MORE THAN PINK®

FY19 IMPACT REPORT

SUSAN G. KOMEN PUGET SOUND

Komen Puget Sound has been expanding access to breast healthcare for more than 21 years. Our community programs foster partnerships with measurable health impacts through education, outreach, advocacy and grants. We reach individuals across Puget Sound with lifesaving breast health services. This year’s Community Impact Report helps tell our story.
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Our work at Komen Puget Sound centers on two key areas – creating health equity throughout the state of Washington and supporting breakthrough research that can help find new treatments and lead us closer to a cure. These two areas support Susan G. Komen's overall Bold Goal - to reduce the nation's 40,000 breast cancer deaths by 50 percent by 2026.

Every four years, Komen Puget Sound undergoes an intensive research process to determine our programming and funding priorities for the next four years. This research, designed to provide an evidence base for guiding our investments, focused on those communities that have the greatest level of breast cancer disparities here in the Puget Sound region.

In 2015, we completed our research and determined our priorities through 2020. The results of this study are available on our website: Strengthening Partners for Community Impact. This report serves as the basis for our time and financial investments, including our own engagement with communities. Our research found high levels of disparity in the Greater Seattle Metropolitan Area and Grays Harbor County.

In addition, the research revealed that women of color were adversely affected by breast cancer outcomes. In particular, American Indian/Alaskan Native, Black/African American, Pacific Islander and Hispanic women have higher levels of disparities when compared to other groups of individuals in our community, including members of the LGBTQ community. These disparities are a direct result of the lack of equity within our healthcare system and society.

RACE ISN’T A RISK FACTOR. RACISM IS.

We know that our diverse community needs innovative programs to respond to patients and eliminate barriers to care. To meet these needs, we participate in community organizing and empowerment efforts, advocate for policies to increase healthcare access, lead coalitions and partnerships, convene events and programs and support community-based
organizations throughout the Puget Sound region. **Komen Puget Sound is on a mission to build equity and social justice for all.** We do this by (1) developing programs tailored to address community barriers, (2) understanding and dismantling systems of power and racial injustice and (3) focusing on communities where the need is greatest. Specifically, Komen focuses on:

- Increasing awareness of breast health services and screening guidelines and empowering patients to access care;
- Improving access to healthcare through insurance navigation and reducing barriers to care (e.g., providing transportation, child care or language interpretation);
- Ensuring quality healthcare services by training healthcare providers on culturally humble care provision;
- Influencing the public and policy landscape to keep breast health on the agenda and
- Raising funds to support partners and breakthrough research.

**PART 1: HEALTH EQUITY PROGRAMS**

**Mammogram Screenings and Health Education**

We know that many women do not have access to adequate healthcare. One way to address this need is to bring the healthcare to women, rather than asking women to come to care. **We meet women where they are.**

This year, **Komen Puget Sound organized and convened six family health and safety fairs to improve the health of communities residing in King County.** These fairs were

“It was 5 years ago last time I had a mammogram screening. I cannot afford to be missed one day of work. I am a single mom and my two kids depend on me.” - Patient

“We are seeing a lot of apprehension within some of the communities we serve. The fear of deportation is real for many clients, and can affect our efforts in assisting clients. However, many clients are extremely grateful to [have access to services] and are thankful for their [ability to get care with] anonymity.” - Community Organizer

**Mammogram Screenings**

We screened 125 women at our health fairs in FY19.

Screenings were implemented through partnerships with the Women’s Health Outreach Program, King County Public Health Department, Swedish Cancer Institute, Seattle Cancer Care Alliance, Univision Seattle, Radio Luz 1680AM and El Rey 1360AM.

Of all the health fair participants:

- 56% of the adults reported they were uninsured, and 32% were covered via the Washington State Plan (Apple Health)
- 95% of children under 18 years old had Apple Health Plan

Of the **125 women screened:**

- 98 were enrolled in the BCCHP program
- 19 had Apple Health Plan (Medicaid)
- 8 had private insurance
- 17 had an abnormal mammogram and needed additional screening
- 7 were diagnosed with breast cancer

**RACE AND ETHNICITY OF PEOPLE RECEIVING MAMMOGRAMS**

- Non-white Hispanic 12%
- African American 6%
- Hispanic/Latino 39%
- Asian 35%
- African Immigrant 8%
supported through a network of partnerships with Molina Healthcare of Washington, Medical Teams International, Puget Sound Clean Air Agency, Consulate of Mexico in Seattle, Al-Shifa Clinic, UW School of Pharmacy, UW School of Medicine, Seattle University School Nurses Association, the Western Washington National Association of Hispanic Nurses, Promotores, Community Health Workers, community-based organizations and faith institutions.

What is a Promotore or Community Health Worker?

A promotora or community health worker (CHW) is a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served. This trusting relationship enables the CHW/promotora to serve as a link between health and social services and the community to facilitate access to services and improve the quality and cultural competence of services delivered. A CHW also builds individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support and advocacy.

One of the barriers we encountered this year was lower participation of minority communities during the Health Fairs due to the political climate. The members of these communities may have perceived our Health Fairs as government-sponsored. For many members of these communities, immigration status is an ever-present fear. When you combine this perception of government involvement and their fears with the current political climate, it is no surprise that attendance at the Health Fairs was low.

Promotores/Community Health Workers (CHWs)

Komen Puget Sound has a long history of investment in Promotores/community health workers (CHWs) and/or patient navigators, granting at least $3.5M to community partners who work with Promotores de Salud and CHWs over the last ten years.

These community advocates have the ability to reduce barriers to care by providing one-on-one education; group education, transportation support; language translation and interpretation and providing reminders to patients about preventative healthcare services such as mammogram screenings.

Promotores/CHWs accomplish these and other outcomes by providing education, advocacy and capacity building in their communities, resulting in:

- **Improved access** to services
- **Better community understanding** of the health and social service system
- **Enhanced communication** between client and health provider
- **Increased appropriate rates of service** utilization
- **Decreased costs** for organizations and government programs
- **Improved adherence** to health recommendations
- **Reduced need for emergency** and specialty services
- **Improved overall community health** status

Given the impact these individuals can have in reducing barriers to care for communities of color, we are taking a more proactive role in helping to facilitate conversations and community organizing for Promotores/CHWs across our state. Our role is to listen and support Promotores/CHWs to define their own success and ensure that they have the
opportunity and resources to enhance the impact they already have in communities, moving towards equity.

In a partnership with DOH as well as 13 organizations, Promotores and CHWs, we hosted the fifth annual Washington State Community Health Worker Conference. This conference is a two-day event that engaged, energized, and inspired CHWs/Promotores and their allies to support their communities. This conference featured 40 learning sessions and training workshops. More than 400 CHWs, Promotores, Health Services Program Directors, Managers and Supervisors attended the conference.

Through the monthly King County Promotores Network (539+ members), Komen Puget Sound brings Promotores/CHWs together to share resources and best practices.

What is Cultural Sensitivity?
Cultural sensitivity refers to a set of skills that allows you to understand and learn about people whose cultural background is not the same as yours. Cultural sensitivity is being aware that cultural differences and similarities between people exist without assigning them a value – positive or negative, better or worse, right or wrong.

Worship in Pink
The Worship in Pink (WiP) campaign is a grassroots effort of Puget Sound churches, synagogues, mosques and temples to educate their congregations and local community about breast health and breast cancer. It enables congregations to help women and men receive lifesaving mammograms and be more aware of their risks for breast cancer.

Typically, volunteers from the different faith institutions have taken the lead, introducing and implementing this program, in order for their members to learn more about breast cancer and the importance of early diagnosis. Most of these volunteers are retired nurses or community members affected with a chronic disease such as breast cancer or have experience working in a medical field. In FY19:

- **27 faith institutions participated** in the FY19 Worship in Pink campaign
- **4,630 members of the African American community and 195 members of the Latino community** increased their understanding about breast cancer
- **5 churches hosted health fairs** during their WiP program with blood pressure, glucose and cholesterol screenings
- **2 churches hosted mammogram screenings during their WiP event**
- WiP campaign participants reported that **18 African-American women, 18 Latina/Hispanic women, 3 Asian women and 5 non-Hispanic women** had mammogram screenings
PART 2: GRANTMAKING

Since 1994, Komen Puget Sound has invested more than $31 million in local non-profit, tribal and government agencies that provide breast health and breast cancer services to residents living in our 16-county service area. In FY19, Komen Puget Sound awarded $635,000 in grants for vital services to underserved women and families.

Komen Puget Sound has three primary funds focused on improving access to breast health services: the Screening and Diagnostic Fund, the Treatment Access Fund and the Health Equity Fund. The first fund pays for direct services, e.g., mammograms, diagnostic tests and biopsies, for those who cannot afford care. The second fund gives emergency financial assistance to patients undergoing treatment to help pay for rent, utilities, food, co-pays or any other financial needs for low-income women. The third fund focuses on decreasing barriers to care for underserved communities, primarily through community health workers and patient navigators. These health equity investments are complimented by a Breast Cancer Research Fund including funding metastatic breast cancer research, which can be used by donors for restricted giving.

Grantees will carry on supporting women to get to and through the healthcare system. We will continue our investments in direct-service provision through our partnership with the Washington State Department of Health as well as our emergency treatment access program with Cancer Lifeline. In addition, we are doubling down on our investments in community health workers and patient navigators as a key intervention in reducing barriers to care for low-income women and, in turn, improving health equity.

FY19 Community Health Grantees

Health Equity Fund

**Women’s Health Outreach/Latino Community Fund – $35,000**

**Women’s Health Outreach**

This program provided no-cost mammograms and health services to minority women in Seattle/King County who did not or could not access them through mainstream clinical resources. Screenings and follow-ups targeted those on limited incomes, regardless of age, sexual orientation or gender identity.

**International Community Health Services (ICHS) – $105,000**

**Breast Health Outreach, Prevention and Education Program**

This funding provided breast health outreach, education and screening to low-income, limited English-speaking Non-Hispanic, African descent, Asian, Native Hawaiian and other Pacific Islander, Hispanic/Latino women in Seattle/King County.
South Puget Intertribal Planning Agency (SPIPA) – $55,000
Native Women’s Wellness Program
This program provided breast health outreach, education, screening and support to women in rural tribal communities in Southwest Washington who rarely or never have been screened for breast cancer.

Korean Women’s Association (KWA) – $125,000
Culturally Responsive and Integrated Breast Health
This program assisted underserved women from many different populations with health benefits, transportation, translators and anything else necessary to get through breast cancer screening and treatment.

Treatment Assistance Fund

Cancer Lifeline – $125,000
Komen Patient Assistance Fund (KPAF)
Cancer Lifeline administered Komen Puget Sound’s KPAF and provided financial assistance and support to close to 350 low-income patients who were in treatment for breast cancer.

Screening and Diagnostics Fund

Washington State Department of Health – $185,000
Breast, Cervical and Colon Health Program (BCCHP)
Funding to the Washington State’s BCCHP provided breast cancer screenings, lifesaving mammograms and diagnostics to more than 4,000 low-income women.

Komen Puget Sound also provides small grants (up to $10,000) to 11 organizations throughout the year. These include churches, tribal entities, community-based organizations and health clinics all focused on their specific communities such as the India Association of Western Washington, Gay City, New Life Baptist Church, Somali Health Board and Swinomish Tribal Health Clinic.

Together with our grantees and partners, we are working to increase health equity throughout our region by creating tailored interventions that align with community needs, building equal opportunity for the highest attainment of health.
PART 3: RESEARCH

Along with our investment in health equity and access to healthcare, researchers throughout the Puget Sound have received grants to understand why cancer grows, where it goes and how to stop it. This investment comes from funds raised at the Affiliate level, as well as through funding provided by our headquarters. Komen’s research program, funded in part by contributions from Komen’s nationwide network of affiliates, which directs 25 percent of funds raised locally to Komen’s national research program, while investing the remaining 75 percent into local community programs. This year, Komen Puget Sound invested approximately $416,000 into research programs.1

These investments go to researchers who contribute to an international advisory group of distinguished scholars and leaders in breast cancer research. Many of these grant recipients also serve as advisors for Komen’s research, education and advocacy programs in the U.S. and abroad. Komen Puget Sound awarded $1.25 M to Seattle area researchers in FY19.

Komen Scholars

Komen Scholars are researching how to overcome drug resistance in breast cancer patients, and are seeking to gain a better understanding of how and why breast cancer spreads, so that we can better treat metastatic breast cancer and hopefully prevent it all together. Our current Komen Scholars include:

Kevin Cheung, M.D. (Fred Hutchinson Cancer Research Center)
Dr. Cheung’s previous research has shown that tumor cells travel as clusters throughout all stages of metastasis, led by a protein called keratin 14. These clusters break off from early stage tumors and travel through the lymph system or bloodstream to organs like the liver or lungs, where they create new tumors. He has also shown that these clusters express, or produce, high levels of adhesion proteins, which he believes are important for the clusters’ signaling and survival. Dr. Cheung hopes to stop the clusters’ spread by identifying new therapeutic compounds to disrupt their integrity.

Mary L. “Nora” Disis, M.D. (University of Washington)
Dr. Disis is working to develop a vaccine to block inflammation in obese, fatty tissue with the goal of reducing the incidence of breast cancer in obese women.

1 Numbers are preliminary.
Julie Gralow, M.D. (University of Washington)
Dr. Gralow is bringing together medical experts, researchers, patients, policymakers and other key stakeholders to discuss opportunities for increasing inclusion of breast cancer patients with bone-only metastasis in clinical trials. Bone metastasis patients are currently under-represented in clinical trials. The meeting will provide an open forum to discuss current knowledge and challenges associated with metastatic breast cancer in the bone, and come to consensus around solutions and opportunities moving forward.

PART 4: VOLUNTEERS

Volunteers are our ambassadors carrying the powerful message of Susan G. Komen and its work into their communities. Volunteers enable the organization to strengthen existing programs, add new programs, procure funds and resources, add specialized skills and talents and increase public awareness of services. The MORE THAN PINK Walk is Komen Puget Sound’s largest volunteer event each year, but volunteers participate in many different ways as summarized in the table below. The value of volunteer hours in 2019 was $24.14/per hour.\(^2\) The value of the 3,041 Komen Puget Sound Volunteer hours is equal to $73,410 for 2019.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>NW Metastatic Breast Cancer Conference</td>
<td>183</td>
</tr>
<tr>
<td>Race for the Cure</td>
<td>1,130</td>
</tr>
<tr>
<td>2019 MTPW (hours in 2018)</td>
<td>38</td>
</tr>
<tr>
<td>Community Impact Celebration</td>
<td>44</td>
</tr>
<tr>
<td>Grace Notes</td>
<td>337</td>
</tr>
<tr>
<td>Lunch for the Cure</td>
<td>81</td>
</tr>
<tr>
<td>Office Administration</td>
<td>949</td>
</tr>
<tr>
<td>Education and Outreach</td>
<td>134</td>
</tr>
<tr>
<td>Survivor Celebration</td>
<td>55</td>
</tr>
<tr>
<td>Third Party Events</td>
<td>90</td>
</tr>
<tr>
<td>Total</td>
<td>3,041</td>
</tr>
</tbody>
</table>

Komen 101
Komen Puget Sound offers Komen 101 classes throughout the year for volunteers who want to get to know more about the work Komen does, and to breast cancer patient and survivors who want to learn more about Komen resources. The classes are two hours in length and offer an overview on breast cancer and breast health, a background on Susan G. Komen national and information on what makes Komen Puget Sound unique. We offered classes at the KPS office and at partner locations throughout our region. In FY19, KPS offered four classes with average attendance of 13 volunteers, breast cancer patients and survivors per class.

Impact Celebration
Last year, Komen Puget Sound welcomed an enthusiastic, supportive group of friends, old and new, on April 24 to the annual Impact Celebration at Museum of History and Industry (MOHAI), in Seattle. Attendees celebrated the announcement of more than $700,000 in funding to Komen’s local FY19 community grantees and joined in congratulating outstanding volunteers and partners. This event, sponsored by Fred Meyer, Swedish Cancer Institute and United Healthcare Community Plan, had over 200 community participants.

\(^2\)Estimated by the Independent Sector. [www.independentsector.org](http://www.independentsector.org)
PART 5: ADVOCACY

The FY19 Komen Puget Sound Legislative Agenda focused on three key areas:

Defend and increase access to healthcare. Health equity, including access to breast cancer information and services, is dependent on adequate access to healthcare. We will work with stakeholders to ensure that healthcare remains a top priority. This will include support for key interventions that reduce barriers to care among marginalized populations.

- **Increased funding for Promotores/Community Health Workers (CHWs).** Promotores/CHWs serve as a bridge between healthcare providers and community members. They reduce health disparities among marginalized populations by helping individuals understand disease and the importance of preventative services, such as early detection. In addition, CHWs ensure that patients get to and through the health system and they receive quality care.

- **Oppose efforts to roll back existing health coverage and support finding solutions that ensure all Washingtonians have access to healthcare.** In addition, efforts at the state and federal levels in recent years have led to Washington reducing our uninsured rate down to 5.8%. As of March 2017, over 1.7 million Washington residents have health coverage through our Washington Healthplanfinder, including over 50,000 children enrolled in the Children’s Health Insurance Program (CHIP), which are now at risk for running out of funding since it has not yet been reauthorized by Congress.

- **Improve access to healthcare by increasing Medicaid reimbursement to Medicare rates.** People on Medicaid often face challenges with finding a provider that will accept Medicaid coverage. This is in large part due to the low reimbursement rates provided for Medicaid. Under the Affordable Care Act, there was a temporary increase to Medicare rates, but that increase has expired and reimbursements returned to the lower Medicaid rates. As a result, clinics and providers are closing their doors to patients on Medicaid. Raising the Medicaid rate will improve access to care in Washington and result in better disease prevention, earlier diagnosis and treatment, and fewer emergency room visits.

**KEY ADVOCACY WIN**

Governor Inslee signed into law House Bill (HB) 1870, which is a huge step forward in healthcare legislation in our state. The law assures access to healthcare for all Washingtonians regardless of what happens at the federal level and provides protections for pre-existing conditions, out of pocket expenses, discrimination, and much more.
The Affordable Care Act put in place several regulations to protect patients and their access to healthcare coverage. The protections help patients gain and maintain quality health coverage without fear of denial, or being dropped from coverage or charged higher rates because of their health status. Patient protections allow individuals and families to have the security of health insurance so they can access preventive care as well as coverage in times of medical crisis.

HB 1870 puts the key patient protections from the Affordable Care Act into Washington state law, providing a guarantee that Washingtonians will have these protections regardless of what happens at the federal level or in the courts. The patient protections that HB 1870 codifies into state law are:

- No one can be denied coverage due to a pre-existing condition or charged more for coverage
- No one can be dropped from coverage once enrolled under a plan (except in cases of fraud)
- The ten essential health benefits must be covered by plans
- There is a cap on out-of-pocket expenses
- Carriers are not able to impose annual or lifetime caps
- Carriers must provide a summary of benefits and coverage explanation
- Prohibits waiting periods of more than 90-days before a patient is able to enroll in coverage
- A carrier may not discriminate against individuals based on age, expected length of life, disability or other health condition

PART 6: SURVIVORS AND METASTATIC PATIENTS

Metastatic breast cancer, which is breast cancer that has spread to other parts of the body like the brain, liver, bones or lungs, is responsible for almost all of the nation’s 40,000 annual breast cancer deaths. More than 154,000 women are living with metastatic disease in the U.S. today.

Komen Puget Sound has prioritized outreach to metastatic patients and has developed a coalition of patients who are advocating for new treatment breakthroughs and, eventually, a cure for breast cancer. Komen Puget Sound collaborates with many local organizations to reach survivors, newly diagnosed and metastatic patients. Through our partnerships, we estimate that we engage with over 5,000 survivors and patients each year.

In addition, breast cancer survivors and metastatic patients are active participants in Komen 101 training, which helps to increase awareness of the work Komen does in the Puget Sound region. Over 3,200 survivors receive the monthly newsletter with updated resources, event invitations and the latest information on breast cancer research. Local survivors serve as resources, volunteers and a sounding board for Komen Puget Sound.

Komen Puget Sound continues to connect with survivors and metastatic patients through outreach programs, classes, networking events and an active Survivorship Facebook networking group with more than 120 followers.
**Survivor Celebration**
Each year, in partnership with Holland America Lines, Komen Puget Sound invites up to **400 breast cancer patients and survivors to the annual Komen Puget Sound Survivor Celebration**, where they enjoy a festive in-port luncheon and live entertainment. This year the event featured a panel of four breast cancer survivors sharing their stories. This event creates community, connections and hope for women throughout their breast cancer journeys.

**Northwest Metastatic Breast Cancer Conference**
On September 26-27, Komen Puget Sound welcomed patients and partners to the 3rd **Annual Northwest Metastatic Breast Cancer Conference**. A free, open-to-the-public event held at the Amazon Meeting Center, the NWMBCC, organized by metastatic breast cancer (MBC) patients for patients whose disease has metastasized, gave patients and caregivers opportunities to learn from prominent breast cancer researchers and advocates.

Five objectives outlined within the context of this framework included:

- Build a better understanding and strong evidence-base of community needs;
- Strengthen the conversation between MBC patients, the breast cancer community and the cancer community at large;
- Create opportunities for dialogue between key stakeholder groups and metastatic patients;
- Move from awareness-raising to action on the part of the public, the breast cancer community at large and metastatic breast cancer patients more specifically and;
- Support localized efforts to strengthen the MBC community.

**Over 348 individuals registered for the conference.** The first day of the conference had approximately 233 participants. The second day had approximately 231 participants. This included 22 individuals who received travel grants from throughout the country. Another 70+ speakers, volunteers, vendors and sponsors were also at the conference. Attendees came from across the country and across borders – as far as Canada and Puerto Rico – with representatives from 17 different states. A broad online presence complimented the in-person numbers with **Facebook video views reaching over 34,000**.

Because of the conference, we were able to achieve the following:

- **Increased collaboration among metastatic breast cancer organizations,** development of improved understanding, and alignment around a common agenda.
- **Increased involvement and engagement of metastatic community in the broader breast cancer conversation.**
- **Increased patient understanding of key treatment options and emerging science,** integrative medicine and healthy lifestyle and advocacy engagement within the health system and in legislative action.
- **Improved relationship between Komen Puget Sound/Komen Headquarters and the metastatic community.**
- **Community-building and increased understanding of Invasive Lobular Carcinoma,** serving as a first-of-kind opportunity for lobular patients from across the world to engage with top researchers.
Perhaps the most compelling outcome of the conference, however, was the cross-agency collaboration and full engagement of metastatic breast cancer patients across the country. Not only did this event foster meaningful conversations between leaders in the field that typically do not engage, it also built community among metastatic breast cancer patients, ILC patients and breast cancer survivors. This community building helped create hope for the community at large – that those organizations, researchers, doctors and advocates with the greatest influence were ready and willing to listen to the patient voice.

“Overall I thank everyone for their efforts in putting this on and working to have it available to everyone. I was diagnosed 5/2/17 with good results and consider myself on the road to being cancer free. However, I want to empower myself and help others learn more about breast cancer and metastatic breast cancer. I was one of those that thought all breast cancer diagnoses were about the same except for the stage, didn’t realize how different they are and how the make-up of tumors can vary. Thank you for educating me to help educate others and spreading the word how self-exams and self-health awareness too are so very important in early detection.”
- Conference Attendee

PART 7: THANK YOU

It is only through the generosity of our donors, partners, grantees and elected officials that Komen Puget Sound has been able to have such a significant impact in our community. This support forms the bedrock of our organization and without, it we would not be able to reach those women and men who are most in need. Here at Komen, we believe that all communities, regardless of color, gender or ethnicity, have the right to quality healthcare, including breast cancer services. Every day, Komen Puget Sound and its partners are working to combat inequities while supporting people’s access to lifesaving breast healthcare. Together we can make change happen.