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.

October 19, 2020 As told to Kate Ferguson

February 2018

After I got a cold in December that refused to go away, I went to the doctor in January. This month, I felt a little pinch in my side, so back to the doctor I went. Last fall, we moved into a new house, so I thought that maybe I had hurt myself while moving around some boxes or maybe I had slept in a wrong position. The pinching wasn't painful, but the feeling in that area lasted for a couple of weeks. I knew that appendicitis and gallbladder issues run in my family, so at that follow-up appointment I requested a chest X-ray and an ultrasound to see why I was still coughing. The ultrasound showed that I had lesions in my liver.

March 2018

I was given a mammogram plus a liver biopsy. The results confirmed hormone-positive breast cancer, with tumor cells that had spread to the liver. I was one of the 6% to 10% of women with metastatic breast cancer who are diagnosed "de novo," meaning the undiagnosed breast cancer cells had already spread to other parts of the body.

It was really scary at that point. I knew this was really dire. When I finally got the confirmation that I had Stage IV metastatic breast cancer, I immediately told my mom, my dad, my husband and my sisters. I took a little bit more time to tell my kids. I also reached out to the oncology and social work team and the resource navigators at my cancer center in Philadelphia.

I connected with an oncology social worker at the cancer center and asked what the best way was to explain this to my kids. I wanted to make them less fearful and to know that cancer is not something that's contagious that would make them sick. I explained to them what cancer means and what this meant for our family.

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I knew I was going to lose my hair and my eyebrows and eyelashes, but I did not disclose to anyone at my job at Education Works—a nonprofit organization—that I was diagnosed with breast cancer. My husband was going through his own colon cancer ordeal and was now disabled, so I was the primary breadwinner. I had actually just started my job five months prior to being diagnosed, so I wasn't sure if I was eligible for FLMA [Family Leave Medical Act] status. The people at work don't really know me all that well yet. I just tried to keep working, keep my benefits and keep my family stable.

On the 27th, I got my head shaved and my eyebrows tattooed. I was set to start chemotherapy the

following week.

Jamil Rivers attends a Good Morning America show segment for an interview with Robin Roberts. She is pictured with her husband, Ricky, and sons, Tre, Joshua and Michael.Courtesy of Jamil Rivers

Honestly, I was devastated. My brain just couldn't conceptualize my kids having two parents with cancer. In addition, the year before, my mom had received a kidney transplant. My diagnosis was mind-boggling. What? Wait? Me? I have cancer? What is going on? I'd felt fine. I was pretty much working full-time, ripping and running, just a typical married mom of three doing my thing. I was really in shock but immediately thought, who is going to take care of my kids? What's going to happen to them?

I did my research and found the National Comprehensive Cancer Network's Clinical Practice Guidelines. I wanted to understand what should be done and what the best recommended treatment was for my situation. Then the doctor at my cancer center presented his recommendations to me. I researched who the top docs are and got a second opinion.

I learned everything I could about cancer and Black women. I learned about the disparities Black women face, the molecular differences in our tumors and how they respond to medication differently. I wanted to see what treatments had the best outcome as far as survival and a durable response. I found that clinical trial participation in America is really dismal when it comes to Black

people, and so I had to look up European and African studies.

I looked up cancer treatment responses of West African women, and my cancer center gave me a menu of options. Weighing that information, what my cancer center had immediately presented and then the second opinion, I decided to go with my cancer center's treatment plan.

April 2018

I began chemotherapy. It was awful! I was in a lot of pain. Every single crack and crevice of my body felt like I had been placed in a barrel and rolled down a hill. It seemed to get progressively worse. I was on a three-week cycle where I would go once a week, and then I would have the fourth week off.

Initially, I experienced hot flashes because of the chemo. I also 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. I wasn't my typical self, and I just felt really bad. I needed to find a way to be able to deal with the pain so they wouldn't feel so fearful.

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. This had really concerned me because where I work, my office is really far from the restroom. I was able to take nutritional supplements, and I began to look into integrative therapies, like acupuncture and massage. I hoped these treatments would help with any side effects. Fortunately, they did help to reduce the pain, gastro issues, skin irritations and hot flashes, which had intensified when I had my ovaries removed.

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, progressively, 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. I'm nurturing myself a lot and take advantage of every single support resource known. Because I'm my husband's caregiver, I didn't want him to be stressed out and overwhelmed with having to switch roles and take care of me.

I accepted support from the American Cancer Society. They picked me up from my job, took me to my chemo appointments and brought me home. I had Cleaning for a Reason, a nonprofit that provides free housecleaning services to women undergoing cancer treatment, come in to clean. I took advantage of an organization that sets up playdates for your kids and people doing grocery

shopping or giving you mail delivery gift cards. My advice is to take advantage of all of that so you can focus on taking care of yourself. When people ask, “Hey, you need anything?” My answer is, “Well, yes, I do!”

October 2018

I had surgery to have my ovaries removed to suppress the estrogen in my body, which promotes cancer growth. I remember being so nauseous and just so 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 the [Susan G.] Komen In My Own Voice event. This event was launched to educate people about the latest advances in scientific research and clinical treatment specific to metastatic breast cancer. The event engages individuals in conversations to learn about their unique needs, barriers they face and possible solutions to improve racial and ethnic breast cancer outcomes.

March 2019

This month my chemotherapy ended, and I launched a mentoring program for women with metastatic breast cancer. Initially, it just started with other women coming into my chemo room and asking, “Hey, how are you doing?” and “You don’t really look like you’re doing so bad. Can you share what you’re doing so we can maybe trade notes?”

That’s how the program started, and then it ended up growing to about 50 women. At that point, I said, “I can’t take on any more people.” My husband looked at me like, Who are you talking to? It’s late at night, and I feel like maybe I’m an oncology social worker or nurse navigator myself, so I started working with the American Cancer Society and Komen. That’s when I got an idea for my own nonprofit, the Chrysalis Initiative. Its goals are to provide mentoring and resource navigation to women with breast cancer as well as help African-American women assess their breast cancer risk through outreach and education. In addition, Chrysalis also offers education to providers.

Then, as an advocate for those living with metastatic cancer, I testified before the Food and Drug Administration.

Jamil Rivers giving FDA testimonyCourtesy of Jamil Rivers

April 2019

People magazine found out about my story and featured me. Then, my whole family and I went on Good Morning America. That's when people at my job found out I had breast cancer. I finally told them what was going on. They were totally shocked; they had no clue. But now that they know me, they can't question my work ethic, performance or anything because I did hold it down.

May 2019

I went to Capitol Hill with Komen for the advocacy summit. I 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. Statistics show that only 2% to 5% of research dollars are focused on treatments for patients with Stage IV breast cancer.

In addition, I participated in the design of a clinical trial to address some disparities, such as the low participation of patients of color.

Also, I reviewed research proposals with the Department of Defense's Breast Cancer Research program and with Komen. They are scored on how inclusive clinical trials are of advocates, diversity recruitment and barrier interventions. I became involved as a science advocate in the

clinical trial design process. I sat at the table along with the researchers and got to see all the different difficulties that scientists think about when they're preparing to kick off a new project.

Some of those concerns include how they make sure that the trial reflects the actual population of breast cancer patients so there's a meaningful percentage of Black people participating. In addition, researchers want to have some community-based partnerships and relationships to make the study more accessible and able to deal with the types of costs that could be a challenge for people to enroll in the clinical trials. This gave me a chance to learn about some of these barriers faced by scientists when they're organizing studies of this kind.

I attended a retreat for metastatic breast cancer patients with my husband. The event was given by METAvivor. This national nonprofit organization is 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, another organization that's hugely involved with advocacy. Project LEAD is a science training program for breast cancer activists that prepares them to participate in local and national forums about cancer research and public policy.

September 2019

I joined the board of METAvivor, became their treasurer and got involved with everything that they're doing. 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.

February 2020

I did the annual New York Fashion Week fashion show with Cancerland and designer AnaOno. The proceeds went to METAvivor. Tickets were 100% tax deductible, and 100% of every donation goes to fund research for Stage IV metastatic breast 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 that doesn't stop people from having a good quality of life.

October 2020

When I get my next set of scans at the end of the month, hopefully, they will still be clear. I'm hoping to ride this out. I'm now on targeted therapy and on an aromatase inhibitor, which suppresses estrogen production in my body. I'm also on a CDK4/6 inhibitor, a drug that, basically, disrupts the cell division process that breast cancer cells must undergo when they start spreading

through the body.

Typically, the standard progression-free survival on this type of treatment is about 28 months, which I'm approaching in January 2021. But I've seen people who have been on this treatment for seven, 10 or 13 years, so, yeah, I'm trying to ride this out as long as possible.

However, I do have a game plan if I get a bad scan. If that time comes, I'll be prepared to deal with it and go through the whole process of testing and second opinions so a new strategy can be mapped out.

Since I made Chrysalis a formal nonprofit and finished the paperwork last month, that task is done. But right now, this is all still fairly new.

I know it's been two and a half years, but the time just kind of flew by. I feel like every day I'm just on guard and waiting for the other shoe to drop. But I'm hoping that with all the new treatments and us getting more money for research, that 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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