



WINTER 2014/2015

A GUIDING FORCE IN TREATMENT:

National Guidelines and You

BY ERIN ROWLEY



ost businesses have "best practices" that they follow.
Auto mechanics know the best way to install brakes.
Florists know how to keep flowers in bloom for as long as possible. Teachers know what methods are most likely to inspire students.

When the business is getting you healthy through breast cancer treatment, those best practices come in the form of treatment guidelines that help doctors give you the best possible care. You may have had doctors tell you that guidelines do or do not recommend a certain test or treatment for you. But what are these guidelines, and how are they created?

"The whole purpose [of guidelines] is to have an evidencebased approach for every aspect of care we provide to cancer patients," says **William J. Gradishar, MD, FACP**, a professor of medicine at the Feinberg School of Medicine at Northwestern University and a member of the Robert H. Lurie Comprehensive Cancer Center of Northwestern University, in Evanston, Illinois. Dr. Gradishar has served as a breast cancer guideline panelist for the National Comprehensive Cancer Network (NCCN) since the organization began.

History of Guidelines

The existence of widely followed, comprehensive cancer guidelines is relatively new, with two of the best known guideline organizations only creating them since the 1990s. NCCN, a nonprofit alliance of 25 of the country's top cancer centers, was formed in 1995 to improve the quality and effectiveness of cancer care. The American Society of Clinical Oncology (ASCO) was founded in 1964, but it didn't begin creating cancer treatment guidelines until 30 years later, in 1994. Its first breast cancer guideline was released in 1996.

Clifford A. Hudis, MD, is chief of the breast medicine service, co-leader of the breast disease management team and attending physician at Memorial Sloan Kettering Cancer Center, in New York City. Dr. Hudis has helped craft guidelines for both ASCO and NCCN. He says many factors likely led to the creation of guidelines at this time, including:

- a growing amount of randomized clinical trial data
- a growing understanding that standardizing treatment improves quality of care and controls cost

Thomas A. Buchholz, MD, FACR, FASTRO, is the executive vice president and physician-in-chief at the University of Texas MD Anderson Cancer Center, in Houston. He serves on an ASCO breast cancer guidelines committee and has contributed to the MD Anderson Care Pathway Guidelines for Breast Cancer. According to Dr. Buchholz, large institutions, such as MD Anderson, may create their own guidelines. Smaller cancer centers, though they may not have their own guidelines, may create *pathways*. Pathways are based on national guidelines and research and suggest what treatment should be given when more than one is considered a good option.

Continued on page 8

INSIGHT STAFF

Nicole Katze, MA, Editor Lindsay Beckmeyer, Staff Writer, Advancement Josh Fernandez, Staff Writer, Programs Erin Rowley, Staff Writer, Programs Anna Shaffer, Staff Writer, Programs Robin Warshaw, Contributing Writer

LBBC STAFF

Jean A. Sachs, MSS, MLSP Chief Executive Officer

Arin Ahlum Hanson, MPH, CHES
Kathy Arocho
Lindsay M. Beckmeyer
Jessica Betts
Joanne Bursich
Catherine Creme Henry, MA
Lynn Folkman
Amy B. Grillo
Janine E. Guglielmino, MA
Dominique Holland
Vicki Klopp
Kendra Lawton
Claudia Lilley, MPH
Sandra E. Martin
Mary Beth Mills, MS

Catherine Ormerod, MSS, MLSP

Celeste C. Terrinoni, CPA Christine Ware, MEd Barbara Yorke Chair, Board of Directors

Megan Roberts

Brittaney Shade

Anna Shaffer

Living Beyond Breast Cancer's *Insight* newsletter is designed for education and information purposes only. The information provided is general in nature. For answers to specific healthcare questions, consult your healthcare provider, as treatment for different people varies with individual circumstances. The content is not intended in any way to substitute for professional counseling or medical advice.

LIVING BEYOND BREAST CANCER®

354 West Lancaster Avenue Suite 224 Haverford, PA 19041 **Breast Cancer Helpline**

(888) 753-LBBC (5222) Tel: (855) 807-6386 Fax: (610) 645-4573 Email: mail@lbbc.org Website: lbbc.org

Blog: livingbeyondbc.wordpress.com

facebook.com/

livingbeyondbreastcancer

@LivingBeyondBC

youtube.com/LBBC1991



pinterest.com/livingbeyondbc



Newsletter design: Masters Group Design

Dear Friends,

2014 has been an exceptional year for LBBC. I am excited to share some of the highlights. This year, we provided over **420,000 people** with trusted information and compassionate support as they navigated their path from diagnosis, through treatment and beyond. This is more people than we have ever reached in our 23-year history.

We reached people in **new ways**, using social media platforms like Twitter, Facebook and Instagram and hosting events live online through Web streaming.

We held **three successful conferences**, each designed for groups with unique needs. One specifically addressed young women; one, women living with metastatic disease; and one, women with specific subtypes of breast cancer.

Our Breast Cancer Helpline recruited new and diverse women and now boasts nearly **100 trained volunteers** and our call volume is steadily increasing.

This fall, we were awarded our **second competitive grant** from the Centers for Disease Control and Prevention. This 5-year grant totaling \$1.75 million will continue to support our Young Women's Initiative.

Yoga on the Steps expanded its national reach, this year being held in **three cities**: Philadelphia, Kansas City and Denver. And, during October, LBBC was featured in **TV commercials** aired across the country, raising our profile and reaching many who had never heard of LBBC.

Finally, we are completing our new **3-year strategic plan** that focuses on extending our reach, implementing more programs for low-income women and building LBBC's reputation as a thought-leader in the breast cancer community.

We have been able to reach so many with our services at little or no cost to them thanks to the generous individuals, corporations and foundations that support LBBC. So as LBBC's family of volunteers and staff gear up for continuing our good work in 2015, we invite you to support our work with a yearend contribution. We couldn't do it without you!

Warmest regards,

Jean Sachs, MSS, MLSP

CEO

Photo: Laurie Beck Photography

Visit lbbc.org/gift to make a secure online donation.

IN THIS ISSUE

- 1 A Guiding Force in Treatment: National Guidelines and You
- 3 My Story: Finding My Voice
- 4 Making the Adjustment: From Giving Care to Accepting Care
- 6 News and Education
- 7 Beyond These Pages
- 10 The 2014 Butterfly Ball

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

MY STORY:

Finding My Voice

BY LIZ QUINLISK



Each fall and spring, LBBC hosts "Writing the Journey," a 6-part workshop series to help women with breast cancer express their feelings and document their journeys through writing. Liz Quinlisk shares "Finding my Voice," a piece she wrote during the spring 2013 program, led by Alysa Cummings. Look for information on our new online writing program coming in spring 2015!

e Still. Look inside your heart, your mind, your body. What is there? What is this disease inside of you called cancer? Listen to your heart beating. What is it telling you? What is that little voice inside you saying, the voice you have drowned out with all of your busyness and running around? Be still and listen to that voice. She has something to say.

Cancer gave me the opportunity to look inside myself and find that little voice that was muffled underneath layers of pain and denial, the voice of a little girl who was waiting patiently for me to find her. Cancer was the doorway that led me into my heart and ultimately toward my healing.

When I first started my treatments for breast cancer, I was a real trouper. I was determined to be cheerful and brave. I was a good patient. But as I went through the surgeries, chemotherapy and radiation, my resolve wore thin. I became cranky, terrified and overwhelmed. The treatments for my cancer were invasive and frightening. Although I was receiving state-of-the-art medical care, it left me feeling like I was just a body part to be cut, poisoned or radiated. I felt fragmented. I knew there had to be more to my healing than what conventional medicine offered. My intuition and search for something better guided me to seek out professional counseling and complementary therapies. I received acupuncture and bodywork and began to practice meditation and yoga—all of which helped me reconnect with my body and to that part of me that felt safe and whole. I began to hear my inner voice more clearly:

There's more to healing than just treating the body. There's something deeper here that needs to be healed. It is scary, but you are not alone. This voice became louder and more insistent. I was compelled to write. So I wrote. And I wrote. And I wrote. With each sentence I wrote, another brick was removed from the wall I had built around my heart to protect it. As the wall crumbled, the pain I had been holding back came spilling out of my heart, through my hands, and onto the pages of my journal. I remembered and wrote about being sexually abused as a child. I had buried my truth and swallowed my voice. I did what I was told to do. I was a good girl. All those years of silence about the awful things that had happened, things I didn't even have words for, could now be brought into the light to be healed. I had found my voice. This was the beginning of my healing.

My healing journey has not been quick or easy. It has been 16 years since I was diagnosed with breast cancer. Through my healing process I have found my center, my voice and my truth. And from this place of healing grows my desire to share my truth with others, to offer encouragement and inspiration and to give voice to the little girl in me who was silenced for too long. I share my truth knowing that I am not alone. I am not the only one who has gone through the shame of childhood sexual abuse or the trauma of cancer.

I will not yield to the messages I received as a child and as an adult.

Don't tell.

Don't speak about it.

Be quiet.

Get over it.

I will not be silenced.

Silence like a cancer grows. ightharpoonup

Through my healing process I have found my center, my voice and my truth."

Liz Quinlisk is a physical therapist and shiatsu practitioner in Ambler, Pennsylvania. Learn more about her at lizquinlisk.com

If you have experienced sexual abuse and need advice or support, we encourage you to contact the **National Domestic Violence Hotline** (800-799-7233; thehotline.org) or the **Rape, Abuse & Incest National Network**, RAINN (800-656-HOPE; rainn.org)

MAKING THE ADJUSTMENT:

From Giving Care to **Accepting Care**

BY ROBIN WARSHAW, FOR LBBC



or those who are caring for someone else when diagnosed with breast cancer, the transition to being in care may be hard. Yet it's vital to recognize personal needs, ask for help and find ways to adapt.

Janice Rackovan, 61, of Phoenixville, Pennsylvania, was concerned about how her breast cancer diagnosis might affect her 89-year-old mother. And her biggest caregiving worry was her sister, who was very ill with a bone marrow disorder that can lead to leukemia.

Her mother had medical problems, so Janice regularly drove her for doctors' visits and errands. She was also the only sibling who was a donor match to give marrow to her sister. Having breast cancer meant she was no longer allowed to donate her

"That affected me most, that I wouldn't be able to help her," Janice says. "I wept and wept."

She turned to family, friends, a support group and her strong faith. Her mother had a stroke, and Janice helped her sisters care for their mother until her death. They rotated shifts caring for their sister, who died before Janice finished radiation therapy.

Like many caregivers, Janice, who is a hospice nurse and volunteer coordinator, had trouble thinking about her own needs. "It was very important for me to give as much care for my mom and sister as possible," she says. "Caregiving helped me get through."

Caregiving Identity

Many of us take care of a child or children, older relative, spouse or partner, patients or others. "Even if a woman doesn't fall into some specific role of caregiver, most women are," says Page Tolbert, LCSW, a New York City psychotherapist specializing in cancer issues. "When a woman gets a diagnosis, she usually is going [into treatment] from some caregiver role."

As a caregiver, you may have trouble reaching out for help and may assume you are the only one who can, or will, take responsibility for the ones you are caring for. Letting someone else step in can stir strong emotions.

Caregiving may be at the core of your identity, says Ms. Tolbert. That's OK, if it doesn't keep you from putting yourself first when you need help. "That's a good thing to learn to do," she says.

The change can be a shock. **Kerry Kenna**, 54, had a home day care in El Cajon, California, and two daughters in college when she was diagnosed. Her surgery was scheduled quickly and parents scrambled to find other child care. At once, Kerry lost her income and some self-esteem.

"It was really foreign to me to feel weak or not well. I was always the support system in the house," she says. "I didn't know how to handle this role."

Too often, caregivers see needing help as failure. But that's not what caregiving is about. "'Caregiver' isn't a box you check. You aren't either a caregiver or a [care] receiver. It's reciprocal and mutual," says Cindy Moore, PhD, associate director of the Marjorie

Time (PACT) program for parents with cancer at Massachusetts General Hospital in Boston.

When diagnosed, Angil Tarach-Ritchey, 53, of Ann Arbor, Michigan, tended to her grandchildren and husband, and ran an elder care support group. Treatment made





tasks challenging, but, as a nurse, she was used to helping other people and didn't want help for herself. Then a friend told Angil she was robbing others of the joy she felt when caring for someone.

"She said I wasn't the only one who should experience that kind of blessing. I still remind myself of that when I really can use help and find myself resisting or feeling guilty," she says.

Giving Care While Getting Care

Some fear help with duties means giving up caregiving entirely. Dr. Moore suggests thinking about what parts are most important and how to continue those.

Stacy Vivino, 43, was "the power mom," a stay-at-home mother, vice president of the home and school board, and active in her Philadelphia parish. She was sure her diagnosis would change none of that.

By the second round of chemotherapy, Stacy knew she couldn't do it all. "It was very hard for me to say, 'I need your help.' All of a sudden, you're not the same person."

When others drove her daughters to school and activities, she felt she was disappointing her family. "Finally, I knew it was better for me to get better, so I could be better for them," she says.

Stacy held onto caregiving she could manage, such as helping with homework on her bed rather than in the dining room. "We changed things around, but I still had some mom role."

Caregivers for spouses or partners may have added isolation and worry. **Irene*** handles chores, medical management and more for her partner, who has a serious condition affecting the

brain. Since her diagnosis, Irene makes care decisions based on whose need is more pressing, hers or her partner's.

With no family support, Irene talks about her caregiving situation only to healthcare providers and members of caregiver discussion groups. "My main support has been online," she says. "I am thankful for the support I receive there."

Sylvie Chartré Paul's husband began chemotherapy for blood cancer 10 months before her diagnosis. Sylvie, 49, cared for him while working two jobs. After her diagnosis, the Toms River, New Jersey, woman continued both jobs out of financial necessity.

Her husband took a treatment break to care for her. Friends and family prepared meals and conducted fundraisers.

Shared caregiving helped in unexpected ways. "When you are both fighting cancer and undergoing treatments, you understand more," says Sylvie. "I admire him for the way he's handling it and he admires me. In a way, it strengthened our relationship."

As a caregiver, it's important to let yourself receive care when you need it.

"This can be an opportunity for you to change something that could be a good thing for you to change," says Ms. Tolbert. "There's always going to be a time of life when you're going to need someone." ~

"Even if a woman doesn't fall into some specific role of caregiver, most women are."

*name changed by request

TIPS FOR FINDING HELP AS A CAREGIVER AFTER DIAGNOSIS

- 1. Tell your healthcare team about your caregiving situation. Ask a social worker for resources.
- 2. Expand where you look for help. You may want one person to do it all, but no one can.
- 3. Create a list of specific needs—practical tasks and emotional support.
- 4. Coach others into action. Examples: "It's helpful when you sit near me." "Can we think about ways to tackle the laundry?"
- **5.** Use an online calendar or website such as Lotsa Helping Hands (lbbc.lotsahelpinghands.org) or TakeThemAMeal (takethemameal.org) to organize helpers.
- **6.** Find services before you need them: housecleaning, babysitting, Meals on Wheels (mowaa.org), Cleaning for a Reason (cleaningforareason.org), lawn maintenance, respite care.
- 7. Prepare to give up some control. It's OK if the pasta your neighbor brings isn't organic or a friend takes your kids to the mall instead of a movie.

News & Education

BY JOSH FERNANDEZ

Young Women's Initiative: LBBC Awarded Federal Grant



In recognition of our innovative work tailored to the needs of young women diagnosed with breast cancer, LBBC has been awarded a grant totaling \$1.75 million over 5 years by the Centers for Disease Control and Prevention. Originally funded through another CDC cooperative agreement granted in 2011, our Young Women's Initiative has engaged more than 100,000 young women and their families.

The new grant will help us develop more resources for young women, including virtual and in-person programs, interactive online content, programs for underserved women and print and online resources. To learn more about our Young Women's Initiative, visit lbbc.org/youngwomen.

Video Series for the Newly Diagnosed

We are excited to announce the development of new educational videos for people recently diagnosed with breast cancer! Our **Video Series for the Newly Diagnosed: What You Need to Know** will focus on helping you understand your breast cancer diagnosis and how to talk about it with family, your partner, children and close friends. The series will be available to watch on lbbc.org in summer 2015.

Fall Conference Recap and News

More than 400 people affected by breast cancer joined us in Philadelphia for our Annual Fall Conference, **Breast Cancer Today: Individual Treatments, Shared Experiences**, on Saturday, September 27. If you missed the conference, visit **lbbc.org/fallconference** to watch our general sessions and download recordings of some of the programs. Our 2015 fall conference will take place September 18 – 20, 2015, at the Marriott City Center in Denver, Colorado. Stay tuned for more details!



Metastatic Breast Cancer Conference Update

Our Annual Conference for Women Living With Metastatic Breast Cancer will take place April 10-12, 2015, at the Loews Philadelphia Hotel in Center City Philadelphia. Visit lbbc.org/events/metastatic-breast-cancer-conference for updates on registration, travel grants and fee waivers.

Survey Update

The findings of our 2013 National Breast Cancer Survey have been accepted for two poster presentations at the San Antonio Breast Cancer Symposium, taking place December 9–13. Our poster on factors that affect emotional and psychological change in women with triple-negative breast cancer will be presented Thursday, December 11. The presentation on education and information preferences for women with triple-negative disease takes place Friday, December 12. Visit lbbc.org/About-LBBC/LBBC-Research for details after the symposium.

New Breast Cancer in Focus Brochure Available



Breast Cancer inFocus: Getting the Care You Need as a Lesbian, Gay or Bisexual Person helps LGB people find and communicate with cancer care teams about your sexual orientation and unique treatment concerns. This brochure, the first of our new series, has companion online content with information and resources for LGB people diagnosed with breast cancer. Trans-specific content is also available. Visit lbbc.org to access our brochure and Web content.

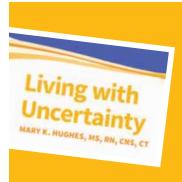
The second brochure in this series will cover breast cancer in men. It will be available on our website in early 2015.

Join the Volunteer Social Share Team

Do you update Facebook or tweet often? LBBC seeks enthusiastic social media users to join our **Social Share Team**. As a share team member, you will help LBBC spread the word about upcoming programs and initiatives through updates on your social media. If you are interested in joining this team, email our community engagement coordinator, Megan Roberts, at volunteer@lbbc.org.

Beyond These Pages BYNICOLE KATZE, MA

Like what you've read? Learn more at lbbc.org



Read the transcript of our program Advanced Breast Cancer: Living With Uncertainty, featuring Mary K. Hughes, MS, RN, CNS, CT



lbbc.org/Event-Archive/2009-02-28-Advanced-Breast-Cancer-Livingwith-Uncertainty



Read a husband's perspective on caring for his wife throughout her metastatic breast cancer journey on the LBBC blog



living beyond bc. word press. com/2011/11/01/through-sickness-and-inhealth-a-husbands-perspective/



Listen to our podcast
Can You Hear Me Now?
Communicating With Friends
and Family, featuring Julie
Larson, LCSW



lbbc.org/Event-Archive/2012-02-25-Communicating-with-Friends-and-Family



Save the Date for 2015's Yoga on the Steps: Denver, Philadelphia and Kansas City



yogaonthesteps.org



Learn more about stress and anxiety after a metastatic breast cancer diagnosis in our *Metastatic Breast Cancer Series: Managing Stress and Anxiety*



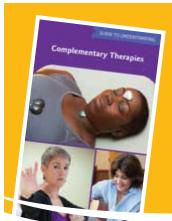
lbbc.org/guides



Host a DIY fundraising event for LBBC



lbbc.org/Get-Involved/Do-It-Yourself-Fundraising-Events



Gain knowledge of nonmedical practices to help you manage treatment side effects in our *Guide* to Understanding Complementary Therapies

lbbc.org/guides



Help support our programs by making a donation



lbbc.org/gift

To learn more about how guidelines will be used in your treatment, ask your doctors these questions:

- What treatment guidelines do you (or does this facility) use?
- What do the guidelines say about the treatments you're planning to give me?
- Why might you recommend treatment that is different from what the guidelines suggest?

Examples of Treatment Guidelines

Treatment guidelines often look at the stage and type of breast cancer and state the best course of treatment for most people who fit that category. For example, a recent ASCO guideline for people with metastatic *HER2-positive* breast cancer, which grows because of a protein called human epidermal growth factor receptor-2, recommends:

- Medicines that target the HER2 protein as the first treatment, except for select people who also have hormone-positive breast cancer, which grows in the presence of estrogen or progesterone. For these people hormonal therapy alone may sometimes be used.
- The combination of *trastuzumab* (Herceptin) and *pertuzumab* (Perjeta), two medicines that attack HER2 proteins, along with a *taxane*, a type of chemotherapy, as the first treatment, unless the person can't have taxane-based chemotherapy.
- If the cancer grows despite HER2-targeted therapy, use of *T-DM1* (Kadcyla), which pairs chemotherapy with a targeted medicine to deliver it directly to the tumor, as the next option. Age is another factor that influences the guidelines. On the topic of breast cancer and fertility, NCCN recommends:
 - Premenopausal women be told how chemotherapy may impact fertility and be asked if they want to try to become pregnant in the future. If they are interested, they should be referred to a reproductive endocrinologist before they start chemotherapy.
 - Women be told not to become pregnant while they are receiving radiation therapy, chemotherapy or hormonal therapy, because these treatments can hurt the fetus.
 - Though research is limited, women with breast cancer should be discouraged from using hormone-based birth control, whether or not they have hormone-positive breast cancer.

Other issues that might prompt a guideline include breast cancer subtype—such as newer guidelines for inflammatory breast cancer—and managing side effects.

How Guidelines Are Created

ASCO has 17 breast cancer guideline panels, each with about 15 members. The panels represent different aspects of breast cancer, such as stage and subtype.

Dr. Hudis says the process of creating guidelines consists of "experts getting together, critically reviewing the available evidence, identifying where there's a consistency and where there are inconsistencies, and making judgments from that about what should be recommended as standard, when possible."

Dr. Gradishar's NCCN panel includes oncologists, surgeons, pathologists and other specialists. Members meet every summer to look at the guidelines in what Dr. Gradishar calls "excruciating" detail, to decide if changes should be made, based on the latest research findings. When there is breaking breast cancer news, as sometimes happens at big events like the annual San Antonio Breast Cancer Symposium, or when an important new study is published, a conference call may be scheduled. If the evidence is very strong, that may lead to an immediate guideline change.

"The guidelines are not static. They're dynamic," Dr. Gradishar says.

Dr. Gradishar mentioned pertuzumab and trastuzumab as examples of medicines whose strong evidence of effectiveness caused the guidelines for HER2-positive breast cancer to be changed quickly. The purpose of quick changes is to help effective new treatments become available to as many people as possible, as quickly as possible.

Ultimately, the purpose of this process, Dr. Hudis says, is to "ensure that good information is translated into benefits for people with breast cancer."

Not One-Size-Fits-All

Treatment guidelines are not meant to speak to every situation. Every person experiences cancer differently, so it is important that your doctor tailor treatment to you.

"Oftentimes, the guidelines cannot cover every patient, tumor or other factors that can go into an individual decision making process," says Dr. Buchholz. "They don't include patient preferences, so it's important for all oncologists to use these guidelines as a base, but then interpret these guidelines in the context of an individual patient."

Christie Hutchison, 58, of Tulsa, Oklahoma, was diagnosed with triple-negative breast cancer in 2013. After a lumpectomy, chemotherapy and radiation, Christie completed her treatment in June 2014. She asked her oncologist for a *PET scan*, a test that uses images to find cancer cells in the body. She was told that post-treatment guidelines don't encourage PET scans to screen for recurrence. She left the appointment confused about why she was discouraged from getting the test, when she knew other women who had gotten it.

"I do wish they would have explained more about what the guidelines were ... and why some people did [get the test] and why some people didn't," Christie says.

Christie, who, along with her husband, Donnie, founded a breast cancer support group called Tulsa TNBC Exchange, later asked her oncologist to better explain why she shouldn't get the test. Unless the stage, type or location of the cancer suggest a person needs the test, he said, he avoids PET scans because they are very sensitive and have a high rate of false-positive results: when a test shows cancer is still in the body, even though there isn't any.

Her doctor's decision was in line with NCCN guidelines that discourage PET scans after treatment for people with stages I-IIB breast cancer for a number of reasons, including that high rate of false-positive results.

Treatment guidelines are not meant to speak to every situation. Every person experiences cancer differently, so it is important that your doctor tailor treatment to you."

If your therapy doesn't follow guidelines, that does not mean you're getting bad treatment, Dr. Gradishar says. But if a facility doesn't treat most people according to guidelines, that could suggest a problem. For that reason, groups like the National Accreditation Program for Breast Centers look at how closely guidelines are followed before giving their endorsement. These programs want to ensure, for example, most people with hormone-sensitive disease are receiving hormonal therapy, since it has been proven effective in many large, well-built clinical trials, he says.

A Reasonable Option

If you worry you're missing out on a better treatment or you want to help doctors find the cancer treatments of the future, Dr. Gradishar advises that you look into *clinical trials*, research studies that compare new medical approaches to the kind of standard treatments featured in the guidelines.

"The guidelines are always based on the underlying premise that a well-conducted clinical trial is a reasonable treatment option," he says.

Those clinical trials could show in the future that a new medicine is the best treatment for a particular type of breast cancer. By participating in trials, you could not only get early access to a new treatment, but could also shape the next generation of guidelines and help other people who have breast cancer.

"The reason we're able to have a discussion about guidelines is that people participate in clinical research," Dr. Hudis says.

Learn More About Guidelines

Guidelines are written for doctors, using medical terms. But many of them are available to you online at the websites of NCCN and ASCO. Some organizations also publish guidelines written for laypeople. One good resource is the NCCN Guidelines for Patients — online booklets that explain the guidelines in plain language. The booklets are divided by breast cancer stage, so you can find the information that applies to you. Find these resources at nccn.org/patients/guidelines.

If a doctor brings up a certain guideline or you read about one and want to know more, don't hesitate to ask your healthcare team to tell you more about it. You deserve to understand why tests and treatments are being recommended or not. If your doctor isn't open to your questions, consider getting a second opinion. Another doctor may be able to better explain why you should or shouldn't have a certain test or treatment, or the new doctor may decide that in your situation, the test or treatment should be done.

For more information about treatment options, clinical trials and guidelines, visit lbbc.org.

Ask Your Peers

"How did you balance cancer treatment with everyday life?"



April Sloan, Greenville, South Carolina "The balance was never equal because treatment was always priority. Cancer does not care what you have going on in your life. Take deep breaths! I simply put me first and did what [my] body was able to do."



Sylvie Chartre, Toms River, New Jersey "My husband and I were in chemo together. I registered my Daisy as an emotional support dog, so that she could be with us. I kept working two jobs throughout my treatments because both of us being self-employed, you do what you have to do, and there is no time to stop and feel sorry for yourself. What doesn't kill you makes you stronger."



Natalie Palmer, West Simsbury, Connecticut

"I took mental time away from breast cancer treatment; even if my body was in treatment, my mind was not. I meditated, prayed, wrote, hung out with those closest to me, practiced yoga—everything that reminded me I was me, not my diagnosis."



Jaime Petersen, Saint Paul, Minnesota "Make it work. Believe that your treatment is just another step. Breast cancer doesn't get to win."

Where did you go for financial information or support? Let us know at editor@lbbc.org

THE 2014 Butterfly Ball

BY LINDSAY BECKMEYER

n Saturday, October 18, Living Beyond Breast Cancer held our annual gala, The Butterfly Ball, presented by White House | Black Market. More than 600 attendees supported the event, which raised over \$700,000 to help LBBC continue our mission of connecting people with trusted breast cancer information and a community of support.





Butterfly Ball













- 1. 2014 LBBC Founders Award recipient Richard DeMaria, PT, and family smile for the camera. From left to right: Rita DeMaria, Richard DeMaria, Katherine Schoen, son Jeffery DeMaria and daughter Amanda DeMaria.
- 2. Mistress of Ceremonies and White House | Black Market President Donna Noce Colaco with Going Beyond Honorees. From left to right: Lu Ann Cahn, Donna Noce Colaco, Robin Bender Stevens, Denise Portner and Margaret Zuccotti.
- 3. Gold Sponsors Michael Dubin and N. Baranes from Manchu Times Fashion with Presenting Sponsor White House | Black Market President Donna Noce Colaco and husband Frank Colaco.
- 4. Butterfly Ball Co-Chairs Willam Toll, Lisa McDonough Toll and Rebecca and Jesse Dougherty.
- 5. Amy Lessack, Lynn Marks, Margaret Zuccotti, Robin Bender Stevens and Barbara J. Yorke, LBBC board chair.
 6. 2013 Founders Award recipient Ellyn Golder Saft and husband Stephen Saft.
- 7. Longtime LBBC supporters Judy Herman and Andi Morris.
- 8. 2014 Founders Award recipient Richard DeMaria, PT, with friend, LBBC supporter and 2012 Founders Award recipient Debra Somers Copit, MD.

DONOR PROFILE

Jessica Weidknecht:

Giving While Combining Two Passions

BY ERIN ROWLEY

hen Jessica Weidknecht decided to start fundraising for LBBC, she did it because it combined two things she is passionate about—breast cancer and yoga.

Jessica, from Centennial, Colorado, was diagnosed with *ductal carcinoma in situ*, DCIS, in 2013, at age 40. One day, at her physical therapist's office, she saw a flyer for our Yoga on the Steps event, which features yoga, music, refreshments and healthy living resources. Yoga on the Steps is held every year in different cities across the country, including Denver.

Jessica was already a fan of yoga and its peaceful, relaxing effects. She was also interested in finding a way to raise awareness that breast cancer can affect anyone, at any age, and encourage women to get screened for it.

After learning more about us, Jessica felt that LBBC was an organization for which she could make a big difference. And that



she did. Jessica's team, "Besties for Breasties," was the top fundraiser at the 3rd annual **Yoga on the Steps: Denver** event, on September 13, 2014. Her team raised \$4,570 from 43 donors.

"I had a lot of support from friends in the neighborhood and friends from out of town. I had a really good response," says Jessica, who finished active breast cancer treatment a few months before the event.

About 25 people, including her husband and two young daughters, donned matching T-shirts and came to the event to support Jessica. She says everyone was excited, telling her they can't wait to do it again next year. They won't be disappointed, because Jessica says she "definitely" plans to continue taking part in Yoga on the Steps: Denver.

DIY Events in Action

BY LINDSAY BECKMEYER

his year, Living Beyond Breast Cancer started a new "Do It Yourself" event program, **DIY events**, which allows you to use your passion and creativity to organize and host events in your communities to benefit LBBC. The DIY program was embraced by many this October, with events ranging in type from virtual to home and community, and themed from sports to shopping.

Some events required extensive planning and coordination while others were simpler to host, but each and every event raised invaluable funds and awareness for LBBC. Here are a few examples of the wonderful DIY events that took place this October:

Fall Field of Champions

Gary Newborn, of Flemington, New Jersey, and his softball team "**Jersey Inferno Gold**" organized a softball tournament that brought over 60 teams from Maine to Virginia together in Edison, New Jersey. Over \$6,000 was raised during the two-day event.

Linda's Loft Day of Shopping to Benefit LBBC

Linda's Loft, a clothing boutique in Jenkintown, Pennsylvania, hosted a day of shopping on November 6. All shoppers received 25 percent off their purchase, with 5 percent donated to LBBC.

Wagner Middle School Walk-A-Thon Wagner Middle School in

Philadelphia, Pennsylvania, hosted a walk-a-thon in which over 500 middle school students walked around their

school's neighborhood in North Philadelphia to raise funds and awareness. In its second year, the walk has raised over \$4,000 for LBBC.

Think Pink Day at Springside Chestnut Hill Academy

LBBC Board Member **John McDonald**'s son, **Jack**, hosted a 'wear pink day' on October 22 to benefit LBBC at Springside Chestnut Hill Academy in Chestnut Hill, Pennsylvania. Students paid \$3 to wear pink to school to raise awareness for breast cancer, and all money raised was donated to LBBC.

Each of these events was very different, but they all raised awareness and funds for LBBC. To host your own DIY event, please visit lbbc.org/Get-Involved/Do-It-Yourself-Fundraising-Events or contact Brittaney Shade at bshade@lbbc.org.









354 West Lancaster Avenue, Suite 224 Haverford, PA 19041

NEWS • INFORMATION • EDUCATIONAL RESOURCES • LEARN MORE ONLINE AT LBBC.ORG

LIVING BEYOND & BREAST CANCER



Every day LBBC provides programs, information and services to thousands of people touched by breast cancer.

LBBC connects those who need information to a community of compassionate support.

Your donation ensures that people affected by breast cancer will have immediate access to trustworthy resources all year long.



















Please donate today to help those who will rely on LBBC tomorrow Visit lbbc.org/gift to make your online donation

WINTER 2014 Calendar

Educational Programs

WEBINARS

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

DECEMBER 19, 2014

Annual Update from the San Antonio Breast Cancer Symposium

Robert A. Somer, MD

JANUARY 29, 2015

Fear of Recurrence

Allison Nilsen, LCSW

Other 2015 Programs:

FEBRUARY

Breast Reconstruction: A Two-Part Series

MARCH

Managing the Financial Impact of Cancer

COMMUNITY MEETINGS

Check lbbc.org for events in the Denver, Kansas City and Philadelphia areas

TWITTER CHATS

MARCH 3, 2015

Triple-Negative Breast Cancer

Panelists TBD

Conferences

APRIL 11 - 12, 2015

9th Annual Conference for Women Living With Metastatic Breast Cancer

Loews Philadelphia Hotel Philadelphia, Pennsylvania

Special Events

Check **lbbc.org** for the latest program information

THANK YOU TO OUR Donors

\$100,000 and above

Genentech

\$65,000 to \$99,999

Amgen

Eisai

Susan G. Komen

The Sherman Sobin Group

2nd Annual Golf Tournament

\$50,000 to \$64,999

Triple Negative Breast Cancer
Foundation

White House | Black Market

\$20,000 to \$49,999AstraZeneca
Centers for Disease Control and Prevention

\$15,000 to \$19,999

18th Annual Paddle Rally
Celgene Corporation
Donna Noce Colaco and
Frank Colaco
Customers of Chico's FAS

\$10,000 to \$14,999
6th Annual Rally for Life
14th Annual Ann N. McDonald
Memorial Basketball
Tournament
Michael Durbin
Kathryn Yates Gaffney and
Christopher Gaffney
GIV Foundation
Greenberg Traurig, LLP
Louise Mauran Groton and
Cal Groton
Independence Blue Cross
Foundation
Merrimack Pharmaceuticals

\$5,000 to \$9,999
AbbVie
AmerisourceBergen
Candace and Joseph Centeno
Cline Cellars
Rita and Richard DeMaria
Field of Champions/Jersey
Infernos Softball Tournament

Misha Kuhn
Lilly
Jennifer Mejasich and
Robert Cocco
Andrea Pedano and
Steve Geckle
Pfizer Oncology
Toll Brothers Breast Cancer
Awareness Month Events

\$2,500 to \$4,999

Abramson Cancer Center Allergan Susan and Marc Bernstein Jenny Burkholder and John Flak Lu Ann Cahn and Phil Houser **Cancer Treatment Centers** of America Katie Clifford and **Thomas Toomey** Debra and Steven Copit Cozen O'Connor Rebecca and Jesse Dougherty Alison and David Finkelstein Fox Chase Cancer Center/ Temple University Hospital Theresa and Larry Frangiosa Alison and Andrew Haimes Susan S. Harmelin Anne and David Hilton Sharon and Steven Katz **Emily Kunze** Anne and Joseph Liberati Rachel and Neil Malhotra Marion and Michael Mariner Meridian Bank Bunny and Peter Merrill Meyer Capital Group Beth and Christopher Mirzai Lisa and Robert Moore Patti and John Murabito Re Business Solutions Retail Resource Group, LLC Todd Sherman Jennifer and Albert Simmons David Trinkley and **Kevin Gianotto** Barbara Yorke and Paul Villa Jane Zolot

Susan and John Zuccotti