

FALL 2017

Insight



LIVING BEYOND
BREAST CANCER®

With you, for you.

BALANCING ACT:

Treating Breast Cancer and Other Conditions at the Same Time

BY ERIC FITZSIMMONS

Kimberly and Shane Dafforn



Kimberly Dafforn, of Fort Wayne, Indiana, is 48 years old and has been living with hormone receptor-positive metastatic breast cancer since 2007, for which she takes different medicines including palbociclib (Ibrance). She also takes methotrexate to treat rheumatoid arthritis, a disease that can cause painful swelling in the joints. Because both medicines can affect her blood cell counts, her doctors continually check her counts and share the results with her. If they get too low, Kimberly knows to speak with her different specialists about what treatments will change, and how.

Dealing with side effects of multiple medicines is just one of the issues people face when they need treatment for more than one condition, a situation that is very common.

Kimberly also has diabetes, so she must deal with arthritis pain, making sure she takes all her treatments on time, and many extra

doctors' appointments. She meets regularly with an oncologist for breast cancer, a rheumatologist for arthritis and an endocrinologist for diabetes.

"Taking care of my health is becoming a full-time job," Kimberly says.

Many factors go into deciding how to treat breast cancer. A comorbidity, a condition you have in addition to breast cancer, can make that decision even more complex. Comorbidities are common and becoming more so. As people are living longer, they are more likely to develop multiple conditions associated with getting older, says **Gretchen G. Kimmick, MD, MS**, a medical oncologist with the Duke University Health System, in Durham, North Carolina.

The same health conditions that are common in people with breast cancer and cancer in general, says Dr. Kimmick. These include heart disease, high blood pressure, diabetes, obesity and other cancers. When you have more than one condition, your doctors must consider possible medicines for each one and how they might interact with each other or affect the other conditions.

Navigating Your Healthcare Team

Monique Lloyd, 51, of Newcastle, Delaware, learned early that finding doctors you trust and making sure they speak to each other and to you is key to dealing with multiple conditions.

Monique has two forms of the autoimmune disease lupus. With an autoimmune disease, your immune system, the organs and cells that protect your body from infections, attacks healthy cells by mistake. Lupus symptoms come in episodes, or flares. These flares can be triggered by taking certain medicines, having surgery, getting an infection, or mental or physical stress, all of which are common experiences during cancer treatment.

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Dear Friends,

At Living Beyond Breast Cancer, we often meet people during some of their most challenging moments. But we also get to see moments of joy and relief: people finishing active treatment, celebrating a certain number of years past diagnosis, or connecting with others who know what they're going through.

We often saw LBBC board of directors members **Ayanna Z. Kalasunas** and **Lauren Bolen** at their best. And they helped us be our best, in many ways.

Ayanna was funny and beautiful, and passionate about being a voice for young women with metastatic breast cancer. She spoke at LBBC programs, wrote blog posts and participated in LBBC photo and video shoots. She received a Going Beyond Award at our 25th Anniversary Butterfly Ball last November.

Lauren was brilliant, and essential in helping LBBC develop our most recent strategic plan. She had a talent for wading through data and figuring out what was most important, and for helping people with different opinions come to an agreement.

But challenging moments were still there. And in May and June, respectively, Ayanna, at age 37, and Lauren, at age 58, died of metastatic breast cancer.

People close to each woman are honoring them by serving out the rest of their board terms.

These losses hurt us deeply. But they make us want to work even harder to honor them and you, our friends who are living with, and beyond, breast cancer. We'll always be here to celebrate your moments of joy and support you during your moments of challenge.

Warmly,



Jean A. Sachs, MSS, MLSP
CEO

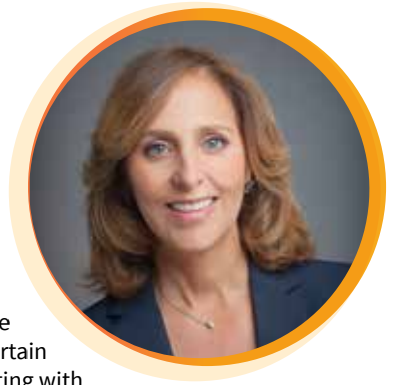
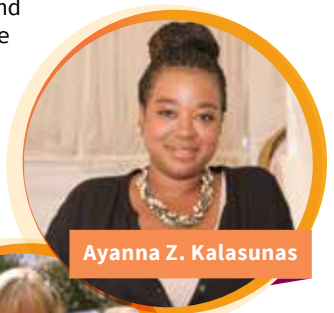


Photo: BECK Photography



Ayanna Z. Kalasunas



Lauren Bolen

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This issue of *Insight* is supported by



News & Education

BY KENDRA LAWTON-AJUBA



Sharing Wisdom, Sharing Strength



There is still time to join us October 6-8 in Memphis, Tennessee, for the **2017 Living Beyond Breast Cancer Conference**. Learn from experts about the latest medical updates while sharing tips and advice with other attendees. The 3-day weekend includes our popular Shimmer & Shine reception on Friday evening, conference sessions on Saturday and our signature yoga event Reach & Raise on Sunday.

View the schedule and register at lbbc.org/2017conference. If you're unable to attend, check our website in early November for resources from the conference.



October 13 Is National Metastatic Breast Cancer Awareness Day

This day is dedicated to recognizing and bringing awareness to stage IV breast cancer. If you'd like to get involved, like us on Facebook, follow us on Twitter and help us share information about metastatic disease.

Visit facebook.com/livingbeyondbreastcancer and @LivingBeyondBC on Twitter.  

Upcoming LBBC Programs on Recurrence

How to prevent cancer from returning, and fear of it coming back are two of the most common concerns among people with breast cancer. LBBC has two upcoming programs that focus on recurrence.

On November 15, LBBC will host a **Breast Cancer 360** program explaining what we know about why breast cancer recurs, which tests doctors use to look for "sleeping" cancer cells and what you can do if you are at high risk for cancer to become metastatic. The program will explore clinical trials, the strengths and limits of tests, and changes you can make in your everyday life to support your good health. You can attend live in Philadelphia or via web stream.

In December, we will present a **webinar** that discusses fear of recurrence: why it happens, what triggers it and how you can get support to manage your fear.

For more information, visit lbbc.org/programs-events.

Lymphedema: What You Need to Know

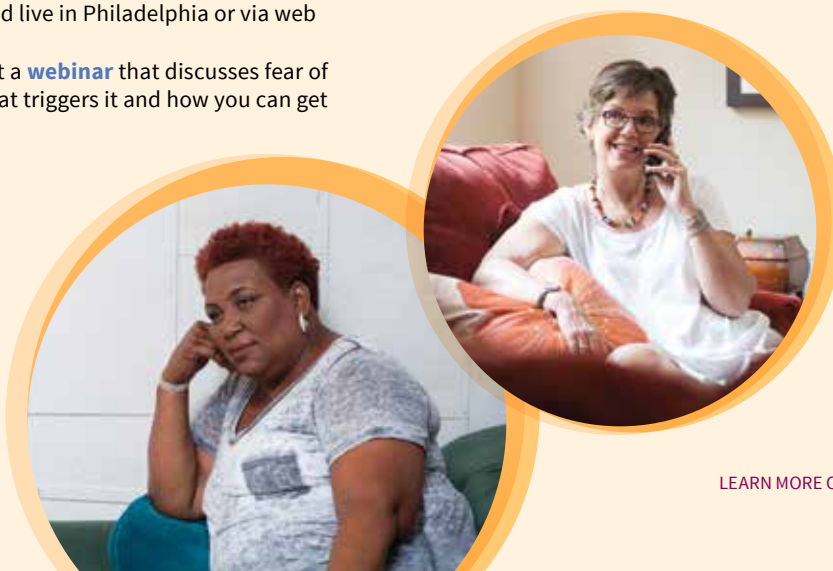
Did you miss our recent webinar on lymphedema? You can still listen to the presentation on our website. During the webinar, you will learn about the causes of lymphedema and about early prevention strategies. Hear our guest panelist, **Stanley Rockson, MD, FACP, FACC**, discuss the treatments available for managing lymphedema, the latest research and how it could impact you.

To listen to this program, visit lbbc.org/lymph.

Breast Cancer Helpline

When you're ready to talk, we're ready to listen. Reach out to our **Breast Cancer Helpline** and we will match you with a trained volunteer who has been diagnosed with breast cancer. They can provide you with emotional support and share practical information. All interactions are completely confidential. Women and men diagnosed with breast cancer and their caregivers are invited and encouraged to use the Helpline.

You are not alone. Visit lbbc.org/helpline to connect to someone who's been there. 🌟



MORE THAN JUST TIRED:

Cancer-Related Insomnia and Fatigue

BY ERIN ROWLEY



Beverly Phelps, 50, from Metairie, Louisiana, says she usually gets just 2-3 hours of sleep a night. She was diagnosed with triple-negative early-stage breast cancer twice, in 2012 and 2015.

Beverly felt like she was the only person in the world experiencing insomnia, trouble falling or staying asleep; and fatigue, extreme tiredness and lack of energy that makes it hard to function, even when you're getting a lot of sleep. Then she started talking to other people with breast cancer and realized she was not alone.

About half of people in treatment for cancer experience insomnia, and almost all feel fatigued at least some of the time, says oncology advanced practice nurse **Evelyn Robles-Rodriguez, RN, MSN, APN, AOCN**. Even after early-stage cancer treatment is done, she says, more than 80 percent of people may experience fatigue related to treatment. And for those with metastatic breast cancer, continuous treatment can mean continuous fatigue.

What's the Cause?

Breast cancer itself puts stress on your body that can cause insomnia and fatigue. So do treatments such as surgery, radiation, chemotherapy and targeted therapy. Hormonal therapy has a reputation for causing extreme tiredness. The menopausal symptoms it can cause, like hot flashes, can make it hard to fall or stay asleep, Ms. Robles-Rodriguez says. Chemotherapy that throws young women into menopause can have the same effects.

Sharon Borrelli, 62, from Weymouth, Massachusetts, was diagnosed with early-stage breast cancer in 1997 and metastatic breast cancer in 2012. She stopped working about 6 months after the metastatic diagnosis, partly because of fatigue. Then whole-brain radiation therapy made it worse.

"[The fatigue]'s very powerful and it affects my life on a daily basis," Sharon says.

She tries to schedule any appointments between 11 a.m. and 2 p.m. so she can sleep late in the morning and nap in the afternoon. Still, by 8 p.m. she's ready for bed. But she usually doesn't sleep through the night. Sometimes, after not sleeping well for days, she'll sleep for 12-18 hours.

Pain keeps many people with cancer from falling asleep, or wakes them in the middle of the night. The emotional toll of cancer can also cause insomnia and fatigue by sending your thoughts racing at night and sapping your energy during the day. Fear of recurrence often keeps Beverly from sleeping.

"I have anxiety because once they tell you you have cancer, you're afraid you'll get it again," she says.

Treating Insomnia and Fatigue

In early-stage breast cancer it's unusual to change treatment because of fatigue, Ms. Robles-Rodriguez says. But if it's caused by severe anemia, a lower than average number of oxygen-carrying red blood cells in the body that can worsen fatigue, your doctor may recommend decreasing your dose of chemotherapy.

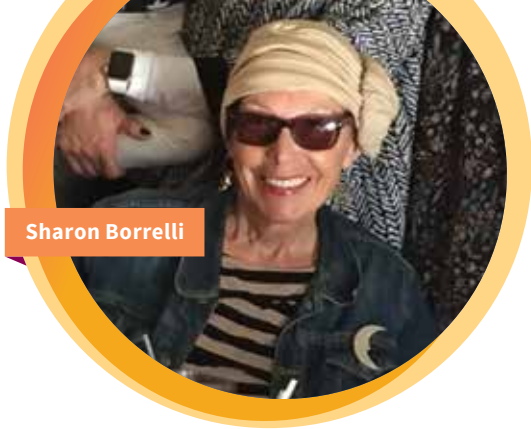
In metastatic disease, though, it's more common to change treatment if it's causing severe anemia that could lead to blood transfusions becoming necessary. Providers want to make sure you can maintain your lifestyle as much as you can, and more importantly, have good quality of life, Ms. Robles-Rodriguez says.

Whether changing treatment is an option or not, "it is really important for patients to discuss these things with their providers. Patients may not realize there are tips and therapies that may help them cope with these problems," Ms. Robles-Rodriguez says. And sometimes providers are so focused on treating the cancer itself, they do not ask about side effects like insomnia and fatigue that are not considered life threatening.

Here are some suggestions for treating cancer-related insomnia and fatigue:

EXERCISE

Though it seems to go against common sense, studies show regular exercise is the best treatment for insomnia and fatigue, Ms. Robles-Rodriguez says. Continuing physical activity you did before your diagnosis during treatment may stop severe insomnia or fatigue from developing in the first place. Even if you weren't



Sharon Borrelli

active before your diagnosis, starting now, under the guidance of your healthcare providers, can help.

Ms. Robles-Rodriguez encourages everyone to get moving, even if you start with just walking to the mailbox and back. Exercise is just as important for people with metastatic disease as it is for those with early-stage disease.

“As long as the patient is physically able to maintain an activity, you want them to do that,” she says.

Complementary therapies like yoga, meditation, guided imagery and tai chi can also prevent insomnia and fatigue. Sharon does yoga and, when she can afford it, gets acupuncture. Sometimes these activities help her fall and stay asleep, she says.

DIET

Caffeine is a stimulant, and having it in food and drinks like coffee, tea and energy drinks in the afternoon or evening can make it hard to sleep. It’s also a diuretic, which means it may make you need to use the bathroom during the night. To prevent those bathroom trips, you should also avoid other fluids close to bedtime (though if a little milk or tea helps you fall asleep, that’s OK). Alcohol may make you sleepy, but it can also hurt your sleep quality and make you wake up early. Avoid big meals close to bedtime: They can cause heartburn, making it hard to sleep.

There is conflicting research on whether supplements, like melatonin, can safely help people with cancer sleep better. Talk to your doctors before taking any supplements. Some could cause your cancer treatment to work less well.

SLEEP HYGIENE

Lifestyle choices that make it easier to fall asleep, stay asleep, and wake up rested are called “sleep hygiene.”

Ms. Robles-Rodriguez says the bedroom should be used only for sleeping and sex. All other activities should happen elsewhere. Many people use electronics near bedtime or when they wake up in the middle of the night, but that can make it harder to sleep.

“The more you wake yourself up by becoming active during that night cycle, the more your body is going to get out of rhythm” and expect to read, eat or watch TV in the middle of the night, she says. “I tell my clients, ‘You don’t need to have that phone next to you at all times. Leave your phone away from you where it won’t disturb your sleep,’” or turn it off.

If you wake up too early, she recommends keeping your eyes closed and meditating until you fall back to sleep. If that doesn’t work, many sleep specialists suggest getting up, leaving your bedroom and doing something relaxing until you feel sleepy again.

PRESCRIPTION SLEEP AIDS

It’s best to use prescription sleep aids only after you have tried everything else, Ms. Robles-Rodriguez says. That’s because some prescription sleep medicines haven’t been studied well in people who have cancer, and could make cancer treatment work less well. They can also be addictive, making them an especially bad option for someone like Sharon, who has experienced addiction in the past.

“I don’t want to start taking [prescription medicines] for sleeping ... unless I’m really desperate,” she says.

Talking About Fatigue With Others

Insomnia and fatigue can affect your relationships. It can make you irritable and more likely to snap at your loved ones, Ms. Robles-Rodriguez says. It can also keep you from doing things you enjoy with people you care about, and from working or doing chores.

Everyone knows what it’s like to feel tired. But people who have not had cancer or another serious illness may not understand how extreme your tiredness can be. Sharon says she must often remind loved ones that cancer means she doesn’t always have energy to make plans.

“Sometimes people don’t understand, because the fatigue that you can have with cancer may not be the same kind of fatigue like ‘I worked hard all day and now I feel tired,’” Ms. Robles-Rodriguez says. Open communication is important to helping loved ones, co-workers and others better understand you aren’t ignoring them or slacking off — that you’d like to do more, but simply can’t.

Ask loved ones along for activities that can lessen fatigue, like walking or yoga. Ms. Robles-Rodriguez also says taking a loved one with you to an appointment so they can hear from a doctor that fatigue is a real and serious symptom or side effect of cancer and its treatments can help them better understand what you’re going through. 🍌

Ways to Quiet the Mind and Save Energy

- 

Cook meals in bulk and freeze for later, or order takeout
- 

Carpool instead of driving yourself
- 

When preparing to go sleep, turn off your smart phone, tablet, computer and other gadgets
- 

Meditate to relax your mind

Faith and Spirituality

BY ERIN ROWLEY



Veronica Johnson

Faith and spirituality often help people with cancer find meaning in illness and provide comfort in the face of fear and uncertainty. Connection to a caring network of support can be another benefit. Faith-based communities may also assist with the practical challenges that come with a breast cancer diagnosis: help around the house, with meals, with rides to medical appointments, and with other types of hands-on care.

Here, three women write about the role faith has played in coping with breast cancer.

Judy Zainfeld, 67 Houston, Texas

Religion: Reform Judaism

Diagnosed with stage I HER2-positive breast cancer in 2010

Breast cancer diagnosis and treatment was quite shocking and unsettling. But I was completely surrounded by an amazing support system: my family, my friends and my faith. I could see my synagogue from the windows each time I went in for infusions. My faith has been guiding me for years, through the worst of times and the best of times. While in treatment I celebrated my 60th birthday and was blessed at my temple. I was able to attend Kol Nidre services, the opening prayer of Yom Kippur, my favorite services, if I promised not to hug or kiss people and sit near the back, to protect my weakened immune system. Just being able to sit in the house of worship and participate in prayers and songs was so important. My legs didn't have the strength to stand, but I was there.

I remember calling my rabbi and asking him for extra prayers. He said he would put my name on the Mi Shebeirach list, for people in need of healing. He knew

I always said prayers and said to me

“Judy, don't forget to include yourself in your prayers.” That took my breath away as I never thought about praying for myself. My rabbi told me years ago, after my father's funeral, that God never takes away without giving back. Six months later I met my future husband. Chemo took away my



Judy Zainfeld

hair and strength, but God gave me plenty of fight. I in turn have helped others with their journey.

God blessed me with the greatest parents, sister, husband, daughter and friends. God held my hand through this long journey. I'm a very blessed woman!

Veronica Johnson, 58 Worcester, Massachusetts

Religion: Nondenominational Christianity

Diagnosed with ductal carcinoma in situ (DCIS) in 2017

It all started with the flu. On January 20, 2017, while coughing up what felt like a lung, I noticed an explosion of blood on my shirt. Within days, I went through the usual tests. While being prepped for the biopsy, the tech offered to play music. I requested Third Day, my favorite Christian rock band. I became teary-eyed as I pondered the likely diagnosis. Then, I heard the Third Day song, “I've Always Loved You.” Some might see this as a coincidence, but I know better. The chorus goes:

Don't you know I've always loved you
Even before there was time
Though you turn away
I'll tell you still
Don't you know I've always loved you
And I always will

And then I cried a little more! What should have been a very painful biopsy was filled with chatting and laughter with the Christian tech. There were many moments like this when I felt God's reassurance.

On February 7, I learned I had breast cancer. Many might see this as a death sentence, but thank God it was ductal carcinoma in situ (DCIS), a non-invasive, stage 0 cancer, localized in one breast. If you're gonna have breast cancer, this was the most favorable kind. My husband and I met with the oncology team and were joking during much of the meetings. The team psychologist couldn't quite understand why I didn't blame anyone, including God. I just smiled and said, “He loves me!” She asked about stress relief. Before I could tell her, my husband blurted out, “She goes into her prayer room and prays!”

And that's what has made the difference. I had a mastectomy on March 2, 2017. It took the two surgeons 9 hours to remove and reconstruct the breast. The reconstruction used tissue from



Harini Ganesan

my tummy. I thought, cool, a tummy tuck and boob job all in one! Since then, I've had two additional surgeries. Though I'm still recovering from the surgeries, the important thing is this: I am cancer-free. I do not require radiation or chemo or any other cancer drugs.

I'm a member of Lifesong Church in Sutton, Massachusetts, a nondenominational Bible-based church that believes in the power of prayer. I feel blessed that God has given me a strong connection to a praying church family, especially a strong bond with a wonderful sisterhood of praying women. When this adventure began, I contacted my chat group of prayer warrior women, known as "the 12." All of these women began to cover me in prayer. With the prayers of so many and my trust in the faithfulness of God, I could only have peace.

Now, I am not saying that there have not been difficult times: uncomfortable drainage tubes, no showers for three weeks, falling off an air mattress the second day out of the hospital, pain, swelling, [and] boredom. I have watched more British TV series than I can count!

I have no bitterness nor do I blame God. I don't feel the need to ask "why me?" I am grateful for the love, support and especially the prayers of friends, family, church family and colleagues. It's been humbling and sustaining. I must also give special props to Cliff, my husband of 16 years. He has shown such strength, love, devotion and care for me that, again, I am deeply humbled and blessed. Sometimes, I feel a little guilty that I am included with those who've had a worse experience with cancer. Still, I am grateful for my outcome and pray for those who have not been as fortunate.

Faith and spirituality often help people with cancer find meaning in illness and provide comfort in the face of fear and uncertainty.

Harini Ganesan, 37 Santa Clara, California

Religion: Hinduism

Diagnosed with stage IIIA, hormone receptor-positive breast cancer in 2015, diagnosed with metastatic disease in 2017

I am Hindu but [I see it as] more than [a] religion. I look at it as a way of life. It allows me to follow good practices and kriyas, exercises that strengthen the body, mind and soul. My journey with Hinduism has led me from ritualistic to spiritual.

Before any of my treatments, to take my mind off of it, not only would I pray, but also chant a few shlokas: prayers or hymns that require my full attention. The words are very soothing and due to the immense concentration it requires, I do not have any other thoughts troubling me. It works well as I get to pray to my Ishta Deveta — favorite god (we do have plenty of them) — and in turn I feel more calm and relaxed before a big scan, procedure or treatment.

A lot of my practices that I learned growing up came in handy when I was initially diagnosed. I took comfort in going back to practicing some of the rituals I used to practice as a kid. I chant "Om" and it reverberates through the mind and body and sets my mind in a pleasant frequency. I do breathing exercises, called pranayama, to help keep my focus and also improve oxygen intake. For the community aspect of it, I go to a temple and attend the worship, called aarti, every week and the hymns calm me down. I also volunteer at the temple and the emotional, physical and spiritual support I get from the other more experienced volunteers has been very comforting. It reassures me that I will be taken care of by the universe. 🙏



BEYOND THESE PAGES

The **2017 Living Beyond Breast Cancer Conference: Sharing Wisdom, Sharing Strength**, October 6 in Memphis, Tennessee, will include a session on faith and spirituality. To learn more, visit lbbc.org/fallconference.

Balancing Act: Treating Breast Cancer and Other Conditions at the Same Time

(continued from page 1)

In 2010 Monique was diagnosed with stage III triple-negative breast cancer. She was concerned about how her body would react to breast cancer treatments. She realized she would have to take an active role and find a healthcare team she was confident would work together to address those concerns.

Cancer specialists may not know a lot about your other conditions. Advocating for yourself and asking questions can help ensure you're getting good care for all your health concerns.

"[With lupus] one misstep and you can wind up in a flare. You can wind up with organ damage. It literally can kill you," Monique says.

When her first surgeon suggested a lumpectomy and radiation, Monique worried the radiation could cause a lupus flare in the same way ultraviolet light is known to. She asked if the radiation could set off the lupus, but her surgeon's "I don't think so" answer failed to give her confidence. She spoke to friends and family and went for a second opinion at a hospital where a panel of doctors from different specialties recommended against radiation therapy.

Monique decided, with her doctors, to get a double mastectomy. Throughout her treatment the different members of her medical team worked together and shared information.

"My rheumatologist and my primary care physician were involved every step of the way," Monique says.

The rheumatologist recommended Monique get steroids before surgery to help prevent a lupus flare. Results of all blood tests were shared with all doctors.

"Everybody was on the same page. They knew what [medicines] I was taking and if [I had] any questions or concerns [they would] be [answered] by them all," Monique says.

Choosing Treatments

Carla Page, 54, of Ormond Beach, Florida, was diagnosed with stage II, hormone receptor-positive, HER2-positive breast cancer in 2008. It recurred to her lungs and liver in 2012. She noticed in 2016 that she was more tired than usual. Any physical activity left her winded and needing a break. She thought it was a side effect of her medicine and didn't tell her doctor until she was struggling with even simple activities.

"I'm talking [the kind of] tired where I had to stop six times as I'm trying to walk around a small block. And [my doctor said] 'Oh, no, that's a problem,'" Carla says.

She was diagnosed with pulmonary arterial hypertension, high blood pressure in the arteries that carry blood from the heart to the lungs. In people with this condition, the heart has to work harder to get blood through, causing it to weaken. Pulmonary hypertension has been linked to some breast cancer medicines, but it is also very common in the general population. Carla's doctors told her that cancer treatments could have caused the high blood pressure, but there's no way to know for sure.

Once she knew the cause of her fatigue, Carla started treatment, which helped her get up, walk and generally get back to her life. But it also complicated her cancer treatment.

At the time, she was taking trastuzumab (Herceptin), a targeted therapy known to impact heart health. In order to treat the high blood pressure, her doctors asked her to stop taking trastuzumab for a while so her heart could recover. Pulmonary hypertension doesn't go away completely, but after treating it for some time, her oncologist felt her heart was healthy enough to start trastuzumab again.

"We did one cycle of the Herceptin again and the effects were to the point where [my doctor] knew [through test results] if [I] continued the Herceptin that ... my heart would not handle it well," Carla says.

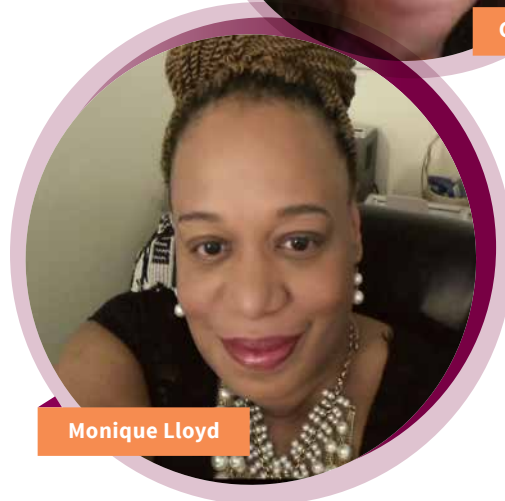
Treating multiple conditions is not as simple as making a list of medicines you cannot take. Finding the right treatment involves combining the right medicines, doses and schedules to best treat the conditions while trying to save you from dangerous or uncomfortable side effects.

"When considering treatment options, you've got a certain percentage chance of side effects, and you have to weigh the pros and cons of both," Dr. Kimmick says. "There's a lot of different factors that go in. The more illnesses you have, the greater chance of complications."

Medicines don't work the same for every person. One medicine may work very well in some people but it may not work as well in others. One person may experience serious side effects and another person may not feel affected much at all. With each added medicine you take, you are more likely to feel side effects from at least one medicine, and it's possible to feel side effects from some or all of them.



Carla Page



Monique Lloyd

Doctors try to choose medicines that give you the best chance of successful treatment with the fewest side effects. But you may face choices if you take medicines for multiple conditions. The pain Kimberly feels from rheumatoid arthritis would normally be treated with a higher dose of medicine, but her rheumatologist doesn't want to add to the high level of medicines she is taking for different diseases. So to avoid the risk of more side effects or her cancer treatment working less well, Kimberly puts up with more pain.

Treating multiple conditions is not as simple as making a list of medicines you cannot take. Finding the right treatment involves combining the right medicines, doses and schedules to best treat the conditions while trying to save you from dangerous or uncomfortable side effects.

Take Charge of Your Health

For Monique, being informed and active in her care means listening to her doctors and learning about her conditions, but also finding doctors who are willing to listen to her. When one doctor wasn't responsive, she found a new one, and you can too. If something doesn't feel right, you should feel confident your doctors will take your concern seriously.

"Anything that looks odd to me, I question," Monique says. "I know that it's to my benefit to know as much or more than [other people] because those questions that don't get asked are usually the things that get you into trouble."

Dr. Kimmick says it's important to visit your primary care physician and continue care for ongoing medical problems as you go through breast cancer treatment. Your primary care provider is better prepared to take care of your non-cancer medical problems than are your cancer doctors.

"A lot of people want to concentrate on the cancer treatment and not pay attention to other [health problems] because they are so busy with cancer treatment, but it's really important to pay attention to [your overall health] too" Dr. Kimmick says. 🍌

Ask Your Peers

What have your healthcare providers done to make you more comfortable (physically or emotionally) during treatment?



Krista Campbell, 63
Old Town, Florida

"My doctors, nurses and the office staff provided compassion, honesty and positive outlooks. Nobody guessed at anything. If they didn't know something, they researched, conferred with each

other and found the best course of action for my survivorship. They gave me hope with a smile."



Gerry Kearney, 63
Old Bridge, New Jersey

"Right before my lumpectomy, my surgeon cupped my face in her hands and said, 'You are going to get through this.' She put me at ease right then and has talked me off the ledge several times these past 3

years when scans were suspicious and biopsies necessary. She is vigilant about my treatment without being overly aggressive."



Lori Gallegos, 53
Aurora, Colorado

"The night of my mastectomy, I fell asleep for about 6 hours — 6 hours of no pain meds. I woke up in so much pain, it took everything to hit the call button and just cry. My nurse came in, sat on my

bed, hit the pump button and held my hand until I got some relief. Then she switched me over to oral pain meds so that wouldn't happen again!"



Andrea Phillips-Cleland, 39
Beloit, Wisconsin

"They treated me as a valued part of my cancer-fighting team. They handed me resources, research and included me in strategic planning sessions. They also talk to each other. I do not have to recap

everything at every visit. My team is amazing!"

🍌 *What do you do to ease lymphedema symptoms? Let us know at editor@lbbc.org.*

Our Corporate Partners Make an Impact

BY KIRSTIE KIMBALL

Every October, companies around the country join Living Beyond Breast Cancer to raise awareness and fundraise for our national programming. Their support is vital to Living Beyond Breast Cancer and we love hearing from people who found us through one of our corporate partners. As we move into Breast Cancer Awareness Month 2017, we want to thank some of our corporate supporters for their vital contributions to LBBC and the people we serve.

WHITEHOUSEBLACKMARKET

White House Black Market

Since 2004, White House Black Market has been Living Beyond Breast Cancer's strongest supporter, donating nearly \$7 million. Those funds have been invaluable in increasing the reach and depth of our programs and services to help people impacted by breast cancer.

White House Black Market's support of LBBC began because they believe "LBBC is the best and most helpful resource we know."

They have three products benefiting LBBC this October: a T-shirt, neckerchief, and scarf. We encourage you to stop into one of their stores in October to buy these products and to thank them for their continued support of Living Beyond Breast Cancer. You can also find the products online at whitehouseblackmarket.com in October.



jane iredale

This Breast Cancer Awareness Month, *jane iredale*, a clean makeup company, celebrates their 10th anniversary of sup-

porting Living Beyond Breast Cancer. Starting September 5 and continuing through December 31, profits from their Magic Mitt, a cloth that removes makeup with no chemicals and keeps harmful bacteria at bay, will be donated to LBBC. In October, we will blog about their past products and why they support LBBC. They tell us LBBC's "goal of support, education and fellowship closely resembles our own mission, making the partnership a natural fit."

You can find the Magic Mitt and other products at janeiredale.com.



CalExotics

CalExotics, a company that sells sexual health and wellness products, celebrates 9

years of partnership with LBBC this year. Products from their Inspire line were created specifically to support LBBC and promote sexual health. This partnership has spread awareness about LBBC and educated many of CalExotics' clients about the sexual and intimacy problems many women face after a breast cancer diagnosis. Visit calexotics.com/collections/inspire.html to view the products and learn more.



Pharmaca

Each year, new companies join our Shop to Support partners to increase funding and raise awareness for Living Beyond

Breast Cancer's programing. On June 15, Pharmaca, a natural beauty store with a focus on sustainable products, joined our group of dedicated supporters by hosting their Summer Shopping Event and donating a portion of the proceeds to Living Beyond Breast Cancer.

Tiffany Plate, senior communications manager at Pharmaca, says one reason they decided to support LBBC is that "so many of us have been affected by breast cancer, including many of our customers, and we believe strongly in the work that LBBC is doing to support and create community for those touched by this disease." Shop their all-natural products at pharmaca.com.



Kendra Scott

In May, Kendra Scott, a jewelry boutique, held a fundraiser at their Ardmore, Pennsylvania location to support our programing and education. On October 12, Kendra Scott stores in Ardmore; Memphis, Tennessee; and Denver, Colorado are hosting an additional fundraiser where 20 percent of profits go to

Living Beyond Breast Cancer. We hope to see you there!

Sara Scott, community relations and events manager of the Ardmore store, says "Kendra Scott is honored to partner with Living Beyond Breast Cancer. The entire company is excited to continue supporting impactful local and national organizations."

You can get more information about the October 12 fundraiser and on our other fundraising events at lbbc.org/programs-events. For more information on Kendra Scott, visit kendrascott.com.

Would you like to help support our programs and services while you shop? Visit lbbc.org/shoptosupport to see all the products benefitting LBBC. 🍌

"So many of us have been affected by breast cancer, including many of our customers, and we believe strongly in the work that LBBC is doing to support and create community for those touched by this disease."

HELPING YOU GET THERE:

Small Organizations Step Up to Fund Conference Travel

BY SANDRA E. MARTIN

In April LBBC hosted **Thriving Together: 2017 Conference on Metastatic Breast Cancer**, one of our annual programs for people with stage IV disease. Women travel from around the country to participate in this conference because there are so few opportunities for those living with metastatic breast cancer to come together and be part of an event specifically designed for them.

We keep our registration fee low and waive it for those who can't afford to cover the cost, but paying for travel and a hotel room can be a barrier, especially for those whose jobs have been disrupted due to treatment and whose savings have run out. For the last 10 years LBBC has offered travel grants to make it possible for more people to attend.

Generous donations from our travel grant sponsors allowed us to help 140 people attend the spring conference. Support was provided by the AmerisourceBergen Foundation, the Paula A. Seidman Fund/Alan Saltiel, the Avon Breast Cancer Crusade, and two small organizations that stepped in to fill a gap in travel grant funds when the major sponsor of the program left.

The Forward4Tobi Foundation

The Forward4Tobi Foundation was established in 2013 to honor the memory of **Tobi Klonecki**, who was diagnosed with metastatic breast cancer at 38. The foundation was founded by Tobi's husband, **Tom**, and her best friend, **Jodi Servino**, with the mission of helping women living with breast cancer improve their quality of life. After Tobi's diagnosis she attended LBBC's metastatic conference twice. There, Tobi connected with others who shared her diagnosis and she received peer support and a deepened sense of community. She also appreciated learning about the complex medical, emotional, social and practical challenges that accompany a metastatic diagnosis.

"Tobi always came back from the LBBC conference excited and energized," says **Rebecca Linscott**, president of the Forward4Tobi Foundation.

The Tutu Project of the Carey Foundation

The Tutu Project of the Carey Foundation's goal is to make a difference in the lives of those with breast cancer and inspire them to live a full life. President and co-founder **Linda Carey** is passionate about providing support to those diagnosed with breast cancer. Having lived with metastatic breast cancer for 12 years, she understands the emotional roller coaster brought about by a diagnosis of cancer. Linda has been a participant and speaker at LBBC's metastatic conference in the past, so when the chance came to help others attend, her organization jumped on it, says its business advisor and digital strategist **Marcela Shine**.

"As someone with metastatic breast cancer, Linda really understands how important not only education but support from the community is to her mental well-being," Ms. Shine says. "She really walked away from that conference with months and months' worth of support and information that she was able to take action on. So we really felt strongly about that." 🌟



Representatives from The Tutu Project of the Carey Foundation meet with travel grant awardees



Kim Jennings

DIY SPOTLIGHT:

Painting for a Reason

WHO: Kim Jennings, LBBC Community Connector

WHAT: A series of four paint nights

WHEN: November 2016 through June 2017

WHERE: Spirited Art, Glen Allen, Virginia

AMOUNT RAISED FOR LBBC: \$634

TOTAL ATTENDEES: 99

Kim says, "After being diagnosed with breast cancer in 2014, I was at a loss for where to turn. I scoured the internet for facts and reassurance. In my search for resources and encouragement, I found Living Beyond Breast Cancer. LBBC's mission to connect people with trusted breast cancer information and a community of support resonated with me. The Community Connector leadership volunteer program has given me the opportunity to give back and help others by raising funds and awareness about LBBC in my local community. This role has been an important part of my healing and survivorship from breast cancer."

—Compiled by LBBC advancement staff

Interested in hosting a Do-It-Yourself event in support of LBBC? Contact Elizabeth Mairs at emairs@lbcc.org to find out more.

THANK YOU TO Our Donors

In 2017

\$200,000 and above



May 1-July 31, 2017

\$50,000 and above

AmerisourceBergen Foundation
Centers for Disease Control and
Prevention
Einstein Healthcare Network

\$25,000 to \$49,999

AstraZeneca
LiquidHub/Linda & Jonathan
Brassington

\$15,000 to \$24,999

AbbVie
Celgene Corporation
Chico's FAS Customers
Husqvarna
Loulie Mauran

\$10,000 to \$14,999

The Allergan Foundation
The Charter Foundation
Marie & Joseph Field
Genentech
Genomic Health
Friends and Family of Michael &
Ayanna* Kalasunas
MD Anderson Cancer Center at
Cooper
Merck
MGF Sourcing
Patient Advocate Foundation
Puma Biotechnology, Inc.
Susan G. Komen
TESARO
Wheels for Wishes
May & Joseph Zipley

\$5,000 to \$9,999

Abramson Cancer Center
Jenny Burkholder & John Flak
California Exotic Novelties, LLC
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Theresa & Larry Frangiosa
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Jade Yoga
The Lipstein Family
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Whole Foods Market

\$2,500 to \$4,999

Jackie Allen/BJNB Foundation
Frederick W. Anton
Aon Foundation
Aria Health
Patricia Chase
Clovis Oncology
Foundation Medicine
FS Investments
The Haverford Trust Company
Rick S. Hock in memory of Susan
L. Wexler
Meyer Capital Group
Sweet Jane's Wish Fund, a
fund of the Chester County
Community Foundation
Sarah & James Van Stone
Victory Brewing Company
Community Fund of The
Philadelphia Foundation

**deceased*

FALL 2017

Calendar

Educational Programs

WEBINARS

All webinars are held from noon – 1 p.m. (ET)

SEPTEMBER 28

For Healthcare Providers: Meeting LGBTQ Needs

BREAST CANCER 360s

Online and in person!

NOVEMBER 15

Breast Cancer 360: Fear of Recurrence

Philadelphia, Pennsylvania

TWITTER CHATS

Online from 8 – 9 p.m. (ET)

OCTOBER 18

BRA Day: Breast Reconstruction Awareness

Conferences and Special Events

THROUGHOUT OCTOBER

Living Beyond Breast Cancer's Reach & Raise On the Road
Nationwide

Learn more at lbbc.org/reachraiseroad

OCTOBER 6-8

2017 Living Beyond Breast Cancer Conference
Sharing Wisdom, Sharing Strength

Memphis, Tennessee

OCTOBER 8

Living Beyond Breast Cancer's Reach & Raise: Memphis

Memphis, Tennessee

OCTOBER 16

2017 Paddle Rally

Newtown Square, Pennsylvania

NOVEMBER 11

The Butterfly Ball

Philadelphia, Pennsylvania

Check **LBBC.ORG** for the latest program information



**LIVING BEYOND
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With you, for you.

40 Monument Road, Suite 104
Bala Cynwyd, PA 19004

Insight

If you received more than one copy of this newsletter or would like to be removed from our mailing list, email information@lbbc.org.

Connecting you
to trusted breast cancer information
and a community of support

Shop to Support LBBC during Breast Cancer Awareness Month



Everything But Water



White House Black Market



Helen Jon

Learn more about pictured items and other products
on page 10 and at lbbc.org/shoptosupport



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