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COMMUNITY PROFILE REPORT 2015

SUSAN G. KOMEN®
MONTANA

EXECUTIVE SUMMARY

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Executive Summary

Introduction to the Community Profile Report

Komen Montana was officially formed in 1999 by a group of dedicated breast cancer survivors, breast health advocates and others who worked tirelessly as volunteers. In 1995, the first Susan G. Komen Montana Race for the Cure® was held to raise funds for mammogram vouchers for women across the State of Montana. In 2005, the Board opened an office in the capital city of Helena, home of the annual Race for the Cure®, and hired the first Executive Director in 2007. In June 2015, Komen Idaho and Komen Montana merged to form Komen Idaho Montana serving the 100 counties in both states.

The entire state of Montana is serviced by the Affiliate. Montana is the fourth largest state in total square miles (147,046) and is a rural and frontier state. The National Center for Frontier Communities ranks Montana as the 3rd most frontier state in the nation. Of the 56 counties in the state, 45 are considered frontier based on population density. Montana has one urban county (Yellowstone) and 10 rural counties, the remainder are frontier counties. The rural nature of Montana is clearly demonstrated by the fact that 440,939 citizens (44.6 percent) live outside of incorporated cities and towns, with 735,993 (76.0 percent) of the population living in areas classified as rural and frontier. According to America's Health Rankings, high geographic disparity within the state remains a significant challenge to the overall health of Montanans.

Montana's largest minority population is the American Indian and Alaska Native (AIAN) population. There are seven Indian Reservations in the State. In Montana, cancer remains the second-leading cause of death, with survival rates among AIAN falling even lower, due largely to late-stage diagnoses. Montana's AIAN population continues to have the poorest five-year cancer survival rates among all racial and ethnic groups, for all cancers combined. Education and screening awareness, lack of services and funding, underutilization of available services, transportation issues, and general social conditions associated with extreme poverty remain critical gaps in prevention, screening, diagnosis and treatment. On average, AIANs residing on Indian Reservations remain one of the poorest groups in America.

Over the past 20 years, Komen Montana has distributed 70 community-based grants totaling more than $1.5 million. The impact of projects funded by community grants has been substantial both on an individual and a community basis. Grant funding has been used to provide free or low-cost screening mammograms, advanced diagnostic exams, survivor support services and distribution of education materials to tens of thousands of Montanans. A testimonial of the positive impact of grants is the May 2013 Women 4 Wellness Health Fair in Pablo, Montana, on the Flathead Reservation. Women who attend often wait for this event, where free breast exams and mammograms are offered, to seek breast cancer screening. At the 2013 event, seven women were diagnosed with breast cancer - seven women diagnosed in one day.

Another effective collaboration with tribal representatives was the formation of an American Indian Tribal Coalition, called b.r.a.v.e., Building Resilience Awareness and Vision through

Education, in 2013 through 2015 that resulted in development of cultural guides and breast cancer education brochures targeting this high-need population.

Purpose of the Community Profile Report

The Community Profile Report evaluates key quantitative data pertinent to the evaluation of how breast cancer affects Montana citizens; evaluates what resources will provide education, screening, diagnosis, treatment and survivorship needs for the population as a whole; and identifies counties with the greatest need of services. Additional examination of qualitative input provides necessary insight for the evaluation of needs as determined by the citizens and providers themselves.

Together, these key pieces of the Community Profile provide Komen Montana Board of Directors with the best available data to design the Affiliate's operational plan, particularly in establishing focused granting and educational priorities. The Community Profile establishes policy priorities to:

- Align strategic and operational plans
- Drive inclusion efforts within the state
- Drive public policy efforts
- Establish direction for marketing and outreach
- Strengthen sponsorship efforts

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

A review of national statistics related to breast cancer in Montana lacked measurable or available data for rural Montana counties that have high rates of poverty, increased AIAN populations, but low populations overall for the county. There are no health indices that typify access to care in rural and frontier Montana communities. There are many standard health indices used to rank and monitor health in an urban setting that do not translate as accurately in rural and frontier areas. In the absence of sufficient health indices for rural and frontier communities in Montana, utilization of available data is done with an understanding of access to care in rural and frontier Montana communities and barriers of disease surveillance in this setting.

Key data in the categories of incidence rates, death, poverty and screening mammography are required to adequately assess the impact of breast cancer in Montana communities. The Community Profile Team recognized that some data vary considerably across AIAN geographic locations so Komen Montana contracted with the Montana Office of Rural Health (MORH) to gather available state level data for establishing priority and target community selection.

The MORH staff established valid selection criteria to identify five communities representing AIAN statewide. Criteria used includes (A) geographic region, (B) target population of Indian Reservations and AIAN populations, (C) high incidence rates of breast cancer per 100,000 women, (D) county level population of AIAN populations, (E) discrepancies in data comparison, and (F) poverty levels.

The Komen Montana Quantitative Data Report (QDR) identified AIANs as the second largest race in the state. Individuals in areas with higher concentrations of AIANs have large gaps in the availability, utilization, and distance to providers when compared to other areas.

For this reason, the Community Profile Team focused on these counties to more closely assess breast cancer statistics in rural communities that have AIAN reservations within their counties. In order to assess the burden of breast cancer statewide, to clarify conflicting data, and to supplement missing data, additional selection criteria were used to identify priority communities.

In addressing the concerns about the lack of health indices, the additional data looked specifically for quantitative data measuring and/or providing:

- Availability of and access to mammography screening facilities in Montana communities
- Trends in breast cancer screening of Montana populations including AIANs
- Input/supplementation for limited or missing data measures in the Healthy People 2020 Forecasts
- Poverty levels for selected races by state

Using national surveillance measures, the Komen Montana QDR identified the following counties as the highest priority:

1. Gallatin County (population: 89,824)
2. Hill County (population: 16,454)
3. Missoula County (population: 107,320)
4. Park County (population: 16,189)
5. Rosebud County (population: 9,190)
6. Sanders County (population: 11,034)
7. Stillwater County (population: 8,687)

Based on the additional analyses performed by MORH and the Community Profile Team, Komen Montana chose eight counties and respective tribes as the highest priority areas. In three instances, neighboring counties with similar health service systems and population were combined into one priority community.

1. Roosevelt County (Fort Peck Indian Reservation) – Poplar, MT
2. Big Horn County/Rosebud County (Crow Indian Reservation/Northern Cheyenne Indian Reservation) – Crow Agency, MT/Lame Deer, MT
3. Glacier County (Blackfeet Indian Reservation) – Browning, MT
4. Lake County/Sanders County (Flathead Indian Reservation) – Pablo, MT
5. Hill County/Blaine County – (Rocky's Boy Indian Reservation/Fort Belknap Indian Reservation) – Box Elder, MT/Harlem, MT

Health System and Public Policy Analysis

In order to assist Montana women with entry into and thorough involvement in the Breast Cancer Continuum of Care (CoC), Komen Montana has analyzed strengths that facilitate participation in the CoC model, weaknesses that may impede successful access to and application of the CoC, and key mission-related partnerships in selected target communities across the state. Strengths and weaknesses noted in these priority communities are strikingly similar with some variation in distances traveled for breast cancer care along the continuum. The priority county communities of Bighorn and Rosebud, Glacier, Hill and Blaine, Lake and Sanders, and Roosevelt share the following strengths and weaknesses:

Strengths:

- availability of health care provider (HCPs) to perform general screening examinations
- health care organizations that are culturally-sensitive for AIAN population
- IHS, CAH,VA and health center availability
- established referral networks within and outside communities
- assistance with financial and transportation for health care purposes
- mobile mammography services via out-of-community resource
- qualified and established support personnel in key health care sites

Weaknesses:

- lengthy travel distances to screening, diagnostic, and treatment centers
- increased levels of poverty which limit healthy lifestyle choices and access to transportation services to screening, diagnostic, and treatment centers
- limited diagnostic services in-county
- no certified cancer treatment facilities in-county
- no specific breast health navigation for diagnostic or treatment in-county
- limited AIAN tribal-specific health care educational material
- increased educational needs, for both patients and HCPs, concerning breast health and breast cancer screening practices

All five target communities lack facilities accredited by or as an American College of Radiology Breast Imaging Center of Excellence, an American College of Surgeons National Accreditation Program for Breast Centers, an accredited National Cancer Institute designated cancer center or a facility with American College of Surgeons Commission on Cancer accreditation. Regional health care general screening needs are facilitated by community-based health care organizations including rural health care centers, Critical Access Hospitals (CAH), Indian Health Service ((HIS) clinics, Veterans Administration (VA) clinics, county health departments and private health care providers. While these providers contribute significantly to general health care needs, cancer screening and treatment is not readily available in all of these communities.

The largest financial providers of breast cancer screening services in these communities are federal organizations whose funds are controlled by legislative action. The Affordable Care Act, through the establishment of health centers and rural clinics, the NBCCEDP, and the VA and

IHS health services provide vital, in some cases the only, health care services within target communities. Komen Montana will work with Montana legislative representatives, both state and federal, to ensure that the funding for these services is maintained and adjusted as need is verified. Sharing of the Community Profile document will increase awareness of community needs and the Affiliate's efforts to address those needs.

Qualitative Data: Ensuring Community Input

The qualitative data collection component of the Community Profile focused on five key questions or variables regarding breast health: overall community health or general health, availability and awareness of services, education and outreach, the role of social support, and utilization of breast health services. Basic demographic data including gender, age, and race/ethnicity were also collected.

Surveys and focus groups were used to collect qualitative data for the Community Profile. The survey instrument and list of focus group questions were developed by MORH staff with guidance from Komen Montana. Staff members from MORH conducted the data collection and implemented protocols for the surveys and focus groups after receiving approval from Tribal review boards to conduct the surveys on reservations. Surveys were an effective method to collect data because surveys could reach more people for a larger sample size and people feel more comfortable sharing information through an anonymous survey. Focus groups were also held in several of the target communities to capture additional detailed responses and in-depth explanations about breast health-related issues in the community. Combining the two methods provides balanced view points and a more complete account of the key variables that were identified.

The counties and Indian Reservations encounter unique challenges in accessing breast health education, outreach, and utilizing breast health screening, diagnostics, and treatments. Many similarities exist among rural Montana counties and Montana Indian Reservations; however, each community and tribe requires different resources and services to meet the needs of their communities with a high dependence on services from larger communities in close proximity. It is important to plan strategies that are tailored to each county's individual culture, customs, and to the resources available in their community.

Further resources and outreach for breast cancer are needed to meet the needs of the community and increase early detection of breast cancer to improve rates of breast cancer survival in these Montana counties.

Mission Action Plan

The Target Communities recommended by Komen Montana involve geographic sites that include one of the seven AIAN reservations in Montana. Based on results of the QDR, Health Systems and Public Policy Analysis (HSPPA), and the Qualitative Data Collection analysis, the Community Profile Team determined that the problems and needs associated with the key elements under consideration vary little between target communities. Therefore, the

problem/need statements, priorities, and objectives will represent the action plan for all target communities.

Problem Statement: AIAN population in Roosevelt County (Fort Peck Indian Reservation), Big Horn County/Rosebud County (Crow Indian Reservation/Northern Cheyenne Indian Reservation), Glacier County (Blackfeet Indian Reservation, Lake County/Sanders County (Flathead Indian Reservation) and Hill County – (Rocky's Boy Indian Reservation) have greater disparities in, and barriers to, access and utilization of breast cancer screening services. These include limited availability of breast cancer education, screening, diagnostic and treatment services; transportation and financial barriers, particularly low income levels and lack of affordable insurance coverage; and limited availability to cultural sensitivity for AIAN women seeking breast cancer screening services.

Priority: Increase support for evidence-based breast cancer/breast health education and advocate for increased funding for culturally competent breast cancer screening, diagnosis and treatment among AIAN in Roosevelt County, Big Horn County/Rosebud County, Glacier County, Lake County/Sanders County, and Hill County.

- *Objective 1:* By 2020, promote and/or participate in annual education forums in each target community utilizing AIAN community representatives, health care providers and breast health advocates to increase evidence-based education concerning breast cancer mammography screening and clinical breast exam guidelines.
- *Objective 2:* In FY 2017, establish meaningful collaborations with the Montana Cancer Coalition (MTCC) and its regional representatives and sponsors of AIAN community health fairs to increase availability and distribution of Komen-sponsored, culturally competent educational material for health fair attendees in each of the target communities.
- *Objective 3:* In FY 2016 and FY 2017, provide continued support of the b.r.a.v.e (building resilience, awareness and vision through education) Coalition education efforts by promoting avenues to increase funding resources for production of culturally sensitive breast cancer screening material in each of the target communities.
- *Objective 4:* Continue representation and collaboration with the Montana American Indian Women's Health Coalition (MAIWHC) of MTCC and the b.r.a.v.e. Council to provide culturally competent outreach efforts in the target communities.
- *Objective 5:* By 2018, Komen Montana's grant RFA will list a key funding priority for evidence-based education and screening programs to encourage applications from organizations that serve the five target communities.
- *Objective 6:* By FY 2016, become a partner in the Montana Healthcare Alliance to promote Medicaid Expansion implementation and increase awareness of available health care programs for low-income citizens in each of the target communities.

Problem Statement: AIAN populations in Roosevelt County, Big Horn County/Rosebud County, Glacier County, Lake County/Sanders County, and Hill County lack sufficient support for care navigation and are required to travel lengthy distances to seek tertiary care for diagnostic examinations and treatment.

Priority: Increase availability and collaboration with culturally competent patient navigators to decrease barriers for AIAN women in each of the target communities who require referral to tertiary centers for breast cancer diagnosis and treatment.

- *Objective 1:* By January 2017, hold two state-wide grant writing workshops, held in central locations, to include representatives of the b.r.a.v.e. group and other AIAN community leaders.
- *Objective 2*: By FY 2017, assist in development of new grant mechanisms to supplement existing navigation services to provide services for AIANs in target communities.
- *Objective 3:* From FY16-FY19, annually co-sponsor state-wide provision of evidence-based, culturally competent education for nurse and patient navigators who serve target communities.
- *Objective 4:* By January 2017, identify and train at least three breast cancer advocate volunteers to develop and serve on a Public Policy committee to educate legislators concerning target community breast cancer data, health care access, and need for coordination of care and health care related funding in target communities.

Disclaimer: Comprehensive data for the Executive Summary can be found in the 2015 Susan G. Komen® Montana Community Profile Report.