

SPRING 2016

Insight



LIVING BEYOND
BREAST CANCER™

BREAST CANCER ADVOCACY:

Using the Law to Make Change

BY ERIN ROWLEY

Stephanie Barr, from Salina, Kansas, was diagnosed with breast cancer in 2010, at age 30. Every spring for the last 3 years, she has gone to Washington D.C. with the National Breast Cancer Coalition to advocate for increased research funding.

She attends a summit organized by NBCC, where renowned scientists talk to participants about important breast cancer research. Then she makes appointments with her state's lawmakers or their aides.

"Just going out and doing it ... you feel really empowered. It's kind of like a rush," says Stephanie, who also volunteers for the [Breast Cancer Helpline](#) with Living Beyond Breast Cancer. "I feel like I'm really doing something to make a difference."

Looking Back

In the late 1980s and 1990s, many people with breast cancer saw how effective HIV/AIDS activists were at raising awareness, getting elected officials' attention and increasing federal funding for research, and they were inspired. They wondered: Could we get similar results for breast cancer?

It was in this atmosphere that breast cancer advocates began to find their voices. NBCC, which was one of the first nationwide breast cancer advocacy groups, led the movement for more federal research dollars. Their efforts resulted in Congress starting to fund the Department of Defense Breast Cancer Research Program in the early '90s, giving it more than \$3.1 billion to date. By partnering with scientists and advocates, the program seeks to fund research that is innovative and has a high impact.

Advocates from a variety of organizations pushed for more access to screening mammograms and other breast cancer tests and treatments. Their accomplishments included:

Stephanie Barr



- In 1990, the Breast and Cervical Cancer Mortality Prevention Act created the Centers for Disease Control and Prevention (CDC) National Breast and Cervical Cancer Early Detection Program. This program provides free mammograms and diagnostic tests to women in need.
- In 1998, the Women's Health and Cancer Rights Act, which says most group insurance plans that cover mastectomies also have to cover breast reconstruction, was signed into federal law.
- In 2000, the Breast and Cervical Cancer Prevention and Treatment Act expanded the CDC early detection program so that people diagnosed through the program could get treatments paid for by Medicaid. It was conceived of and lobbied for by NBCC.

Many of the same issues those early breast cancer advocates worked on, like finding cures and getting health insurance coverage, are still the focus of today's advocates.

Research

The federal government is the biggest public funder of cancer research in the U.S. The National Institutes of Health (NIH) does its own medical research and supports researchers at universities, hospitals and other institutions across the country. In 2014, the NIH spent about \$682 million on breast cancer research.

The NIH experienced budget cuts during the last few years. But in December, legislation passed by Congress and signed by the president increased its budget by \$2 billion. This increase

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Dear Friend,

You may already know that 2016 marks the 25th year Living Beyond Breast Cancer has provided assistance to women impacted by the disease and their caregivers. What you may not know is that two of our major events are also reaching exciting milestones this year. We're also introducing a new publication that embodies our vision of a world where no one impacted by breast cancer feels uninformed or alone.



Photo: BECK Photography

Get [more] with us.

On April 8, we will open **Thriving Together: 2016 Conference on Metastatic Breast Cancer**, our 10th annual conference for people living with stage IV disease. The event will be held at the Sheraton Philadelphia Society Hill Hotel in the heart of a beautiful neighborhood near Center City that boasts the highest concentration of original 18th- and early 19th-century residential architecture in the United States. Conference attendees will learn the latest information about treatment, interact with some of the country's leading healthcare professionals and be surrounded by others who understand what it means to be living with metastatic breast cancer. If you're attending, you'll definitely want to consider taking advantage of our walking tour of the area.

Get [inspired] with us.

In May, we'll hold our signature fundraising event and celebrate 15 years of doing "yoga on the steps" of the Philadelphia Museum of Art to raise money in support of LBBC's free programs and resources. **Reach & Raise** will continue our tradition of bringing thousands of people together for a morning and afternoon promoting wellness and healthy living. We will recognize how this one-of-a-kind fundraiser helped define our commitment to bringing awareness of the disease to the forefront and tailored resources to the people who seek them. We hope you'll join us in Philadelphia or one of our other host cities.

Get [included] with us.

Men can and do get breast cancer — and being diagnosed with what is usually seen as a "woman's disease" can lead to feelings of isolation. To help them, we've introduced *Breast Cancer inFocus: Breast Cancer in Men*, a brand new title in our library of free *Guides to Understanding Breast Cancer*.

This spring you're invited — to get more, to get inspired and to get included with Living Beyond Breast Cancer!

Warmly,

Jean A. Sachs, MSS, MLSP
CEO

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Newsletter design:
Masters Group Design

'Will My Baby Be OK?'

BY LAUREN SMOKE, FOR LBBC

Two-thousand fifteen was going to be a good year. I was a newlywed. I had just returned from my honeymoon and had found out I was pregnant. I had looked forward to pregnancy my whole life, and as a music teacher for infants and toddlers, I definitely had a case of baby fever.

I dreamed of cute maternity dresses, prenatal yoga, baby bump pictures, and eating all the food I desired. I wasted no time Googling fetal development and pregnancy symptoms. I pulled all-nighters designing the nursery on Pinterest. I was too excited to mind any of the first trimester annoyances like needing to pee every hour or having sore boobs.

While massaging those sore boobs one night, I was surprised to feel a small hard lump in my left breast. A sinking feeling stayed with me as I made an appointment for an ultrasound and a biopsy. The doctors assured me it was probably nothing, so I put the lump out of my mind and focused on my baby bump.

At 8 weeks I finally had a visit with my OB/GYN, and my husband and I got to see our raspberry-sized baby for the first time! It seemed things were going perfectly, until our happiness was cut short when 2 hours later I got the phone call that I had breast cancer — stage IIA triple-negative invasive ductal carcinoma.

The only question I was able to form was, "Will my baby be OK?"

The doctor hesitated and replied, "I don't know."

I was prepared for morning sickness. I was prepared for stretch marks. I was not prepared for cancer. I still shudder when I think about that phone call and the hours and days that followed. I sobbed as I wondered what would happen to the tiny baby I had already grown so attached to.

I screamed that it wasn't fair. I was a vegetarian, in great shape and thought I had been doing everything right. I exhausted myself trying to figure out what I did to cause this. I was 33, healthy and pregnant. This wasn't supposed to happen to people like me.

But it did.

Since my diagnosis, I have met dozens of women who were diagnosed with cancer during pregnancy. And from all these other moms, I found hope. I realized that I wasn't alone. My cancer mama friends are what got me through some of the hardest moments of my diagnosis. They answered the scary questions that kept me up at night. They gave me the courage I needed to finally shave my head when I couldn't take the clumps of hair coming out in my brush from the chemotherapy.

I believe I might have drowned in darkness that first weekend after my diagnosis if it hadn't been for the help of these brave women. They gave me hope that my baby and I could fight cancer together and come out stronger on the other side.

My miracle baby, Nico, made his appearance at 35 weeks, on Sept. 15, 2015. He was tiny, but otherwise absolutely perfect, with a full head of hair.



"I believe I might have drowned in darkness that first weekend after my diagnosis if it hadn't been for the help of these brave women. They gave me hope that my baby and I could fight cancer together and come out stronger on the other side."

Words cannot describe our bond, or the love and pride I feel when I look at his sweet face.

But with that love comes more worry. I finished up treatment on Christmas Eve, and the cancer appears to be gone, but for how long? What if it comes back? How much time do I have with him? These are questions I just can't dwell on. Nico needs his mommy to be strong. My goal this year is to cherish every *single second* I have with my little warrior baby. 🍌

Lauren Smoke was photographed for, and contributed to, the content of the newest title in our *Breast Cancer InFocus Series, Breast Cancer During Pregnancy*. Check LBBC.ORG for publication updates.

Nutrition and Breast Cancer

BY LIAM MCKENNA, FOR LBBC



Kimberley Jennings

Before her breast cancer diagnosis, **Kimberley Jennings**, 50, of Richmond, Virginia, ate healthfully. She was diagnosed with stage II breast cancer in August 2014. She had chemotherapy, a *bilateral*, or double, mastectomy, more chemotherapy, targeted therapy and then radiation therapy.

“Boy, did my taste change,” says Kimberley. “I had plenty of appetite, but nothing tasted good.” Only salty and greasy foods had flavor. Potato chips and fast food were her go-to meals after treatment sessions. She gained 15 pounds.

“I was not prepared for weight gain by any means,” Kimberley says.

Why Weight Gain?

It’s not uncommon for people with breast cancer to gain weight during treatment, rather than lose it. **Suzanne Dixon, MPH, MS, RD**, registered dietitian and epidemiologist, says your metabolism — the processes the body uses to maintain life, including how it breaks down food for energy, maintenance and repair — can slow down, causing weight gain. And, slower metabolism and weight gain can be a direct side effect of some cancer treatments. If this is true for you, losing weight can be very challenging.

Christine Zoumas, MS, RD, director of the healthy eating program at the University of California — San Diego Moores Cancer Center, says weight gain also may be a result of being less active or not active at all during treatment. Side effects like fatigue or anemia may make you feel too tired to go to the gym or carefully shop for food. Nausea, diarrhea and pain can make eating or working out difficult.

The cancer, its treatments and how you feel each day can impact what you eat. Some people overeat while in treatment, says Ms. Zoumas, out of a fear of the extreme weight loss many people associate with cancer.

It’s OK to worry about your weight while you’re dealing with cancer. But remember that your first priority should be getting the treatment you need.

“Treatment may not be the time to focus on weight loss, but if weight gain is approaching or exceeding a BMI [body mass index] of 25, your doctor or nutritionist might recommend a change in diet,” Ms. Zoumas says.

BMI is a way to measure whether a person is a healthy weight for their height. A high BMI can mean a person is carrying too much body fat. For example, a BMI of 27 is considered to be overweight, while a BMI under 18 is considered underweight. A BMI between 20 and 25 is considered a normal weight. Ms. Zoumas says many people she sees have a BMI of over 25.

Eileen Z. Fuentes, 41, of Hasbrouck Heights, New Jersey, tried many popular diets before her diagnosis. Frozen low-calorie meals and 100 calorie snack packs were standard.

After being diagnosed with stage II triple-negative breast cancer in 2008, she realized weight loss diets and healthy diets aren’t always the same.

“It wasn’t until I got sick that I started looking at health-supportive foods,” Eileen says. She found a book, *Anticancer: A New Way of Life* (Penguin Publishing Group, 2009), that inspired her. She started to follow a vegan diet.

Unlike Kimberley, Eileen experienced weight loss during treatment. Chemotherapy left her with no appetite, nosebleeds, and she often vomited. “I associated food with fear because I was throwing up so much,” Eileen says.

Finding a Healthy Diet

Ms. Dixon cautions that people can get hung up on the particulars of some diets and miss the larger point: health.

Ms. Zoumas agrees. “Somebody can look at tomato sauce and be panicked that the sugar [in it] is going to cause cancer, and they shouldn’t have the tomato sauce. The bottom line is: sugar does not cause cancer and the tomato sauce actually contains lycopene [a natural chemical], and other nutrients that may be beneficial to people with cancer.”

Your diet may be led by your treatments and the side effects you experience. For example, if you have metastatic breast cancer your diet may aim to ease vomiting, fatigue, or nausea because your treatment — and its side effects — is ongoing.

Overall, a plant-based diet is often recommended for people with cancer, as long as you are not having symptoms or side effects that make it hard to eat well and maintain a healthy weight. Being overweight or obese is common in the United States, and people with cancer face this issue, too. Many plant-based foods are lower calorie, making them ideal for people struggling with weight gain.



Eileen Fuentes

But if symptoms or side effects make it hard for you to eat or upset your stomach, plant foods may not be right for you. They can be tough to chew and hard to digest. Foods that are higher in calories and protein may help you meet your nutrition needs while you're coping with treatment.

Carotenoids, the pigments in plants that make vegetables red, yellow and orange, have antioxidants and other health properties that may lower cancer risk and possibly lower risk of recurrence. *Cruciferous vegetables* such as kale and broccoli contain a natural chemical called *glucosinolate* that may have anti-cancer properties. More research is needed to know whether eating these foods helps slow tumor growth or kill a cancer cell.

Research shows, Ms. Dixon says, the type of diet a woman adopts after breast cancer appears to affect the risk of recurrence. Maintaining a healthy body weight, which often comes from eating a well-balanced diet, goes a long way toward keeping people healthy after being diagnosed with cancer.

What You Can Do

Fruits and vegetables are the foundation of a healthy, plant-based diet. Both contain fiber, vitamins and minerals.

Ms. Dixon and Ms. Zoumas recommend you avoid or limit:

- 🍷 processed foods
- 🍖 red and processed meat
- 🍷 alcohol
- 🍬 added sugars and fats

"I won't sugar-coat it. It's difficult," Ms. Dixon says. "It's completely normal to find it challenging... Weight management is very challenging under any circumstances, let alone when you're going through breast cancer treatment."

Changes in taste caused by chemotherapy can affect how water tastes to you, making dehydration possible. **Stacy Kennedy, MPH, RD, CSO, LDN**, senior clinical nutritionist at Dana-Farber Cancer Institute and Brigham and Women's Hospital in Boston, suggests squeezing lemon or adding mint, basil, cucumber, melon, berries or other fruits and fresh herbs into water. This "infused water" may taste better than plain water, and can add nutrients. Soups and smoothies can help, too. Getting enough fluids can relieve constipation, fatigue and sometimes, changes in taste.

Ms. Zoumas suggests some flexibility. If one burger is going to make you happy and help keep you on an overall healthy diet, go for it. Or, you may prefer dramatic diet changes. Ms. Dixon says

if it's a shift towards a healthier diet, that's alright, too, but making gradual changes works well for many people.

If you're losing too much weight or finding it hard to eat, Ms. Kennedy suggests instead of eating more at each meal, try a small, well-balanced plate. She suggests using a guide like the Harvard School of Public Health's Healthy Eating Plate, found at hsph.harvard.edu/nutritionsource/healthy-eating-plate/.

"There are options for everyone," Ms. Kennedy says. "You can take it anywhere: [use it] at home, dining out, at a party."

Talk with your oncologist before dramatically changing your eating habits. He or she will be able to ensure you don't make any changes that may make treatment harder to tolerate.

Eileen was raised on homemade Dominican meals cooked by her mother and grandmother. After diagnosis, her mother-in-law cooked for her, creating Dominican cuisine from scratch. Eileen later combined fresh ingredients like kale, turmeric and other foods with the dishes she grew up eating.

"For once, it felt like I was eating real food again," Eileen says. "I was sleeping better. I felt better. I looked better. It was a huge transformation."

Today, Eileen works at the Columbia University Medical Center's Herbert Irving Comprehensive Cancer Center in New York as a clinical coordinator. Her job includes empowering those with breast and gynecologic cancers to navigate their care and improve their lifestyle. She says to achieve ideal health we should look to our ancestors. She makes it her mission to teach others how to shop for and prepare good food that takes into account their ethnic background.

Kimberley made small, gradual changes to her eating. First she stopped drinking soda, then stopped using artificial sweeteners a few months later, and so on. She encourages this slower pace to make the change less jarring.

Kimberley finished traditional chemotherapy in July 2015, but continues with targeted therapy. Targeted therapy is scheduled to end in March 2016.

While chemotherapy made healthy foods taste worse, she's found that fresh foods are more edible since she's been on the targeted therapy. Switching to a healthier diet does take effort though: she makes sure everything she buys has four or fewer ingredients, to make sure nothing is too highly processed.

Since making the change, Kimberley has no sugar cravings and doesn't snack or feel fatigued. For breakfast, she has homemade yogurt, grains and fruit. For lunch, a salad with seasonal fruits, nuts, seeds and protein. Seafood and beans replace red meat. Dark chocolate may sneak in. Dinner is usually like lunch. She wants to follow this diet for the rest of her life.

"I'm back at my pre-cancer weight and feeling quite well," she says. 🍌

LBBC's Board Members Get Involved!

Read Dr. Pallav Mehta's new book, *After Cancer Care: The Definitive Self-Care Guide to Getting and Staying Well for Patients after Cancer* to learn more about post-treatment health.

News & Education

BY JOSH FERNANDEZ

Helpline Online Chat: Get Support When and How You Want It

Our **Breast Cancer Helpline** is now available via online chat! Monday through Friday, from 9 a.m. to 9 p.m. ET, you can get the support you need from a trained Helpline volunteer via your computer or smart phone. This is a great option, whether you don't like talking on the phone or prefer the convenience offered by chatting online.

If you're looking to connect with someone who understands and knows what you're feeling, try our online chat by visiting lbcc.org/helpline. We can help.

Young Women's Initiative News

Check out the latest additions to our **"Let's Talk About It" Video Series**. The latest installments in the series feature young women reflecting on their diagnoses, discussing their experiences with early menopause and giving advice to other recently diagnosed young women.

The **I am a Young Woman** section of LBBC.ORG also features a number of resources, news articles and other tailored information on topics like pregnancy, breast-feeding and building families after a breast cancer diagnosis.

Watch the videos and get the information and resources you need at lbcc.org/youngwoman.



Guides Get an Upgrade

A few of our **Guides to Understanding Breast Cancer** have been updated with the latest information and a new look. Learn more about the topics that matter to you from these updated *Guides to Understanding: Fear of Recurrence, Hormonal Therapy, Lymphedema, Triple-Negative Breast Cancer, Yoga and Breast Cancer, Your Emotions*, and the *Guide for the Newly Diagnosed*.

Download or order free copies at lbcc.org/guides.



Learn and Connect at an LBBC Conference

Attending an LBBC conference provides you with a way to learn the latest medical and quality-of-life information while also meeting people like you.

Join us in Philadelphia April 8–10 for **Thriving Together: 2016 Conference on Metastatic Breast Cancer**, a weekend of learning and connecting for anyone living with metastatic breast cancer. In addition to networking opportunities, you will learn from national experts in large sessions, and more personalized breakout sessions. Learn more at lbcc.org/thrivingtogether.

From September 23–25, LBBC's **Annual Fall Conference** will give you the latest news and information you seek while meeting others facing similar diagnoses. You can follow a track for triple-negative, hormone receptor-positive or HER2-positive or metastatic breast cancer, or attend individual sessions based on your specific concerns. The conference takes place at the Pennsylvania Convention Center in Philadelphia. Check LBBC.ORG this summer for more information.

Tweet With Us and a Community of Support

Twitter Chats are live discussions that take place on Twitter, a popular social media platform, using a unique hashtag (#) that threads the conversation together for users to follow and reply.

This year, we're increasing the number of Twitter Chats we're offering from 4 to 6, to provide you with more opportunities to learn about particular topics by engaging with experts, advocates and others diagnosed with breast cancer. Our first chat, in February, featured menopausal symptoms. The next chat, to be held in May, will highlight the unique needs and concerns of young women with stage IV disease.

Learn more about these and other Twitter Chats at lbcc.org/events. 🐦

Beyond These Pages

BY JOSH FERNANDEZ

Like what you've read?
Learn more at LBBC.ORG



Discover more about fertility and pregnancy

lbbc.org/young-woman/your-medical-needs/fertility-and-future-pregnancy



Register for Reach and Raise: Philadelphia

reachandraise.org



Learn about coping with the stress of a metastatic diagnosis with children and other loved ones

lbbc.org/learn/types-breast-cancer/metastatic-breast-cancer/living-metastatic-breast-cancer/coping-stress



Share your story on our blog

lbbc.org/get-support/get-involved



Learn more about breast cancer advocacy and how you can get involved

lbbc.org/young-woman/lifestyle-and-practical-matters/peer-support-advocacy/getting-involved-advocacy



Watch our video on making informed decisions about care for metastatic breast cancer

lbbc.org/mbc360



Read about nutrition and other nonmedical support in our *Guide to Understanding Complementary Therapies*

lbbc.org/get-support/print/guides-to-understanding/guide-understanding-complementary-therapies



Make a donation to support our programs and services

lbbc.org/gift

Breast Cancer Advocacy: Using the Law to Make Change

(continued from page 1)

makes up for those cuts, and adds more money on top of it. It's something many breast cancer advocates are calling a big win.

"This is the most significant progress we've made on this issue in a decade," says **Erin O'Neill**, senior director of grassroots campaigns for the American Cancer Society Cancer Action Network (ACS CAN). Many of the organization's volunteers called their legislators and attended local and national events in support of the budget increase. "We engaged over 150,000 volunteers throughout the year to work on this issue," Erin says. "So I think they all feel not only that they had a stake in this issue but that they really contributed to the outcome."

In January, President Obama created a White House task force on cancer, led by Vice President Joe Biden, in an effort to "make America the country that cures cancer once and for all." This initiative, and the NIH budget increase, could bring us closer to a goal set by NBCC. In 2010, through a program called Breast Cancer Deadline 2020, NBCC challenged researchers to know, by Jan. 1, 2020, how to end breast cancer. Their focus is finding a way to prevent breast cancer from becoming metastatic, and finding a vaccine that could prevent breast cancer in the first place.

NBCC encourages supporters to talk to their legislators about how they can help researchers meet the deadline. Volunteers can also get involved in the group's Project LEAD programs, which prepare them for activities like working with scientists to design breast cancer research and giving presentations at scientific meetings.

Health Insurance Coverage

Advocates are still fighting for more and better insurance coverage for breast cancer prevention and care. Two bills that many breast cancer advocates are now working to get passed into law are the Lymphedema Treatment Act and the Cancer Drug Coverage Parity Act.

Lymphedema, a chronic condition that causes swelling in the hand, arm, breast, chest wall or under the arm, is a common side effect of breast cancer treatment. Lymphedema isn't curable, but it can be treated with compression supplies, like sleeves and gauntlets. Those supplies aren't covered by all insurers though, including Medicare. The Lymphedema Treatment Act would make Medicare cover lymphedema compression supplies, with the hope that Medicaid and private insurers would follow.

Today, insurance tends to cover more of the cost of chemotherapy given by IV than of chemotherapy pills. The pills often come with high copays that can add up to thousands of dollars in out-of-pocket costs. The Cancer Drug Coverage Parity Act would require insurers to cover the cost of chemotherapy pills as favorably as they cover infusions.

LBCC supports the Lymphedema Treatment Act. For more information, visit lymphedematreatmentact.org



Jo Evelyn Ivey

...And More

Other issues many advocates have embraced include speaking out against:

- Environmental factors that may increase the risk of breast cancer. Advocates are pushing for legislation related to fracking, a drilling technique used to release natural gas from the ground, which has been linked to cancer; and chemicals, such as those in some cosmetics and plastics
- Campaigns that sexualize breast cancer, such as "Save the Ta-tas" or "Save Second Base"
- Gene patenting, the idea that genes, such as *BRCA1* or *BRCA2*, which are linked to breast cancer, can be owned by a company. In 2013, in a victory for advocates, the Supreme Court ruled that it is illegal to patent human genes in the United States.

Metastatic Advocacy

Jo Evelyn J. Ivey took part in Living Beyond Breast Cancer's **Hear My Voice: Metastatic Breast Cancer Outreach Program**. The program provides tools and training to help people living with metastatic breast cancer make a difference in their communities. Jo Evelyn enjoyed connecting with other women with metastatic disease who, like her, were motivated to make changes.

"I think if you look across the board at all the things that women in Hear My Voice have accomplished, it's absolutely incredible," she says.

One of those things is MET UP, an advocacy organization that was started in April 2015 by Hear My Voice participants. Jo Evelyn, who has been living with metastatic breast cancer for about 5 years, is the organization's legislative director. She works to get laws passed that could help the metastatic breast cancer community.

Last year on Oct. 13, Metastatic Breast Cancer Awareness Day, MET UP held a "die-in" in Washington D.C. About 113 participants lied down on the Capitol Hill lawn to represent the more than 100 people who die of metastatic breast cancer every day in the U.S. Participants also met with about a dozen members of congress or their staffs.

Because about 20–30 percent of those diagnosed with early-stage breast cancer will develop metastatic disease, MET UP and other organizations would like to see at least 30 percent of federal breast cancer research dollars go toward metastatic disease. According to a 2014 study by the Metastatic Breast Cancer Alliance, that number is about 7 percent. MET UP also supports passage of the Ensuring Equal Access to Treatments Act. This legislation would help people on Medicare whose hospitals currently get incentives to use older, cheaper treatments get access to newer treatments that may be more effective.

Other groups that have a big impact on metastatic breast cancer education and advocacy include the Metastatic Breast Cancer Network and METAvivor.

An issue of huge importance to all these groups is how the national database that tracks cancer, SEER, counts cases of metastatic breast cancer. Just 6–10 percent of metastatic breast cancer cases are stage IV at diagnosis, but those are the only ones SEER currently records.

You Can Make a Difference

The first time Stephanie went to Washington D.C. to talk to her legislators, she wasn't sure what to expect.

"It was kind of scary," she says. "I'm like 'I can't do that.' I thought, 'I'm a terrible speaker, nobody's going to listen to me.'"

But a mentor who had professionally lobbied in the past walked Stephanie through the process and her confidence has grown every time she's done it. She plans to attend this year's NBCC Advocate Leadership Summit and Lobby Day on Capitol Hill, from April 30–May 3.

Stephanie feels good about having gotten a few of her state's representatives to agree to sign a bill and about making her voice heard. "The politicians work for you," she says, so it's up to you to let them know what's important to you and how they can help.

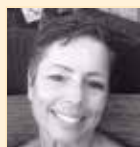
"Going to your legislator does make a difference," says **Karuna Jaggar**, executive director of Breast Cancer Action, a group that focuses on the root causes of the disease and on producing broad public health benefits, so fewer women develop and die of breast cancer. "I think that a lot of people can feel intimidated, that they need to know the various lines of the bill, or this or that. All you need to do is talk from personal experience." 🐾

Interested in becoming a breast cancer advocate?

- 🐾 Think about what activities you want to take part in. Options include: calling lawmakers, meeting with them in person, recruiting friends and neighbors to support your cause, and writing letters to the editor.
- 🐾 Learn about advocacy organizations (The ones mentioned in this article are a good start). Different organizations care about different issues and go about supporting those issues differently.
- 🐾 If you find organizations you like, contact them to learn how you can get involved.

To learn more about LBBC's *Hear My Voice Outreach Program*, visit lbcc.org/hearmyvoice

Ask Your Peers



Colleen Yanco, 56, Laguna Niguel, California

Diagnosed with stage IV HER2-positive breast cancer in October 2013

"I used LBBC; SHARE, which provides support for people with breast or ovarian cancer; and

HER2support.org, which provides an online support group for people with HER2-positive breast cancer, and their friends and families."



Laura L. Looman, 44, Grand Rapids, Michigan

Diagnosed with triple-negative breast cancer in February 2015

"I like myBCTeam.com, a social network for people affected by breast cancer, and its app. I

sometimes prefer in-person support like through the local Gilda's Club programs for people with cancer and their families and friends, and Beautiful You, a program at Profile Salon, in Grand Rapids, Michigan, that provides free monthly salon and spa services for women with cancer."



Iris Grimster, 58, Liverpool, United Kingdom

Diagnosed with breast cancer in 2013

"I used Breast Cancer Care (A UK-based nonprofit) and Living Beyond Breast Cancer's websites. I like reading personal stories published by these

organizations. I felt so alone sometimes, which is why I love reading how other women are fighting this horrible disease. It gives me hope."



Nancy Stordahl, Menomonie, Wisconsin

Diagnosed with stage II breast cancer in 2010

"I went to Breastcancer.org first. I didn't know about Living Beyond Breast Cancer then. During chemo, I discovered bloggers and then I started blogging myself. That is where I received, and still receive,

a great deal of support. As far as online sites, be sure to stick to reputable ones. That is the key."

🐾 *What's the most helpful thing your caregiver has done for you? Let us know at editor@lbcc.org.*

15 Years of Doing Yoga for a Reason

BY CHRISTINA MEEHAN

Fifteen years ago, 100 people gathered in the rain on the steps of the Philadelphia Museum of Art for the first-ever Yoga Unites for Living Beyond Breast Cancer, LBBC's now annual yoga fundraiser. The event has grown tremendously in the years since, and the name grew with it. You may have heard the news that in 2016 our yoga event is now called **Living Beyond Breast Cancer's Reach & Raise**.

Our yoga fundraiser has grown because of the support of many, including Philadelphia yoga instructor and event co-founder **Jennifer Schelter**. In 2001, she and **Courtney Kapp**, who had been diagnosed with breast cancer, approached LBBC CEO **Jean A. Sachs, MSS, MLSP**, about holding a yoga event on the iconic steps of the Philadelphia Museum of Art.

"We took a leap of faith when the event first started, knowing it would be small but hoping that over time the idea would catch on," says Ms. Sachs. "Our patience paid off and 15 years later thousands of people have attended, and a handful have been with us every year since 2002."

Through the years, the grassroots fundraising event grew and, to date, has raised more than \$2 million to support LBBC's programs and services.

Crafting a Name

Since its inception, our annual yoga fundraiser, which many people know — especially Philadelphians — as Yoga on the Steps, has also been called Yoga Unites for Living Beyond Breast Cancer and for a short time, Yoga 4 Living Beyond Breast Cancer. But as the event expanded to other cities like Kansas City, Missouri, Washington D.C., Denver and Fort Myers, Florida, we knew that we needed a new name that would resonate with people across the country.

Interviews with past participants, LBBC staff and a national survey helped us develop the new name. Many told us the event is much more than an outdoor yoga class. It's a morning of inspiration, connection and community that gives attendees an opportunity to celebrate, reconnect, remember and support others.

Amy Reichbach of West Roxbury, Massachusetts, wanted support after being diagnosed with breast cancer in 2013 at age 38. Last year she attended LBBC's **Wellness Weekend** in Denver, which combined our fall conference and yoga fundraiser.

"I was really excited to see [yoga] offered at Wellness Weekend," Amy says. "The music was amazing. The people

were amazing. Just looking at all the survivors and supporters around us was really inspiring; my friend and I were in tears in the beginning."

The Meaning of Reach & Raise

Reach: We chose "reach" to represent reaching out to friends, family, colleagues and neighbors to be part of the event. We're reaching the communities that we serve. You're reaching your goals — both on an individual and team level.

Raise: You raise up those who have been affected by breast cancer and need your support. You raise awareness about the effects of breast cancer. You raise critical dollars that help LBBC create and continue providing programs and services to help those impacted by breast cancer.

Why Yoga?

Studies show that yoga is beneficial for those in treatment for breast cancer and beyond. Some women report less pain, fewer hot flashes and improved strength and body image. And nearly anyone can do yoga, because many of the poses can be modified based on a person's ability.

Madge Hamilton of Cape Coral, Florida, participated in LBBC's 2015 yoga fundraiser in Fort Myers, Florida, with six friends from Ohio. Some of those friends had never practiced yoga. Linking arms with other participants to perform tree pose is one of Madge's most unforgettable moments.

"Together, everybody was able to do that pose. You depended on each person," she says. 🙏

Mark Your Calendars

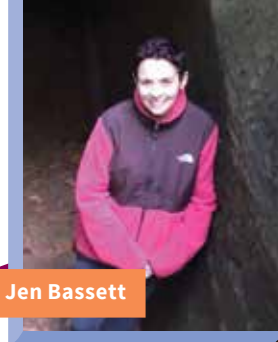
2016's Reach & Raise takes place in Philadelphia on Sunday, May 15, at the Philadelphia Museum of Art. This fall, we'll host 25 simultaneous yoga events in 25 cities in honor of LBBC's 25th anniversary. Check our website to see if we'll be near you! Register for Reach & Raise online at reachandraise.org.

Can't make it to an event this year? Host your own yoga fundraiser or ask your local yoga studio to hold a donation class to benefit LBBC. Learn more at lbcc.org/diy.



Five Helping LBBC Reach 25

BY CHRISTINA MEEHAN



Jen Bassett



Libby Aldridge



Ron Kern, Jr.

Forever Cellars



Darby Fire Co.

As we prepare to celebrate our 25th anniversary, we want to thank some of the young donors who give back to Living Beyond Breast Cancer.

Three months after being diagnosed with stage II breast cancer at age 30, **Jen Bassett** learned her cancer had metastasized.

“When I [learned I] was stage IV, I started to really dig deep and research the breast cancer community,” says Jen.

Jen joined LBBC’s Young Advocate program and also participated in LBBC’s 2015 yoga fundraiser, raising more than \$1,200.

“By doing advocacy work it gives me a chance to leave a legacy and footprint,” she says.

“My mission in life is to give back to organizations that hit close to home, as breast cancer has affected many of my close friends,” says **Lindsey M. James**, 34, owner of Forever Cellars of San Luis Obispo, California, an LBBC Shop to Support partner. Shop to Support is an initiative in which sponsors give a percentage of their profits to LBBC.

“I chose LBBC because I appreciate their passion and efforts to help raise awareness, support those who are battling, those who have lost the fight, and the end goal to find the cure.”

Elizabeth “Libby” Aldridge, a junior at Tulane University, serves as the president of the student club Tulane Lives Beyond

Breast Cancer, which organizes an annual yoga fundraiser called Yoga on the Quad.

“We had 71 girls sign up for the [2015] event and donate. It poured but it was still a great event. We raised \$2,058 for LBBC.”

Mike Norman, 37, deputy chief of Manoa Fire Company in Pennsylvania, got involved with LBBC after his cousin, Maureen, was diagnosed with breast cancer.

“For 14 years LBBC supported my aunt and my cousin. They continue to support my aunt since my cousin’s passing,” says Mike. He sold T-shirts for the Darby Fire Company No. 1’s 2015 fundraiser and suggested the proceeds be donated to LBBC.

Ron Kern, Jr.’s wife was diagnosed with breast cancer at the age of 28.

“Like others facing a diagnosis, we were lost,” says Ron, 35, an LBBC Board Member and native Philadelphian. “LBBC was one of the first organizations that we found after her diagnosis. During her treatment, LBBC provided us with information and support.”

“I serve on the Board to try to give back to the organization that helped my wife and me; and to try to help others who are recently diagnosed or survivors.” 🍌

Connecting for a Cause in Maryland

BY CHRISTINA MEEHAN

Cheryl Walls of Maryland had the idea to host a breast cancer fundraiser while out with co-workers for their weekly girls’ night. Each woman had either had breast cancer or knew someone who did. Cheryl herself had a double mastectomy in 2009.

Over the next 7 weeks, Cheryl and her co-workers organized Connect for a Cause, an event that raised over \$4,000 for Living Beyond Breast Cancer.

“If you have a plan and a checklist, you’re good to go,” says Cheryl. Her plan included a buffet dinner at a local restaurant in Bel Air, Maryland, called 510 Johnny’s. The event also featured

T-shirts, a live band and a DJ. Tickets, sold through word-of-mouth and social media, were \$40. LBBC received half the proceeds.

“Facebook is an amazing place to connect with people,” she says.

Cheryl chose to donate to LBBC because of our direct impact on people with breast cancer. She says “every woman [diagnosed] needs a good place to start.”

The women are already busy organizing 2016’s Connect for a Cause.

“It was definitely a lot of fun,” says Cheryl. “We were all overwhelmed by the number of people who wanted to help.” 🍌

In honor of LBBC’s 25th anniversary we’re looking for 25 people — or more — to host DIY events in October! Now is the perfect time to start planning. Download our Getting Started guide at lbbc.org/diy.

When you’re ready, register your DIY event on our website so that we can include you in this special 25th anniversary event. We’ll have special giveaways, social media and other fun surprises! As always, don’t hesitate to contact us with questions!



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The Traveling Vineyard
Linda and Leonard Walmsley

November 2015 – January 2016

SPRING 2016

Calendar

Educational Programs

WEBINARS

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

APRIL

Lifestyle and Nutrition After Breast Cancer

JUNE

Annual Update From the American Society of Clinical Oncology

TWITTER CHATS

MAY

Young Women and Metastatic Breast Cancer

Conferences and Special Events

APRIL 8–10

Thriving Together: 2016 Conference on Metastatic Breast Cancer

Philadelphia, Pennsylvania

MAY 15

Reach & Raise Philadelphia

Philadelphia, Pennsylvania

SEPTEMBER 18

Reach & Raise Denver

Denver, Colorado

NOVEMBER 12

The Butterfly Ball

Philadelphia, Pennsylvania

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