

A Metastatic Breast Cancer Diary: Jamil Rivers

Jamil Rivers, 42, is the board president of METAvivor, a nonprofit breast cancer organization. She was diagnosed with metastatic breast cancer at age 39.

December 14, 2020 As told to [Kate Ferguson](#)

February 2018

I got a cold in December that refused to go away, so I went to the doctor in January. This month, I felt a little pinch in my side, which lasted a couple of weeks, so back to the doctor I went. I requested a chest X-ray and an ultrasound to see why I was still coughing. The ultrasound showed lesions in my liver.

March 2018

I was given a mammogram plus a liver biopsy. I had Stage IV metastatic breast cancer. The results confirmed hormone-positive breast cancer with tumor cells that had spread to the liver.

I told my mom, my dad, my husband and my sisters but took a little bit more time to tell my three kids. I did not disclose it to anyone at my job at a nonprofit educational organization, where I just started five months prior.

I did my research and found the National Comprehensive Cancer Network's clinical practice guidelines. The doctor at my cancer center in Philadelphia presented his recommendations to me, but I also got a second opinion.

I learned everything I could about cancer and Black women. I wanted to see which treatments had the best outcome as far as survival and a durable response. I weighed all the information and decided to go with my cancer center's treatment plan.

April 2018

I began chemotherapy. I was in a lot of pain that seemed to get progressively worse. I experienced hot flashes and had gastrointestinal issues, skin irritation and rashes. One time, I was lying down on the couch and my kids were looking at me with real concern and fear. But there were light moments too. One day, my son said to me, "I know you're wearing a wig, Mommy, and I'm not going to leave the room until you show me your bald head."

May 2018

Luckily, I did not have nausea or diarrhea, so I continued to work. I took nutritional supplements and looked into integrative therapies, like acupuncture and massage. These treatments helped to reduce pain, constipation, skin irritation and hot flashes.

July 2018

I decided to go through Living Beyond Breast Cancer's advocate training program. I saw a dearth of information addressing Black women and the unique challenges we face.

September 2018

Slowly, I got through chemo and finished those treatments. I had pictures of scans in my phone when 60% of my liver was taken over by tumors. Now, I could see all the tumors shrinking.

October 2018

I had surgery to have my ovaries removed to suppress estrogen in my body. I remember being nauseous and out of it. My husband literally had to carry me out of the hospital.

January 2019

Since this month started, I've been clear: no new tumors, no new progression, no recurrence. I did [Susan G.] Komen's "In My Own Voice," an event that educates people about advances in scientific research and clinical treatment specific to metastatic breast cancer. It engages individuals in conversations about their unique needs, barriers they face and possible solutions to improve racial and ethnic breast cancer outcomes.

March 2019

Chemotherapy ended, and I launched a mentoring program for women with metastatic breast cancer. Initially, it started with other women coming into my chemo room and asking how I was doing. The program grew to about 50 women. I also started working with the American Cancer Society and Komen and got an idea for my own nonprofit, the Chrysalis Initiative. Its goals are to help African-American women assess their breast cancer risk, provide mentoring and resource navigation to women with breast cancer, and offer education to providers.

April 2019

People magazine found out about my story and featured me. Then, my whole family and I went on Good Morning America (GMA). That's when people at my job found out I had breast cancer. They were totally shocked.

Jamil Rivers with her husband, sons and GMA's Robin Roberts
Courtesy of Jamil Rivers

May 2019

I went to Capitol Hill with Komen and met with Congress about different legislation that needs to pass so breast cancer patients can get better support and more money for metastatic breast cancer research. In addition, I participated in the design of a clinical trial to address disparities, such as the low participation of patients of color. I became involved as a science advocate and got to see all the difficulties scientists think about when they're preparing to kick off a new project.

My husband and I attended a retreat for metastatic breast cancer patients given by METAvivor, a national nonprofit organization dedicated to funding research for Stage IV metastatic breast cancer. I was already familiar with the organization; I had supported them and donated to them.

July 2019

I did the Project LEAD training offered by the National Breast Cancer Coalition. Project LEAD is a science training program for breast cancer activists.

September 2019

I joined the board of METAvivor and became their treasurer. METAvivor is the only U.S. organization dedicated to funding annual Stage IV breast cancer research. They speak out about the lack of research for this type of cancer.

July 2020

I was just announced as METAvivor's first Black board president! In this new role, I plan to contribute to the organization's mission of transitioning metastatic breast cancer from a terminal illness to a chronic, manageable disease.

October 2020

I'm now on an aromatase inhibitor (which suppresses estrogen) and a CDK4/6 inhibitor, a targeted therapy that disrupts the cell division process that breast cancer cells must undergo when they start spreading through the body. For this type of treatment, the standard progression-free survival is about 28 months, which I'm approaching in January 2021. Also, last month, the Chrysalis Initiative became a formal nonprofit.

Every day, I'm on guard and waiting for the other shoe to drop. But I'm hoping that with all the new treatments and more money going into research, I can be one of those people who can live with this disease for a long time. I want to see my kids grow up so I can meet my grandkids.

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<http://beta.docker.cancerhealth.com/article/metastatic-breast-cancer-diary-jamil-rivers-1>