Cancer Health™

“But You Look Fine!”

Latonya Wilson advocates for better understanding of metastatic breast cancer and more outreach to African Americans.

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Latonya Wilson, a 42-year-old former U.S. Army staff sergeant, was working in Iraq for a defense contractor in the spring of 2016 when she first developed a bad cough and shortness of breath. The problem persisted during her vacation back home in South Carolina, so she told her oncologist about it.

The doctor had treated Wilson since early 2008, when she was diagnosed with Stage II breast cancer at age 32. Five years after that, a small tumor was found in the same breast, and Wilson had a double mastectomy to remove both breasts.

This time, the tests for the cough showed that the cancer had spread into her lung, meaning she had Stage IV, or metastatic, breast cancer—the most advanced stage of the disease.

“I knew it was gonna be a lifetime of treatment, though I didn’t know what that treatment was gonna be,” says Wilson.

“I got the results the day I was flying back to Iraq,” she recalls. “I came to my mom’s house and told them what happened. I wasn’t crying. I was just sitting there thinking.” Everyone else was crying.

“I couldn’t deal with that,” she adds. “I said, ‘When y’all finish crying, I’ll come back home.’” She flew out that night.

Early Treatment

Wilson got her first breast cancer diagnosis while working in Afghanistan. African-American women younger than 40, as Wilson was then, have a higher risk of breast cancer than other young women (Click here for more info).

She saw a local medic about a breast lump in September 2007 and was sent to doctors at a hospital in Dubai. “They assured me it wasn’t anything,” she says, so she waited until her December vacation to have the lump removed in Dubai and then flew back home to the United States.

Days later, Wilson received an email telling her she had breast cancer. She quickly found an oncologist in Lexington, South Carolina, near her family. More tests discovered cancer in three of her underarm lymph nodes. The breast cancer was hormone-receptor positive, meaning the hormones estrogen or progesterone could make any remaining cancer cells grow (see “Targeting Tumors” below).

Wilson’s oncologist advised her to have a total hysterectomy and ovary removal to reduce hormone production. “I didn’t want to do that,” Wilson recalls, “because I didn’t have children and I wanted to have children.”

Instead, she was treated with chemotherapy and radiation, and she took tamoxifen for five years to block estrogen. After chemo and radiation, she returned to Afghanistan.

In late 2013, when Wilson was 37 and working in Kuwait, a doctor found the small tumor that led to the double mastectomy. Wilson started working again but says, “I was a little insecure about not having breasts,” so she returned to the United States to start a new life in Houston.

Targeting Tumors

Breast cancer is classified by the kind of receptors it expresses. A majority of breast cancers carry receptors for estrogen or progesterone, and treatment usually includes hormone-blocking drugs such as tamoxifen. About 20 percent of tumors express the HER2 (human epidermal growth factor 2) receptor and can be treated with HER2 inhibitors like Herceptin (trastuzumab). Triple-negative breast cancer doesn’t express any of these receptors, making it harder to treat, but new drugs are being developed for this type of cancer.

Community Advocacy

In Texas, Wilson started the Cherished Hearts Breast Cancer Foundation and spoke at churches, women’s empowerment meetings and fundraising walks. She talked with patients and distributed brochures about breast cancer.

“My main focus at that time was the African-American community,” Wilson says. She felt that African Americans often knew little about breast cancer because they had insufficient information and support resources available to them and because their families traditionally did not talk about cancer. “I was trying to educate people on breast cancer, on getting checked, on what you do if something happens,” she says.

Wilson’s advocacy work helped with her decision not to have surgery to rebuild her breasts. “At first, I didn’t want any more surgeries. I was comfortable with it,” she says. A Houston doctor suggested she might want breast reconstruction because she wasn’t married yet. “I guess she figured a guy probably would have had a problem with me being breastless,” Wilson says.

She began reconsidering her decision to stay flat. Then she met a young woman who couldn’t afford reconstruction. (Some health plans and Medicaid in certain states don’t cover it.)

“The young lady thought she was ugly and she wasn’t a woman. That became my motivation to say, ‘You know what? I don’t need it,’” Wilson says. “I’m showing other women that if you can’t afford certain things, it’s OK. Breasts don’t make us female. Regardless of how your body changes, we’re still here and we’re still alive.” She describes herself now as “blessed, breastless and beautiful.”

Moving Forward

After learning she had metastatic breast cancer in 2016, Wilson told her employer she couldn’t continue working overseas. She returned to South Carolina and, still hoping to become pregnant someday, took hormone-blocking medication for a year until finally deciding to have a hysterectomy and ovary removal. Tests showed cancer in one of the ovaries.

The cancer was gone for a while but reappeared in Wilson’s lung this past April. She is now being treated with letrozole, a hormone-blocking drug known as an aromatase inhibitor, and Ibrance (palbociclib), a targeted therapy that blocks CDK4 and CDK6, two proteins that play a role in regulating cancer cell growth. She feels good but says she is a little tired from the treatment.

Today, there are more therapies for metastatic breast cancer than ever before, with new ones currently being developed. When one treatment stops working or its side effects become too difficult to tolerate, another option is often available. Joining a clinical trial can be a good way to access the latest experimental therapies.

Wilson is now engaged. When she met her fiancé, she told him she had metastatic breast cancer. “He said, ‘OK,’ and laughed it off. He understood—but he didn’t understand,” she says. “So I explained to him and he said, ‘But you look fine!’ And I said, ‘What’s cancer supposed to look like?’”

In June, Wilson and her fiancé went to Disney World with more than a dozen of her relatives. Their wedding will take place in November, soon after she turns 43. “I found love after Stage IV,” she says.

Building Support

Wilson continues to advocate for people with breast cancer in South Carolina. At the hospital where she gets treated, “the doctors are doing their job, but the educational part is not there,” she says. When she met the hospital’s breast cancer manager, Wilson bluntly asked, “Where were you when I first got diagnosed at 32?” The facility has some helpful resources, she says, but not all patients hear about them.

As an example, she talks about the visit she and the breast cancer manager made to the hospital’s breast cancer support group. “I was the only African American there. I asked her, ‘Are y’all just letting the Caucasian people know [about the group] and not the African Americans?’ This is why we say it’s unfair to the Black community. Why do they know and we don’t know? It’s not about just one type of patient.”

Wilson attends conferences and advocacy training offered by national organizations such as Living Beyond Breast Cancer (LBBC) and the Young Survival Coalition (YSC). She distributes educational material from both groups at community events and at the hospital. She is a YSC state leader, and as an LBBC volunteer, she connects with others living with Stage IV breast cancer. She works with the African-American outreach program for the Metastatic Breast Cancer Project, which encourages people with advanced cancer to participate in research. She is also completing courses for her bachelor's degree in human resources.

Wilson's advocacy work led to the formation of a monthly support group. Members come from the South Carolina towns of Columbia and Sumter and are African American, White and Hispanic. "The community doesn't stop in just one place—it's everybody," Wilson says. Members talk about their concerns and help local patients who need rides to medical appointments or help paying overdue bills.

"People need to come together and realize that this cancer thing is taking a lot of us—how can we cope with it?" she says. "Everybody's got something. Some have high blood pressure, some have diabetes. I have cancer. I'm gonna roll with it."

Click here to learn about breast cancer among men.
