

# Executive Summary

## **Introduction to the Community Profile Report**

The Inland Empire Affiliate of Susan G. Komen® was founded in 1996 in Temecula, California. In 1998, the Inland Empire Affiliate was incorporated and pledged that it would do all it could to provide needed resources and improve breast health/breast cancer in the communities within the area of Riverside and San Bernardino Counties. In 1999, the Affiliate held its first Susan G. Komen Inland Empire Race for the Cure®. In 2009, the Affiliate opened the Susan G. Komen Inland Empire Breast Cancer Resource Center located in Rancho Mirage, California. The Komen Promise is to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find the cures is supported by many dedicated individuals and community partnerships wanting to make a difference.

Seventy-five percent of the net funds raised by the Affiliate remain in the Inland Empire to provide breast health education programs and community grants to nonprofit organizations that offer education, screening, diagnostic services and treatment support programs, while the remaining 25 percent supports breast cancer research. Since the 1999 inaugural Komen Inland Empire Race for the Cure®, the Affiliate has funded more than \$6.4 million in local community grants to meet the Inland Empire breast health needs for the uninsured or underinsured residents, and over \$2.3 million to the Susan G. Komen® Research and Training Grants Program.

The Inland Empire Affiliate serves more than 4.3 million people residing in Riverside and San Bernardino Counties, hosting 27,000 square miles of diverse geographic terrain from mountains and valleys to below sea level in the desert. The majority of the population is concentrated in the southwestern area of both counties. Many miles of the service area are national parks, military bases and desert.

The Inland Empire Affiliate was the recipient of the 2008 and 2011 Service/Charitable Organization of the Year by the Temecula Valley Chamber. This award recognized the Affiliate's generosity and philanthropic efforts that benefit many women and families throughout the community. Furthermore, the Affiliate has received various recognitions from local cities and elected officials throughout the years.

Advocacy plays a crucial role in the Inland Empire, state of California, and the U.S., where the Affiliate serves as a committed partner with other community partners, Komen Affiliates, and policy makers to ensure access to services and continued research funding for breast cancer.

The Affiliate participates in the local state cancer coalition, Inland Empire Access to Cancer Care Coalition (IEATCCC), working with various hospitals, businesses and organizations to address the cancer care needs of the region and the state as a whole. Furthermore, the Affiliate hosts the region's only Breast Health Collaborative (BHC), comprised of hospitals, businesses and organizations providing breast health services in the Inland Empire. Together, both the IEATCCC and BHC are imperative to leveraging partnerships and resources to meet the breast health needs of the region. As the leading breast cancer organization, Komen Inland Empire strives to integrate best practices, funding opportunities, and field knowledge among community health professionals, health systems, breast health and cancer organizations, as well as community members.

In order to fulfill our Promise, a Community Profile assists the Affiliate by identifying communities facing breast health/breast cancer disparities. Through analyzing the gaps in breast health/breast cancer services and programs, as well as barriers to accessing breast

health care, we are able to understand community needs, develop objectives to address community needs, and leverage partnerships, funding, as well as resources to fulfill the needs of our communities. The Community Profile serves as a “roadmap” for the Affiliate’s education, outreach, community grant funding priorities, and advocacy strategies. Furthermore, the Community Profile is relevant to the overall strategic planning activities of the Affiliate. Finally, the Community Profile provides an analysis of community data, as well as the voices of those residing in the communities we serve.

The Community Profile is used in various capacities by the Affiliate to address the breast health needs and concerns of the community. It is further used to inform health care professionals and systems, community organizations, governments, and community partners about the breast health needs of the region, and assist in developing viable, community-based solutions to fulfill those needs as a region.

### **Quantitative Data: Measuring Breast Cancer Impact in Local Communities**

In order to provide focused target communities, this report uses the Medical Service Study Areas (MSSAs) as the unit of analysis. Based on these criteria, and on the Quantitative Data Report findings, the three following target communities are identified (presented in numeric order):

- MSSA 128 (Riverside County) includes the communities of Arabia, Coachella, Desert Beach, Flowing Wells, Indio South, La Quinta East, Mecca, Oasis, and Thermal
- MSSA 145.2 (San Bernardino County) includes the communities of Adelanto, Phelan, Pinon Hills, and Victorville
- MSSA 151g and MSSA 151k (San Bernardino County) includes the communities of Highland, Muscoy and San Bernardino

The Quantitative Data Report identified that the communities within MSSA 128 are extremely impoverished, and nearly half of residents lack a high school education. Furthermore, nearly a fourth of the population residing in these communities are unemployed, lack health insurance and are medically underserved. The majority of the population in MSSA 128 is Hispanic/Latina and it has been noted that more than a quarter are considered to be linguistically isolated and foreign-born.

The MSSA communities of MSSA 145.2 and MSSA 151g and 151k indicate that Black women in these communities have higher breast cancer incidence rates, late-stage incidence rates, and death rates than their White counterparts. In addition, these communities are considered to be impoverished, with low education rates, high unemployment rates and a large percentage indicated as being uninsured or underinsured, as well as considered medically underserved. Furthermore, language barriers to receiving healthcare have been identified as well in these communities.

### **Health System and Public Policy Analysis**

The breast cancer “continuum of care” (the continuum) defines the best practice for how an individual should move through the health system to be screened for breast cancer, receive any necessary diagnostic care, get treatment if breast cancer is diagnosed, and receive follow-up care after treatment. The best case: individuals move through the continuum quickly and seamlessly, receiving timely, quality care to ensure the best outcomes.

The continuum is also used to: 1) assess and understand why some individuals never enter or delay entry into the continuum; 2) uncover gaps in service availability; 3) identify barriers faced; and finally 4) figure out what can be done to address those gaps and barriers.

However, finds from the Health System and Public Policy Analysis indicate several strengths and weaknesses of the continuum of care in specific communities:

- **MSSA 128**, in Riverside County, includes the communities of Arabia, Coachella, Desert Beach, Flowing Wells, Indio South, La Quinta East, Mecca, Oasis, and Thermal. There are approximately eleven community health centers offering breast health screening services. All of these facilities provide clinical breast exams, a fewer number also provide screening mammograms and/or offer referrals for mammograms. However, only two facilities provide any diagnostic services, treatment services and/or support services. There is only one hospital in this area; however it does not offer patient navigation services. Another weakness identified, is that none of the facilities maintain quality of care indicators. It should be noted that this is considered a rural community of a large size. Furthermore, access to transportation services is severely limited. To strengthen collaboration and community partnerships in this target area, the Affiliate will reach out to community and business leaders, community health centers and imaging centers to introduce Komen's mission, provide a primer on the services available and begin to identify potential programs to bridge the barriers to care that have been uncovered.
- **MSSA 145.2**, in San Bernardino County, includes the communities of Adelanto, Phelan, Pinon Hills, and Victorville Northwest. The area's greatest strength is that it contains six centers for breast health and one hospital. However, not all of the breast health centers offer clinical breast exams and/or mammography; all other resources refer out for mammogram screenings. Three of these facilities offer diagnostic, treatment and/or support services for breast cancer; and none maintain quality of care indicators. It should be noted that this is considered a rural community of a large size. Furthermore, access to transportation services is severely limited. To strengthen collaboration and community partnerships in this target area, the Affiliate will reach out to community and business leaders, community health centers and imaging centers to introduce Komen's mission, provide a primer on the services available and begin to identify potential programs to bridge the barriers to care we have uncovered.
- **MSSA 151g and 151k**, in San Bernardino County, includes the communities of Muscoy, Highland, San Bernardino East and San Bernardino Central. This region contains thirteen community health centers, three hospitals and three imaging centers. The area has at least one resource for each step of the continuum of care. Only one facility maintains one quality of care indicator. While having a resource for every step of the continuum of care is a great benefit, there is still only one resource for treatment services and one resource for support services in this target area (a former Komen Inland Empire grant recipient). It would be ideal to have more than one option for the size of the population the facility serves. The variety of resources may be greater than other target communities, but the need is greater in this area as well. The Affiliate intends to strengthen collaboration and community partnerships in this target area, the Affiliate will reach out to community and business leaders, community health centers and imaging centers to introduce Komen's mission, provide a primer on the services available and begin to identify potential programs to bridge the barriers to care we have uncovered.

In addition to the priority communities discussed, further findings from the Health Systems and Public Policy Analysis indicate that the Affiliate service region throughout Riverside and San Bernardino Counties face several other barriers to care. The majority of the Affiliate service region is considered largely rural, breast health services are primarily located in the western portion of the Affiliate service area and thus transportation to access breast healthcare services is a primary barrier to care for the majority of rural communities. Furthermore, financial assistance remains a barrier to care throughout the 27,000 sq. mile service area, as only one financial assistance program for breast cancer patients is available that serves the entire service area. Furthermore, state and federal programs for breast cancer screening, detection and treatment also impact constituents residing in Riverside and San Bernardino Counties. In addition, last resort safety net programs may be available for California residents that meet specific criteria. The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) supports the provision of the following breast cancer services: clinical breast exams, mammograms, and diagnostic testing for women whose screening outcome is abnormal, as well as referrals to treatment. The program is supported by the Centers for Disease Control and Prevention (CDC), which provides a federal grant to each State. The California state program is named Every Woman Counts (EWC).

In California, EWC has a payer of last resort requirement, which exhausts all other possible payers before EWC (such as California's Low Income Health Program (LIHP – through a Medicaid Demonstration Waiver). However, EWC does not cover medically-necessary diagnostic MRIs certain biopsy services, as well as BRCA testing.

Treatment is provided to eligible individuals through the Breast and Cervical Cancer Treatment Program (BCCTP). The federal BCCTP provides full-scope Medi-Cal to eligible women who meet all the federal criteria. However, there are specific limitations to the state and federal treatment programs, including immigration status, permanent residency, gender, rediagnosis, and limited access to breast health providers.

While much excitement has surrounded the Affordable Care Act, Medicaid expansion, and the roll out of the healthcare marketplace, a lot remains undetermined in terms of quality, access and utilization for residents in the Inland Empire and the MSSA communities discussed above.

### **Qualitative Data: Ensuring Community Input**

The Qualitative Data Report further supplements the identified priorities within the target communities within Riverside and San Bernardino Counties. Through key informant interviews, focus groups and document review, it has been noted that financial assistance, insurance/access to care, culture, transportation and survivorship are barriers within the targeted communities. The financial impact of breast cancer on middle and low-income individuals is a significant barrier to care and quality of life long-term. Furthermore, access to care has been identified as extremely limited for those that are uninsured and underinsured, even under the state's Medicaid program, Medi-Cal, and indicates that late-stage diagnosis is more prevalent, as well as a decreased chance of survival.

Transportation remains a common theme throughout the sections of the Community Profile, as the Affiliate service region is more than 27,000 square miles. The Qualitative Data Report indicates that transportation is a serious barrier to care throughout the continuum of care, from accessing screening to treatment services. Survivorship also is a key concern in the Qualitative Data Report, with limited access to patient navigation, education surrounding healthy lifestyles,

and future implications of treatment affecting health. However, the Qualitative Data Report outlines that family and friend support was imperative throughout treatment.

Culture was also addressed as a barrier to care, as breast cancer is often not a topic of conversation in some cultures, specifically in some Hispanic/Latina and African-American communities. Cultural beliefs and behaviors are also identified as being a barrier and delay in accessing screening and treatment due to religious beliefs, care delivery prejudices, and pessimistic expectations of survival.

Overall, the communities within MSSA 128 indicate that Hispanic/Latina communities are most at-risk and face issues related to access to care for screening, diagnostic, treatment and support services, as well as transportation and financial assistance. Programs should further address cultural and survivorship needs, in addition to overall breast health education.

Overall, the communities within MSSA 151g and 151k indicate that African American communities are most at-risk and face numerous issues related to access to care for screening, diagnostic, treatment and support services, as well as transportation and financial assistance. Programs should further address cultural and survivorship needs.

### **Mission Action Plan**

These priorities were developed to address the needs of MSSA 128 and MSSA's 145.2/151g/151k, and as identified throughout the Community Profile process. By addressing these specific priorities, a measurable impact to reduce disparities within the targeted community is expected in years to come. The Mission Action Plan below is developed using the following structure to outline problems/needs, priorities, and objectives for each MSSA community.

#### **MSSA 128**

- Hispanic/Latina communities in MSSA 128 lack health insurance and are medically underserved.
  - Improve access to breast health services along the continuum among women age 40 and older in MSSA 128.
    - By 2017, collaborate with at least three providers that serve Hispanic/Latina women to provide culturally competent breast health services and community-based patient navigation services for residents of MSSA 128.
- Communities within MSSA 128 have very limited access to culturally competent breast health education.
  - Increase access to culturally competent breast health education among Hispanic/Latina women in MSSA 128.
    - By 2016, launch an Affiliate-based culturally-competent breast health education program, addressing the needs of Hispanic/Latina women in MSSA 128, as measured by reaching 1,500 Hispanic/Latina women through education and outreach.
    - By 2017, expand Affiliate-based Prayer in Pink, faith-based breast health education and resource program in MSSA 128 to improve breast health education and knowledge of local resources to 1,500 residents annually.

- Communities within MSSA 128 have extremely limited access to culturally competent breast health care services including screening, diagnostic and treatment, especially related to the lack of insurance, transportation, and financial assistance.
  - Reduce barriers to care by addressing transportation and financial assistance needs in MSSA 128.
    - By 2017, develop new, collaborative relationship with at least one community-based organization to provide transportation services for residents of MSSA 128.
- Communities within MSSA 128 lack culturally competent survivorship programs and patient navigation.
  - Increase access to culturally competent breast cancer survivorship and patient navigation services for women in MSSA 128.
    - By 2017, develop new, collaborative relationships with at least three community-based organizations whose target population is Hispanic/Latina women in MSSA 128 to engage in culturally competent survivorship services.

### **MSSA's 145.2/151g/151k**

- African American communities in MSSA 145.2/151g/151k have higher than average breast cancer incidence rates, late-stage incidence rates, and death rates.
  - Increase knowledge regarding breast health, access to screening and breast health resources to potentially reduce the chance of late-stage diagnoses within African American women residing in MSSA's 145.2/151g/151k.
    - By 2017, expand Affiliate-based Circle of Promise program to address cultural and community resource education needs for 1,000 African American women in MSSA's 145.2/151g/151k.
    - By 2017, expand Affiliate-based Prayer in Pink, faith-based breast health education and resource program in MSSA's 145.2/151g/151k to improve breast health education and knowledge of local resources to 5,000 residents annually.
- African American communities in MSSA 145.2/151g/151k have limited access to culturally competent breast health care services including screening, diagnostic and treatment, especially related to the lack of insurance, transportation, and financial assistance.
  - Improve access to culturally competent breast health services along the continuum of care among African American women age 40 and older in MSSA's 145.2/151g/151k.
    - By 2017, collaborate with at least three providers that serve African American women to provide culturally competent breast health services for residents of MSSA's 145.2/151g/151k.
  - Reduce barriers to care by addressing transportation and financial assistance needs in MSSA's 145.2/151g/151k.
    - By 2017, develop new, collaborative relationship with at least one community-based organization to provide transportation services for residents of MSSA's 145.2/151g/151k.
- Communities within MSSA 145.2/151g/151k lack culturally competent survivorship programs.

- Increase access to culturally competent breast cancer survivorship services for women in MSSA's 145.2/151g/151k.
  - By 2016, develop new, collaborative relationships with at least three community-based organizations whose target population is African-American women in MSSA's 145.2/151g/151k to engage in culturally competent survivorship services.

### **Overall Affiliate Service Region**

- Affiliate service region of San Bernardino and Riverside Counties have limited access to care related to lack of transportation and financial assistance.
  - Reduce barriers to care by addressing transportation and financial assistance needs throughout Affiliate service region.
    - Beginning with the FY2017 Community Grant Request for Application, programs that assist with the financial needs of accessing breast health services and treatment support for residents of San Bernardino and Riverside Counties will be a funding priority.
    - Beginning with the FY2017 Community Grant Request for Application, programs that provide transportation services to and from breast health service appointments for residents of San Bernardino and Riverside Counties will be a funding priority.
- Residents of the Affiliate service region that are enrolled in EWC lack access to medically-necessary diagnostic MRIs, BRCA testing, some diagnostic biopsy services, and breast surgeons/general surgeons.
  - Improve access to medically-necessary MRI, biopsy services, and breast surgeons/general surgeons for EWC and Medi-Cal enrollees residing in Affiliate service region.
    - By 2019, collaborate with California Komen Affiliates, EWC program and Medi-Cal to address disparities in breast cancer diagnostic services for EWC enrollees to improve timely access to care by qualitative measurement of meeting minutes and policy changes to EWC.
- Residents of the Affiliate service region that are enrolled in Medi-Cal may lack access to a local breast surgeon/general surgeon.
  - Improve access to medically-necessary MRI, biopsy services, and breast surgeons/general surgeons for EWC and Medi-Cal enrollees residing in Affiliate service region.
    - By 2019, collaborate with California Komen Affiliates, EWC program and Medi-Cal to address disparities in breast cancer diagnostic services for EWC enrollees to improve timely access to care by qualitative measurement of meeting minutes and policy changes to EWC.
- Residents of the Affiliate service region that are enrolled in the NBCCTP may lack access to additional breast cancer treatment when rediagnosed with breast cancer after initial treatment period has ended.
  - Improve access to treatment services for rediagnosed patients ineligible for NBCCTP enrollees residing in Affiliate service region.
    - By 2019, collaborate with California Komen Affiliates and the BCCTP program to address disparities in breast cancer treatment for rediagnosed

breast cancer patients to improve timely access to care by qualitative measurement of meeting minutes and proposed policy changes to BCCTP.

- Male residents within the Affiliate service region are not eligible for diagnostic services through neither EWC, nor treatment for breast cancer through the BCCTP.
  - Improve access to diagnostic services and treatment programs for men residing in Affiliate service region.
    - By 2019, collaborate with California Komen Affiliates, grant recipients, EWC, and BCCTP programs to address disparities in breast cancer diagnosis and treatment for men by qualitative measurement of meeting minutes and proposed policy changes to EWC and BCCTP.