

# Take charge of your health today. Be informed. Be involved.

This month, the "Take Charge of Your Health Today" page focuses on disparities in breast cancer outcomes. Bee Schindler, community engagement coordinator with the University of Pittsburgh's Clinical and Translational Science Institute, and Esther L. Bush, president and CEO of the Urban League of Greater Pittsburgh, spoke about this topic.

**BS:** Good morning, Ms. Bush. I thank you for the chance to talk with you today about breast cancer outcomes, a topic that is relevant to so many readers—especially as breast cancer is the most common cancer diagnosis for women.

**EB:** Yes, Bee. This is a topic that most people can relate to, especially in the African American community where Black women are dying at a disproportionate rate. Research shows that the rate for white women dying from breast cancer

## Disparity in Breast Cancer Outcomes

is 22 percent, while that rate nearly doubles to 42 percent for Black women. We have to pay attention to this.

**BS:** Absolutely! In addition to thinking about social determinants of health—in which conditions where folks live, learn, work and play affect a wide range of health risks and outcomes—researchers note that African



ESTHER BUSH

**EB:** That's important to mention because African Americans are on their own in

American women are often affected by aggressive kinds of cancer that are harder to treat. A big part of the issue is that not enough Black women have been included in research, which limits how well the disease is known, prevented, detected and treated.

health decisions. Taking charge can start by joining a research study and learning more about how to reduce the risk of getting breast cancer.

**BS:** I second getting more African American women involved in breast cancer research. Also, despite the disparities, survival rates are better when people see something, feel something and advocate for themselves.

**EB:** Thank you so much for having this conversation with me, Bee. I hope our readers take away from our conversation that it's important to advocate for themselves when their health is concerned—to, in other words, take charge of your health. I look forward to next month as we discuss men's health.

## Black Women and Breast Cancer Research

by Margaret Rosenzweig, PhD

As a cancer nurse, I focus on ensuring all women with breast cancer I work with receive timely diagnoses, treatment and support. As a researcher, I focus on better understanding why racial disparity in breast cancer treatment exists. My team's work in research and outreach initiatives has been to address racial and economic disparities in breast cancer survival. In 2011, my team and I launched the Attitude, Communication, Treatment, Support (ACTS) Intervention to Reduce Breast Cancer Treatment Disparity, funded through the American Cancer Society. We learned that almost all Black women, when recommended to begin chemotherapy for breast cancer, did initiate therapy, but about half of the women were not able to get the full dose on time due to symptoms and distress. The lessons learned from the ACTS study led to the Symptom Experience, Management and Outcomes According to Race and Social Determinants (SEMOARS) study, funded by an R01 National Institutes of Health grant. The SEMOARS study follows 179 Black and 179 White women undergoing chemotherapy treatment and describes the



MARGARET ROSENZWEIG, PHD

patient's ability to receive full chemotherapy dosages. Clinician communication may be a component of racial bias during cancer

therapy, so we are also audiotaping and coding clinic visits.

Our work with women with breast cancer has also made our team aware of the importance of breast cancer education and screening in the clinic. Our team works with several advocates within the Allegheny County Breast Collaborative (ACBC), a group of more than 20 representatives from the community, health care and academic organizations. ACBC chose Pittsburgh communities with particularly high breast cancer mortality rates—McKeesport, Braddock and Penn Hills—in which to begin outreach. Our work began in Braddock, and in June we will begin operations in McKeesport. We work intimately with these communities, and our team tailors community outreach plans to best benefit these communities. In Braddock, the ACBC team hosts presentations and support sessions, while connecting women to existing breast cancer resources. Our goal is to establish in each community a sustainable system of community support, education and advocacy after one year.

(Margaret Rosenzweig, PhD, is professor and vice chair of research, Department of Acute and Tertiary Care, University of Pittsburgh School of Nursing.)



CAROLA NEUMANN, MD

### Why the Disparity?

Many of us may be familiar with statistics about breast cancer: One out of eight women are diagnosed with the disease, according to the National Cancer Institute. The Centers for Disease Control and Prevention report that, after skin cancer, breast cancer is the most common cancer in women, regardless of race or ethnicity. A breast cancer diagnosis is too common for all women in the United States.

What may not be as familiar is that, even though the incidence rates are similar, the outcomes of women with breast cancer vary differently by race and ethnicity. Research from the American Cancer Society tells us that African American women are 42 percent more likely to die from their breast cancer than white women. In Allegheny County, the National Cancer Institute reports that the breast cancer mortality rate (deaths per 100,000 people) is 22 for white women and 35.1 for African American and Latinx women.

Why is there such a large disparity? Researchers do not know the exact cause for this difference. They do have some ideas, though more research needs to be done. Part of the disparity could be the kind of breast cancer African American women have more typically than white women.

"African American women are affected at an earlier age and more often by an aggressive kind of breast cancer called triple negative," says Carola Neumann, MD, associate professor of pharmacology and chemical biology at the University of Pittsburgh School of Medicine. According to the Breast Cancer Research Foundation, African American women have twice the rate of triple negative breast cancers than any other racial group in the United States.

One way to categorize breast cancers is by their receptors. The three most common receptors are estrogen, progesterone and human epidermal growth factor (HER2). These three kinds of breast cancer receptors can be targeted specifically with hormone therapy or other drugs. Triple-negative breast cancers do not have any of those three receptors and are, therefore, harder to treat (though they can be treated with surgery, chemotherapy and radiation therapy).

Researchers think some African American women are more likely to inherit triple-negative breast cancers, though more research needs to be done. Another factor possibly contributing to the disparity is access to health care. This includes being underinsured or uninsured and difficulty in getting to and from care.

So, what is being done to get rid of this disparity? Dr. Neumann cites the need for more research on identifying the biology of aggressive breast cancers in African American women. "Without research and clinical trials, very little will change," she says. "African Americans in general are underrepresented in research. But we need to study this population to know why they are dying from breast cancer more often and what treatment will better treat their cancers."

Early detection is important. Breast self-exams and mammograms are first steps to early diagnosis. Dr. Neumann says that equally important, however, is knowing about your disease and your treatment options. Education is key to empower and become an advocate for yourself. Thanks to research, treatment options for breast cancer have clearly improved over the years. However, Dr. Neumann reminds us that patients, scientists and physicians have to work together to develop better treatments for metastatic disease.



WAMO 100 personalities Kiki Brown and Portia Foxx, pictured here, hosted a Breast Cancer Survivor's Happy Hour at Savoy, in the Strip District, in 2017. "We wanted to bring more awareness to our community with free screening vouchers and on-site information about self-examination and early detection because it's still an issue right now," Brown said. (File Photo by Tationna Smalley)

## bcRAN advocates work to improve patient outcomes

by Karen DiVito

A breast cancer diagnosis means having some form of treatment—perhaps surgery, radiation, chemotherapy, oral medications or any combination. After treatment is complete, many patients return to their prediagnosis lives. This is a win! Sometimes, too, a diagnosis changes patients in such a way that they want to continue to learn about breast cancer and to have a positive impact for people who may be diagnosed in the future. Such is the case for the patients who have become advocates for the Breast Cancer Research Advocacy Network (bcRAN).

Research advocates with bcRAN are at least one year post treatment. They also commit to receive ongoing education about what is happening in the scientific community regarding new therapies and to listen to what is happening in the patient community with respect to unmet needs. Advocates, therefore, serve as a collective patient voice, to inform researchers about what is important for patients. Conversely, bcRAN advocates

serve as liaisons and commit to performing outreach and education in the community so that the research process is better understood.

One area where there is a gap, or unmet need, is in patient outcomes. The Centers for Disease Control and Prevention (CDC) report that Black and white women get breast cancer at about the same rate but that Black women die from breast cancer at

a higher rate than white women. This is true in Pittsburgh.

Research is the key to understanding disparities such as the example above. Through collaborations with many other organizations, such as the Urban League and Susan G. Komen Greater Pennsylvania, bcRAN advocates are out in the community talking with survivors, current patients and even people who have never had a diagnosis. Let's hear what your experience has been, positive or negative, so we can better understand what can be improved! Let us share with you the facts about clinical trials and research and why both are so very important in order to improve not only outcomes, but treatments and, ultimately, prevention.

If this sounds like a mission that you share, or if you would like representatives from bcRAN to speak to a group in your community, please contact us at [UPCIBcran@upmc.edu](mailto:UPCIBcran@upmc.edu) or follow us on Facebook by searching "[bcRANpittsburgh](https://www.facebook.com/bcRANpittsburgh)."

(Karen DiVito is co-leader of bcRAN (Breast Cancer Research Advocacy Network))



The PNCBank team was honored to join with the Pittsburgh community at Race for the Cure on May 13, 2018. Our Region Pres. Louis R. Cestello had the added honor of presenting Ms. Karen DiVito with the 19th annual PNC Community Caring Award. (Twitter Photo)