health provider summarized it this way: “I feel that when a person gets a cancer diagnosis and the doctor or I take control of their case, the person wants to take some of that control back again by using holistic information and means.” From providers and advocates to survivors and supportive family of survivors, participants at the World Cafe expressed their collective desire for the *empowerment* of individuals. This should be no surprise given that it echoes the SGK mission “To save lives and end breast cancer forever by *empowering people*, ensuring quality care for all and energizing science to find the cures” [emphasis added]. A key question remains: How do we help women achieve empowerment at every stage of their lives, particularly in connection to breast health?

One obvious answer is for the Susan G. Komen for the Cure Central Wisconsin Affiliate to provide visionary leadership, part of which is to act as a convener and facilitator for the creation of a well-functioning breast health community in North Central Wisconsin. The World Café event was an excellent first step in this direction as it created a shared expression and anticipation—perhaps even an expectation—that, at a minimum, the conversation will continue. As one participant observed, “This format today is unique in that I can interact with patients versus just clinical talk with the client.” She concluded simply, “we need more of that.”

## **Addendum One**

### **Susan G. Komen for the Cure Central Wisconsin Affiliate Board Members**

Susan Ford-Hoffert, President  
Dr. Pamela Galloway, Vice President  
Maria Bruggink, Treasurer  
Gretchen Schultz-Thuot, Secretary  
Ellyn Fuchsteiner, Grants  
Bev Sartori, Events  
Karla Kurtz, Volunteers  
Julianne Fondell, Education  
Sally Gartmann, Communications  
Gerry Klein, Technology  
Susan Coleman, Education

### **Susan G. Komen for the Cure Central Wisconsin Affiliate Public Forum Planning Committee**

Judy Burrows (Chair)	Marathon County Health Department
Susan Coleman	BOD and Marshfield Clinic
Susan Ford-Hoffert	BOD and UMR
Pam Frary	
Dr. Pamela Galloway	BOD and Breast Center of Central Wisconsin
Linda Grilley	Aspirus
Sheri Holmes	Aspirus
Mandy Myszka	Marathon County Health Department
Gretchen Thuot	BOD and Integrity First Bank
Erin Zastrow	American Cancer Society

## Addendum Two

### World Café Reference Materials (Sample)

- Brown, J. and D. Isaacs (2002). *The World Café Presents Café to Go: A Quick Reference Guide for Putting Conversations to Work*. Mill Valley, CA: Whole Systems Associates.
- Brown, J., et al, (2002). “Strategic questioning: Engaging People’s Best Thinking.” *Systems Thinker* 13(9): 2-6.
- Herzig, M. and L. Chasin (2006). *Fostering Dialogue Across Divides: A Nuts and Bolts Guide from the Public Conversations Project*. Watertown, MA: Public Conversations Project.
- Vogt, E., et al, (2003). *The Art of Powerful Questions: Catalyzing Insight, Innovation, and Action*. Mill Valley, CA: Whole Systems Associates.