

Metastatic Breast Cancer

FEEL THIS MOMENT:

Making Goals and Celebrating Milestones

BY ERIN ROWLEY

There aren't many things more distracting than metastatic breast cancer. It can be hard to find joy in everyday life when all you can do is worry about your next appointment or your next scan. You may also worry you'll miss out on big moments — like reaching a certain birthday, or seeing your children or grandchildren get drivers' licenses, go to the prom, graduate from school, get married or have kids.

"Those [big milestone events] are very motivating for people, and those help people. But ... we try to find other things that are [also] motivating that are just a little bit more mundane but are also part of the joys of life," says **Pamela Ginsberg, PhD**, a licensed psychologist who is in private practice, and on staff at Doylestown Hospital, in Pennsylvania. Dr. Ginsberg specializes in women's health and wellness.

Dr. Ginsberg often talks to people she treats about how being present in the moment can help them enjoy life more. Having dinner together as a family, writing your thoughts in a journal, or going for a walk and taking the time to enjoy a beautiful day, and truly focusing on what's happening in those moments without letting your thoughts wander, is worth looking forward to and enjoying, she says.

But these moments don't always happen on their own. By making and meeting achievable goals like meeting up with a friend you haven't seen in years, going to a place you've never been, learning a new skill, attending a child's recital or finding a new hobby, you can create small, memorable moments every day.



Krista Lawrence, left, on vacation with her daughter

Here are three women's stories of how metastatic breast cancer affected the way they make goals and celebrate milestones in their lives.

'Carpe the Heck Out of Each Diem'

Krista Lawrence, 54, from West Hartford, Connecticut, looks at those big life milestones, like seeing her children get married and have kids, as "bonuses." Of course she hopes to be here for them, but she doesn't dwell on those hopes.

Instead, she enjoys the time she has with her loved ones by creating memorable moments worth celebrating. About a year after she was diagnosed with metastatic breast cancer in July 2014, she took a trip to Montana with her grown children. Since then, she has also gone to Paris with her son and Aruba with her daughter.

"What I try to do today is seek out the relationships that I value," she says. "It's no longer about what I can accomplish, what I can do, it's really about making solid connections and spending meaningful time [with the] people that I love on a daily basis."



Lesley Glenn



Gwynne Martin

“My greatest joys are the littler, more immediate moments of every day. They’re all huge because they are all part of what is making the fabric of my life. I am living fully and actively with joy, hope and fun.”

After the Montana trip, she realized she didn’t want to spend her remaining time in an office. So she listened to the recommendation her doctors had made all along, and left her job, taking long-term medical leave that eventually led to early retirement.

Though it wasn’t the normal circumstances that cause most people to celebrate retirement, not working has allowed Krista to make the most of each day, or as she puts it, to “carpe the heck out of each diem.”

She doesn’t make very long-term goals, because she doesn’t know how she’ll be feeling. Planning last January to take part in a breast cancer walk in the fall, with the understanding that she wouldn’t participate if she wasn’t feeling well, is about as far ahead as she gets. (She successfully completed that walk in October.)

She recently remembered rollercoasters aren’t just for use in metaphors about the ups and downs of metastatic breast cancer, when she and a friend went to an amusement park and rode them all day long. Though that might be a fairly ordinary day for some, for Krista, it was an important milestone.

She sees each day as a goal, and the moments and experiences that are part of those days are her milestones.

“My greatest joys are the littler, more immediate moments of every day. They’re all huge because they are all part of what is making the fabric of my life,” she says. “I am living fully and actively with joy, hope and fun.”

‘I Wanted to Take Control of My Life’

Lesley Glenn, 51, from Chino Hills, California, was diagnosed with metastatic breast cancer in 2012. In 2015 she decided to start making one big goal for herself each year, as well as smaller goals to help her get there. Her big goal that year was to climb California’s Mount Whitney, the highest summit in the lower 48 states. In training for that, she also completed the 52 Hike Challenge, which encourages participants to hike once a week for a year.

Lesley couldn’t have imagined setting goals like these in the months following her metastatic diagnosis.

“It probably took me a good 2 years to navigate exactly what it meant to live with a stage IV diagnosis,” she says.

But slowly, things began to change. She hadn’t been an outdoorsy person before, but now, the outdoors called to her. When she first started, she could barely hike a mile. But she trained, and eventually found herself at Mount Whitney. Overwhelmed with emotion, she cried her way to the top of the mountain. Lesley, an LBBC volunteer, also used this climb to raise more than \$3,000 for Living Beyond Breast Cancer.

In 2016, she made and completed small goals including rock climbing (“I was horrible at it!” she says with a laugh) and trail running. In September, she completed her big goal — a 1-week backpacking trip into Havasu Falls, an area in the Grand Canyon.

“It’s one of those magical places that everyone says ‘You have to go there before you die,’” she says.

But there have been some bumps along the road. The first months of 2016 were rocky. Lesley lost several friends to metastatic breast cancer. That got her thinking about her own mortality. She started to wonder “Why am I doing this?” and “What’s the point?” But ultimately, she decided she wanted to continue making the most of every day.

“What I have learned ... is that I wanted to take control of my life and how I was going to live with [metastatic breast cancer],” she says. “Getting outdoors, making these small goals for myself, and making at least one big huge one for

the year is something that has motivated me and helped me to advocate for myself [as I cope] with stage IV breast cancer.”

Turning ‘Some Day’ Into Now

In October, **Gwynne Martin**, 49, from Mechanicsburg, Pennsylvania, walked 50 miles in 3 days for the Susan G. Komen 3-day walk in Philadelphia. She did this despite blisters on her hands and feet, caused by the chemotherapy she gets for metastatic breast cancer. She had signed up before she was diagnosed. But she had a team that was counting on her.

Doing a walk like that isn’t something Gwynne thought she was capable of immediately after she was diagnosed with metastatic breast cancer, in May 2016. At first, the only goals she could make were getting through the next doctor’s appointment. Symptoms and side effects made even leaving the house difficult. But family and friends helped her adjust to the changes her diagnosis brought, so she could start living life to the fullest.

Gwynne and her sister were planning a Christmas vacation to Key West when Gwynne was diagnosed with metastatic disease. They booked a place to stay, but hadn’t yet booked

flights. Despite the diagnosis, Gwynne’s oncologist was very positive, and Gwynne’s sister was enthusiastic about going ahead with the planning. So this Christmas, Gwynne and her family will be in sunny Florida instead of cold (and likely snowy) Pennsylvania.

Post-diagnosis, Gwynne rarely turns down an opportunity to see a loved one, even if it means driving a few hours and back just for dinner.

Friends and family also helped her create a “bucket list” of sorts. One thing on the list that Gwynne had wanted to do for a long time was take a class at the King Arthur Flour Company, in Vermont. Gwynne had previously shrugged it off and said she’d do it “some day.” But a friend of Gwynne’s decided “some day” should be now. She signed them up for a pizza dough-making class, and off they went, making the 7-hour drive, stopping wherever they felt like — no kids, no husbands, not even a hotel booked beforehand. It was out of character for women who are usually careful planners, Gwynne says, but that’s part of what made it so fun.

“I didn’t think about my cancer one time when we were on that trip,” she says. 🍷

LIVE LIKE A QUEEN:

A Q&A With Sarah White

BY ERIC FITZSIMMONS



Sarah White

Sarah White, 36, of Huntington, West Virginia, does not mind the spotlight. She first participated in pageants in her teens, and when she was diagnosed with early-stage, triple-negative breast cancer in 2013 she dealt with it in a very public way by joining a dance competition in the style of “Dancing with the Stars.” When she learned last year that she had metastatic breast cancer, she went back to her roots and pursued a state pageant crown. She entered a pageant run by Miss All-Star United States and in April won the title of Mrs. West Virginia. Since then, Sarah, a special education teacher and mother of two, has been using her crown to help bring attention to breast cancer issues at schools and in the state capitol, where she has worked with legislators to increase access to breast cancer screenings. Sarah has been open in news coverage about her decision to enter a clinical trial and her mission to help other people see them as treatment options.

She spoke with Living Beyond Breast Cancer's copy editor and content coordinator **Eric Fitzsimmons** about what it was like competing in a pageant as a woman with breast cancer and how she has been using her crown to inspire others.

Eric

What inspired you to enter a pageant as someone with breast cancer?

Sarah

As a teenager I always wanted to be a state titleholder, but it was always about the crown. It had nothing to do with what you could do with a crown or a title, it was just "Ooh, a pretty tiara!" This time it was about what I could do with it, the platform that I could [use to] show other women that are fighting the [same] fight that they don't have to wallow in it — that they can be a queen. They can be what they want to be and do what they want to do. ... Stage IV does not mean that you are dying right now.

Eric

What challenges did you face getting up on stage after being diagnosed?

Sarah

I have been on the stage since I was about 3 years old. I have been in front of people my entire life, so being on stage was not the difficult part. It was preparing my body, because I was not ready for pageantry at all. So when I decided to do this last October I had to start taking care of myself, and I needed to change [my lifestyle] anyway because of cancer, so this was a good way for me to do that.

I started doing Pilates twice a week. I started eating healthier. ... I was trying to not eat a lot of processed foods and [I paid attention to] portion control.

So that was the hard part, having that mindset and that goal to prepare my body for being on stage because it wasn't just eveningwear, it wasn't just an interview, I had to put on a bathing suit, and as a mom with two kids I didn't have the bikini body that I wanted.

Eric

What impact did having had breast surgery, wearing a wig, and dealing with treatment side effects have on you as you competed in the pageant?

Sarah

It was actually kind of easy with the wig ... where other women are fretting about their hair, I just put [the wig] on my head and fixed it and didn't have to worry about my hair!

And it's all about confidence ... regardless of how large your breasts are or how small they are, being in a bathing suit, being onstage or offstage, it's all how you feel about yourself.

Eric

How are you using the Mrs. West Virginia title to bring attention to breast cancer issues?

Sarah

Right now, I work with the American Cancer Society's "Look Good, Feel Better" program where I teach women how to apply their makeup, draw their eyebrows, hide their scars. And [for them] it is a relief when I take off my wig and they see that the person teaching them is also going through this traumatic experience of chemotherapy. I am also working with some of the high schools in my area. I am talking about breast cancer and self-checking and awareness to the high school students.

Eric

You have spoken about clinical trials. Why do you think they are important?

Sarah

Well, I'm on a clinical trial. I quit responding to chemotherapy in May and Cleveland Clinic had a clinical trial that accepted me. A lot of people are afraid to try clinical trials. "What if it doesn't work? What if my body rejects it?" ... People are afraid. We only live once and a clinical trial can save your life. I have two babies: I have a 7-year-old and a 3-year-old. I want to see them grow up — that's what my fight is. Life is short and you have to live it, and if you want to live it to the fullest, you have to try to do everything you can. So, if a clinical trial is there, why not? 🍷

BEYOND THESE PAGES

Aside from providing the people in the trial with a new treatment that has the potential to extend their lives, clinical trials advance research and help doctors learn more about breast cancer. All of today's standard treatments exist because of clinical trials.

For more information, read our *Guide to Understanding Clinical Trials*, available at LBBC.ORG

