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Improving Health in the Mississippi Delta through Powerful Engagement

A PCORI Engagement Award enables a cancer awareness and prevention program to expand its reach within rural, largely African-American communities facing high cancer rates.

Barbara Young is a survivor. The lifelong Mississippi Delta resident beat cancer four times in a place where healthcare resources are scarce. When she was first diagnosed with breast cancer, in 1987, Young and her husband were raising three small children. She was also working two jobs and running a cake-baking business from home. “I thought I was just tired from working two jobs; I didn’t know I had cancer,” she says. “I had all the warning signs, but I didn’t understand them.”

Young says a lack of information and resources in the small town where she lived made decisions about the most appropriate cancer treatment difficult. After choosing a mastectomy, Young developed cancer in her other breast. In the years following treatment of that tumor, she went on to have uterine cancer and stomach cancer. “The pain from stomach cancer was unbelievable,” she says. “I couldn’t do anything. I couldn’t even brush my own teeth.”

During her treatment, she received a call from Freddie White-Johnson, MPPA, of the local cancer outreach program, the Mississippi Network for Cancer Control and Prevention, a program of the University of Southern Mississippi. That changed her life.



Freddie White-Johnson visits the home of a man who is experiencing prostate cancer symptoms. In addition to giving him information about cancer screening, she noticed he had no heat and brought him an electric heater. (Photo courtesy of Freddie White-Johnson)

Young says White-Johnson’s daily calls and the information she provided motivated her not only to continue with treatment but to become involved in health outreach, using her experiences to educate others about preventing cancer and to help those facing the disease. Today, she is a community health advisor in the cancer network and Fannie Lou Hamer Cancer Foundation, which is using a [Eugene Washington PCORI Engagement Award](#) to advance breast and prostate cancer prevention, diagnosis, and treatment and encourage the community to participate as partners in research. PCORI’s support of the network received recognition in proclamations from a city—Greenwood, Mississippi—where the award team has been active, as well as from the state legislature and the lieutenant governor.

“When I was first diagnosed, we didn’t have access to computers and other technology. Our local health department was the only source of care. Right now, we still don’t have a lot of access,” Young says. “Before you talk about cancer, you’ve got to talk about other needs.”

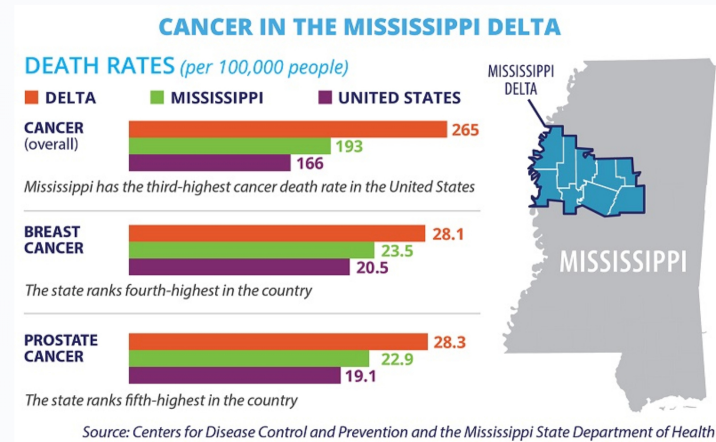


“There are so many people still out there in Mississippi in 2017 who don’t have any direct support or health resources. There are men who don’t even know what a prostate is. There’s so much work that still needs to be done.”

Freddie White-Johnson

Where Hardships Are Common

The financial, educational, and healthcare challenges of Mississippi Delta residents can be as vast as the Delta itself. In this region that stretches over northwest Mississippi, 30 percent of families live below the poverty line, with some groups affected more severely than others. For example, 10.2 percent of white families in the Delta live below the poverty line, versus 41.7 percent of black or African-American families. In Mississippi as a whole, 18 percent of those over age 25 lack a high school diploma, higher than the national average of about 13.3 percent.



In the nine counties that make up the Mississippi Delta, breast and prostate cancer death rates are higher than the state averages, which are themselves among the highest cancer death rates in the country. (Click the image for a larger version)

The Delta faces other social problems including high rates of teen pregnancy and incarceration, and many people who lack sufficient food and clothing. Some residents have no indoor plumbing.

According to the US Centers for Disease Control and Prevention, the number of new cases of cancer in Mississippi are highest for prostate and breast cancer. The story of prostate cancer in the region is particularly stark. The new case rate in black or African-American men in Mississippi is almost twice as high as the new case rate in black or African-American men nationally.

Health care can be hard to come by, and not just because some people lack insurance. The area has few healthcare providers, transportation is difficult, wait times are long, and appointments may be brief. For example, a Delta ob-gyn with a nurse practitioner may see 50 to 60 patients a day, White-Johnson says.

So, a simple phone call from her or a member of her team can make a world of difference.





Freddie White-Johnson visits a community member at her home around 2005. She had been alerted that the woman had never had a mammogram, had no running water, and had no support system. (Photo courtesy of Freddie White-Johnson)

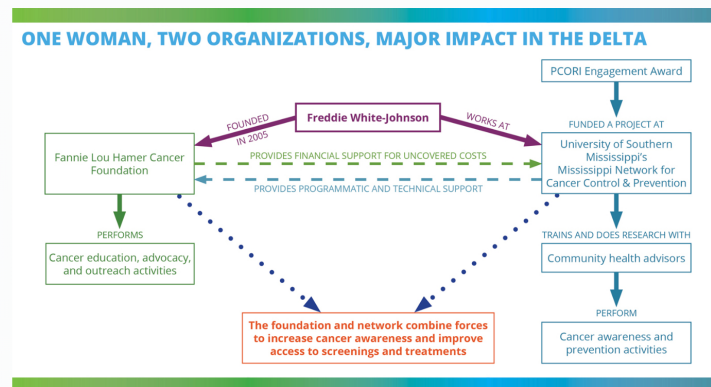
From a Movement to an Empowered Community

Although Delta residents may be unfamiliar with the Mississippi Network for Cancer Control and Prevention, Freddie White-Johnson is a well-known name. She almost single-handedly created a community cancer outreach movement under the most unlikely of circumstances.

In 2005, she founded the [Fannie Lou Hamer Cancer Foundation](#), which uses private and public funding to support cancer awareness and prevention activities and works to improve the daily lives of those affected by cancer. Volunteers often run the activities, many of them from the [Mississippi Cancer Network](#), an organization for which White-Johnson now serves as the program director.

Run by community members for community members, the network focuses on education, outreach, and advocacy related to cancer, with an emphasis on breast and prostate cancer. Since its beginning, the network has trained more than 1,000 community members as community health advisors.

The network selects as potential advisors people who already make a difference in their communities by helping others. Trained advisors teach community members about breast and prostate cancer, including warning signs, symptoms, and the importance of screening.



The community health advisors meet community members wherever they are—at churches, recreation centers, shopping areas, and even fire stations. They provide food and bring activities to occupy families' youngest members, so that parents are free to learn. They also hold health fairs, distribute literature, and recruit people for cancer screenings. After these events, advisors follow up with community members who have never been screened even though guidelines suggest they should have been.

"When people learn, they do better. Once we change mindset and attitudes, you are going to start seeing behavior change," White-Johnson says.



PCORI received proclamations from the state of Mississippi and the city of Greenwood for supporting the network's cancer education and awareness efforts in the Delta. (Click to view as PDF)

White-Johnson and community advisors also call and visit homes of those living with cancer. They provide transportation to medical appointments and help patients compile questions to discuss with their doctors. They even help take care of some patients' most basic needs, which can include providing food, heat, and clothing, and teaching proper hygiene.

The PCORI Engagement Award allowed White-Johnson and her team at the University of Southern Mississippi to expand their more than a decade's worth of work helping those in the Delta by developing a training curriculum for advisors. The project's other leader, Carol Connell, PhD, RD, a professor of Nutrition and Food Systems at the University of Southern Mississippi, says that to develop the training, the team conducted interviews with advisors to understand how they do outreach, particularly about cancer. The team then met with a community advisory board to discuss the findings.

From these interviews, the team learned that the community members contacted by community health advisors did not understand the concept of research and were deeply concerned about exploitation. They thought that becoming research participants would make them guinea pigs, says White-Johnson. By the end of the award, in April 2017, the team had created a training program that addressed the community's concerns.

Fighting Prostate Cancer Man-to-Man in the Delta

Sammy Foster has never had cancer, but he knows cancer well.

"I've been in the health insurance business for over 30 years, so I've come into contact with people in all kinds of serious health situations without health insurance," says Foster, who lives in the Mississippi Delta, in Greenwood. "I've been a health-conscious person since my 20s because of it. I want to live as long and healthy a life as I can."

His front-row seat to health disparities led Foster to want to spread that message, first as an American Cancer Society volunteer, and then on the local hospital board. Now, he leads a group of community health advisors in the Mississippi Network for Cancer Control and Prevention.

Called [Community Health Advisors Men in Black and Blue Fighting Prostate Cancer](#), the group fights prostate

cancer through prevention and education about screening. Its members interact with African-American men in the community at health fairs, give talks at local venues,

and follow up with attendees to connect them with prostate cancer screening resources. If caught early enough, prostate cancer is highly treatable.

The group has faced a challenge: encouraging African-American men to attend the group's events, let alone to be active in their health care. The community health advisors reach out individually to men in the community or to family members to tell them about upcoming events. Health fairs are daylong events that provide breakfast, free health screenings and information, and speakers who are cancer survivors.

"The men don't believe in going to the doctor even for a regular checkup," Foster says.

"The worse thing is that people aren't knowledgeable about health and cancer. They are afraid to have a simple prostate exam because they don't realize the importance of preventive health."



A Life Dedicated to Helping 'People Like Us'

White-Johnson once was a community member in need of help, like those she serves today. She grew up poor on a cotton-and-soybean plantation; neither of her parents completed

high school. In 1977, when she was 17, her father was diagnosed with stage IV lung cancer. At the time, her family had never heard of cancer and had no health insurance.

"He was treating what was cancer with Epsom salts and warm water and gargling," White-Johnson says. "The pain got worse to the point that finally my mother said he had to go to the doctor. They ran tests and told us immediately that it was lung cancer."

Just before he died, her father gave her advice: "The world owes you nothing. If you want anything out of life, you are going to have to work for it. Go to school and get an education. Then come back and help the people like us."

"That's what I've done," White-Johnson says. She earned a master's degree in public policy and administration and became a program director at the University of Southern Mississippi. It's where she created the Fannie Lou Hamer Cancer Foundation to provide support to the Mississippi Delta. When she approached the university in 2004 about launching the foundation, she envisioned building a nonprofit foundation as large as Susan G. Komen for the Cure.

Funding support from the university, local, statewide, and national organizations such as the University of Southern Mississippi, the Sunflower County Board of Supervisors, and the Mississippi Partnership for Comprehensive Cancer Control of the State Department of Health helped the foundation get off the ground. But some people said her ideas were just too ambitious for the area and its resources.

"I was afraid of failure at first, but I wanted to see if the foundation could give people a whole different perception of true community engagement and community-based participatory research," White-Johnson says.

Enthusiasm was high when she held her first informal meeting about developing the foundation. Around 75 people attended, including staff from the University of Southern Mississippi, researchers, community health advisors, community leaders, healthcare providers, and representatives from social and welfare agencies. However, no one wanted to lead the foundation. So, White-Johnson stepped up to take charge.

In 2010, when some of the early funding ended, the university chose to independently continue the network, now called the Mississippi Network for Cancer Control and Prevention. White-Johnson's foundation supports the network with supplementary funding. Additional funds came to the university in 2015 with the PCORI Engagement Award.

"There are so many people still out there in Mississippi in 2017 who don't have any direct support or health resources," White-Johnson says. "There are men who don't even know what a prostate is. There's so much work that still needs to be done."

White-Johnson adds, "I love doing what I do, being that voice for the underserved that makes a difference and gives many people who are in need a ray of hope."



Barbara Young, a community health advisor and cancer survivor, talks with a young man about cancer prevention outside of a local Walmart. (Photo courtesy of Freddie White-Johnson)

Enabling Better Decisions for Better Health

With the training curriculum developed through the PCORI Engagement Award, the network can teach more community members how to find answers to their questions and get more involved in their own health care. The advisors can also learn to more effectively support community members—as White-Johnson has always done.

“Freddie just sees a need. She didn’t see that I was 97 pounds or that I had lost all of my hair,” Young says. “She just saw a human being who needed help and pushed everything else aside. She helped save me and passed the want to serve others on to me. And I’m going to pass it on to somebody else.”

White-Johnson continues the fight to eliminate cancer health disparities in a place where health is just one of many challenges. “You’ve got to get in there and make something happen,” she says. “If there is no door, make one, build one.”

At a Glance

Building on a Culturally Sensitive Network for PCOR/CER Dissemination

Project Leads: Carol Connell, PhD, RD; Freddie White-Johnson, MPPA

Goal: To determine the most effective ways to disseminate patient-centered outcomes research findings and to increase interest in research participation by African-American residents in the Mississippi Delta.

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By Melissa Schenkman, Writer and Editor

Posted: October 12, 2017

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