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CHEMOBRAIN:

Getting Through the Fog

BY ERIN ROWLEY

ail Hughes, 63, from Teaneck, New Jersey, had a 4.0 GPA in college. She earned a master's degree, taught junior high school science for years and then ran a daycare out of her home, often working 12-hour days.

So after being diagnosed with stage IV, HER2-positive, inflammatory breast cancer at the end of 2010 and starting chemotherapy, the symptoms of chemobrain hit her hard. The term *chemobrain* describes cognitive or thinking problems, including issues with memory, concentration and multitasking, that appear after a person begins cancer treatment.

After 3 months of chemotherapy, Gail had trouble remembering what day of the week it was. Simple math problems became hard for her. Phone numbers that had been in her head for years were no longer there.

"It may seem simple to most people, but it gets frustrating when it's repeated and repeated," Gail says.

What We Know About It

Gail is not alone in this experience. It is estimated that up to 75 percent of people who have chemotherapy during breast cancer treatment experience chemobrain. The problem isn't unique to breast cancer, but it is possible hormones that are often involved in breast cancer, such as estrogen and progesterone, contribute to it.

Though the problem is common, doctors haven't always believed it was real, or that its symptoms were caused by breast cancer or breast cancer treatments. Today, more researchers are studying chemobrain.



After seeing a family member's experience with cancer, Heather Jim, PhD, became interested in the different ways that people react to cancer treatments. Dr. Jim is an associate professor in the department of health outcomes and behavior at Moffitt Cancer Center in Tampa, Florida. She's spent about a decade researching chemobrain. Because of how common breast cancer is and how vocal its advocates are, much of the research that has been done on chemobrain has involved people with breast cancer, Dr. Jim says.

"The message to survivors is that chemobrain is a real thing. It's not all in patients' heads."

"What we've found is that even though some doctors still aren't sure whether chemobrain exists, it really does exist," she says. "The message to survivors is that chemobrain is a real thing. It's not all in patients' heads."

But there is still a lot we don't know about this condition, including how it works and why certain people get it and others don't. The theories we do have may be connected to the doubts some people have about it being real, says Arash Asher, MD. Dr. Asher is the director of cancer survivorship and rehabilitation at the Samuel Oschin Comprehensive Cancer Institute at Cedars-Sinai Medical Center, in Los Angeles.

In the past, it was thought that most chemotherapy medicines couldn't cross the *blood-brain barrier*, an area inside the body

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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®

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Dear Friends,

After many months of work, I am so excited to share LBBC's new logo. We are retiring the old logo, replacing it with a new image with striking colors that convey the values that define our organization: strength, connection and hope.

I wanted the new design to reflect LBBC's key values and personality, which is a lot to capture in a little mark. Thanks to a process that began with reaching out to you, we arrived at this new evolution from the original mark.

We asked you to describe what you saw when you looked at our old logo, what you value about us and what is and has been most important to you about LBBC. Over 1,200 of you told us that:

STRENGTH helps you face breast cancer; the logo must be solid and powerful.

CONNECTION AND INTERCONNECTION

describe LBBC and our services; you learn invaluable lessons from others with similar experiences, and LBBC provides a variety of ways for you to meet and share those experiences.

HOPE grows as you use the resources LBBC offers and the support we give.



The new logo was one step in redefining our mission and vision. Another is a re-imagined, re-organized version of our website, LBBC.ORG. Expected to launch in summer 2015, the redesigned site will better serve you. And in January 2016 we will begin to celebrate 25 years of providing information and support to all those impacted by breast cancer.

Let us know what you think of the new logo and what is important to you about LBBC. Contact us on Facebook or by writing to info@lbbc.org.

Jean Sachs, MSS, MLSP

CEO

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Being an Advocate

BY MELISSA AARON AND MICHELLE TEMONEY, FOR LBBC

Through Living Beyond Breast Cancer's **Young Advocate Program**, 47 young women have been trained to use their personal experience to make a difference in their communities. The advocates were diagnosed before age 45, have limited incomes and are within 3 years of diagnosis or living with metastatic breast cancer. Upcoming Young Advocate Trainings will be held June 12–14 and September 18–20. Visit lbbc.org/youngwomen for information on how to apply.



Melissa Aaron

Being a Young Advocate for Living Beyond Breast Cancer has been a blessing and a tremendous honor. LBBC was a lifeline for me early in my treatment.

I was living overseas with my husband and young daughters when I was diagnosed. My first question to my medical team was, "Do you have any information about breast cancer?" To my dismay, they said, "No." And they weren't kidding. There was not even a pamphlet available. So I was left to troll the Internet for information, which is exactly as awful as it sounds. I was convinced I'd be dead in 6 months.

"You can do it. I did it and I'm still here."

After resettling in the States to start my treatment, I heard about the LBBC Young Advocate Program. I applied and was accepted to attend an LBBC conference in Washington state in March 2013 as a Young Advocate trainee. At the conference, I attended seminars and workshops. And most important, I got to look around a conference room filled with hundreds of young women walking my same path. I left that conference no longer comfortable focusing only on MY recovery—I was determined to share all the knowledge I gained with other women who need to hear that there is life beyond breast cancer.

As a result, today I am a volunteer for the LBBC Breast Cancer Helpline, which takes calls from across the nation, answering questions and providing resources to people who have experienced breast cancer, as well as their caregivers. I love hearing the relief in a caller's voice when I tell them my story ... and that I'm still here.

Sometimes, when we are in the middle of chemo and those drugs are kicking our butts, we really need to hear someone on

the other side of it saying, "You can do it. I did it and I'm still here." I am honored and privileged to be able to pass on that hope and encouragement. I am also an advocate in my community. LBBC provides materials for me to share with groups and individuals, to be a light in a sometimes dark situation. I'm thankful for LBBC and will continue to share my story and be a resource to others starting on this path so that they will know there is life beyond breast cancer.

Melissa lives in Honolulu, Hawaii. She was diagnosed with stage III breast cancer in 2011, at age 34. She has been declared NED (no evidence of disease).

Michelle Temoney

As an LBBC Young Advocate, I have been able to keep people who have experienced breast cancer informed about new treatments and survival tips. I'm able to share current statistics with them and direct them to LBBC resources, such as webinars and the Breast Cancer Helpline.

I have been invited to speak in churches, schools and many organizations that are affiliated with the oncology world. I love being able to get free pamphlets from LBBC to pass out to people and organizations in my community. These pamphlets help educate breast cancer survivors as well as their caregivers. They also help those who may not be seeking treatment or care due to fear or lack of resources. I'm very proud to be a Young Advocate for an amazing organization like LBBC. Most importantly, I love being an extension of LBBC and being able to give back to my community.

Michelle lives in Greenbelt, Maryland. 👝

To learn more about LBBC's Young Advocate Program, contact Arin Ahlum Hanson at arin@lbbc.org or visit lbbc.org/youngwomen.

LET'S TALK ABOUT SEX (AND INTIMACY):

Communicating With Partners

BY JOSH FERNANDEZ



fter she was diagnosed with stage I breast cancer in 2000, Cindy Papale, of Miami, barely had any desire for intimacy.

She and her husband John were so concerned about getting her through treatment that they they ignored the hurdles they faced. As a result, problems arose and couldn't be fixed. A year after she was diagnosed, they ended their 12 years of marriage.

"We just swept it under the covers and lived day-by-day," Cindy, 60, says. "It was an emotional rollercoaster from diagnosis to treatment, and I was just trying to survive."

What Cindy experienced is common; whether in relationships or single, many women find sex and intimacy difficult after a breast cancer diagnosis, during treatment, or after. Effective communication between you, your partner and your healthcare providers can be key to avoiding long-term issues.

The Challenge of Talking About Sexuality

Loss of desire for sex, difficulty reaching climax, vaginal dryness and tightness and pain during sexual intercourse—these are some ways breast cancer and its treatments may impact your physical relationship with a partner or spouse. The changes to your body from surgery and treatment may also impact your body image. To learn more about body image, read the Spring 2014 issue of *Insight* on LBBC.ORG.

Good communication is the basis for any intimate relationship, especially when dealing with side effects of breast cancer. But

when it comes to sex and intimacy, it is sometimes hard to start the conversation.

Don S. Dizon, MD, FACP, founder and director of the Oncology Sexual Health Clinic of Massachusetts General Hospital in Boston, says there is no cookie-cutter way to communicate these issues.

"When a couple comes to see me, they usually don't know how to have that conversation with a spouse or partner," Dr. Dizon says. "When it comes to someone who is single or dating, they worry that disclosing their diagnosis or showing scar tissue will complicate matters when they want to become intimate or have sex."

Susan DiPronio, 63, of Philadelphia, told a woman she dated that she had surgery for breast cancer. The woman seemed OK with it, but when she saw Susan's chest, she looked away.

Despite being a confident person, bringing up breast cancer or its impact on her sex life makes Susan nervous. But she tries to talk about it with potential partners because intimacy is important to her.

"Good communication is the basis for any intimate relationship, especially when dealing with side effects of breast cancer."

"One of the worst things about breast cancer, besides looking mortality in the face, is not feeling desired," Susan says. "When you lose that, your self-esteem crumbles a little."

This is where being single has its own challenges. Initiating sex or intimacy with a new partner can be difficult if you feel pain from sex or if sharing your diagnosis intimidates the person you date.

Cindy tried dating after her divorce, but the dates felt awkward. She avoided talking about breast cancer, which was hard since Cindy publically spoke about the disease as well as wrote and published her experience in her book *The Empty Cup Runneth Over*.

"I'd mention it and my dates showed compassion, but I barely got a second date," Cindy says. "I felt undesirable, like I was less of a woman."

Married or partnered women sometimes face challenges, too. Even the strongest of couples experience obstacles to communicating about sex and intimacy.

Following her diagnosis with metastatic breast cancer in 2007, **Debbie***, 55, of Seattle, lost her desire to be sexual and experienced pain during sex. Starting the conversation with her husband was not the problem. It was moving toward solutions. "We would talk

*Name changed by request.

about issues we had, but we really haven't done a good job of following up on it," Debbie says.

Reclaiming Sex and Intimacy Through Communication

It's important to know that reclaiming sex and intimacy after breast cancer takes time, Dr. Dizon says.

Having a conversation with your partner about sex and intimacy worries may be difficult, but even just saying how you feel gives your partner something to respond to. "What I tell patients is not to project elsewhere, but to communicate about how they feel," he says. "Don't say 'you,' say 'l.' 'I feel,' 'I want,' 'I need.""

"...it takes time to feel comfortable and even sexy or proud."

As part of her breast cancer treatment, Debbie had a hysterectomy. Following her surgery, sex became very difficult. She told her husband, and the two talked about what it meant for their sex life. Her husband said it was more important to him that Debbie be around to share their lives together; sex wasn't his main priority.

"Hearing that reassured me that we've been on the same page this whole time," Debbie says.

Licensed psychotherapist Julie Larson, LCSW, notes that reclaiming your sex life often begins with reconnecting with your sexual side. This process may involve learning to feel comfortable or confident with how you look after breast cancer surgery and treatment.

"As much as sex and intimacy seem to be two-person activities, they begin alone—the moment you take your clothes off or look at yourself in the mirror," Ms. Larson says. "After experiencing so much change and loss, it takes time to feel comfortable and even sexy or proud. Those underlying feelings of confidence make a big difference in how you feel as you share sexual or intimate moments."

Five years into her divorce, Cindy and her ex-husband began dating again. After they were able to discuss their intimacy issues, the two wondered why they divorced. They remarried in November 2014.

"Without proper communication, a relationship becomes stressful and doesn't work out," Cindy says. "Once we faced the truth, we realized our love for each other was much stronger than our intimacy issues."

Whether single or in a relationship, Susan says practicing what you want to say can help you feel ready to express what's on your mind.

"It's integral that you have close and intimate relationships after cancer because it changes who you are," Susan says.
"You must be able to talk about these issues, so get it ready, write it down, record it and play it back to rehearse if you have to."



Sharing With Healthcare Providers

It's important to be able to talk with your healthcare providers about your sexual concerns. Sometimes, though, providers don't bring them up.

"Some oncologists may not be very comfortable talking about sex, but in reality, they also just may not be very *good* at talking about it," Dr. Dizon says.

This is why Dr. Dizon recommends oncologists and other medical center staff know where to turn to get sexual health information. This way, if you have a concern, your oncologist or the staff can point you to resources. Our *Guide to Understanding Intimacy and Sexuality* lists resources and provides practical tips for managing and talking about the sexual side effects of breast cancer. Consider bringing a copy to your appointment so your doctor can learn about the resources available. You can order print copies or download one online on LBBC.ORG.

Ms. Larson recommends you write down the specific questions or symptoms you have. Knowing what you want to ask ahead of time may help you begin the conversation with your providers.

Rehearse what you want to say out loud, in front of a mirror or a trusted friend, family member or your partner. When you make the appointment or at the start of the visit, let your doctor know you have a few questions.

"You may not get answers in that moment, but you are putting the ball in the provider's court to get you a referral or information you can use," Ms. Larson says.

Diagnosed with breast cancer while in her 30s, the My Fabulous Boobies blogger Nicole McLean of Washington, D.C., did not shy away from discussing sex and intimacy with her doctors. But she did have to bring it up herself.

"I wanted to get married and have kids, so sex was important [to me]," Nicole, 45, says. "It's an awkward conversation to have, but I've usually found that when I brought up sex and intimacy with anyone from my care team, they responded well or pointed me to someone who could help." ~

News & Education

BY ERIN ROWLEY

Building Trusted Programs for You

A major focus of LBBC's programs is giving you trusted information in a variety of formats so we can meet your needs.

If you like to meet in person, our conferences are for you. If you like to dig into information from your computer or phone, go to LBBC.ORG day or night.

Our brochures can be downloaded from our website. For visual learners, we offer Web streaming from our live programs. And we feature the stories of those impacted by breast cancer in videos, blogs and features.

For fans of social media, attend our Twitter Chats—you can learn a lot from 140-character tweets. (Access transcripts at LBBC.ORG to see for yourself!)

If you want to talk to a trained peer volunteer, dial our Breast Cancer Helpline at (888) 753-LBBC (5222).

No matter your learning style, we have information for you. We archive most programs to meet your schedule. Drawing on the country's leading doctors, nurses, and mental health providers as speakers and reviewers, we ensure our information is medically accurate, informed by people impacted by breast cancer, and given in plain language, with compassion. Learn more below or visit LBBC.ORG.

Join Us for Wellness Weekend!

This year, our Annual Fall Conference will take place in Denver as part of *Wellness Weekend: Information and Inspiration for You*, September 18–20. Wellness Weekend brings together our Annual Fall Conference with our signature fundraising event, Yoga on the Steps.

The conference will kick off on Friday evening with a welcome reception and will continue Saturday for a full day of educational programming. This conference will help people with all stages and types of breast cancer learn about the latest medical and quality-of-life updates while connecting with others. Travel grants will be available. On Sunday, join hundreds of others who support breast cancer at Yoga on the Steps:

Denver, a one-hour all levels outdoor yoga class followed by a Healthy Living Expo.

As we did at last year's conference, at this year's event we will offer tracks for people with triple-negative, hormone-and HER2-positive, or metastatic breast cancer.

For more information on Wellness Weekend, visit lbbc.org/wellnessweekend.

Triple-Negative Awareness

On March 3, LBBC and people around the world marked TNBC Day, which recognizes the unique challenges of people with this subtype of breast cancer. Using a Twitter Chat and a blog carnival, we brought together experts and people with the disease to share their experiences, ask questions and learn from each other. Visit LBBC.ORG to find the blog posts and a transcript of the Twitter Chat.



In April, our annual TNBC webinar series will return with a medical update. Visit lbbc.org/Events for more information.

In July, visit lbbc.org to read or submit questions to our triple-negative Ask the Expert column.

Last year, we conducted the first-ever study of the psychosocial, nonmedical needs of women with triple-negative breast cancer. The study shows women with TNBC have higher levels of fear, anxiety and worry than women with other subtypes of breast cancer. It also shows these concerns continue throughout treatment and beyond. In December, LBBC's senior director, programs and partnerships, **Janine Guglielmino**, **MA**, presented two posters about the research at the annual San Antonio Breast Cancer Symposium. To see the findings, visit lbbc.org/About-LBBC/LBBC-Research.



National Volunteer Week

In recognition of National Volunteer Week, April 12–18, 2015, we'd like to say 'Thank You' to all of our volunteers who lent us a hand in 2014!

Young Women's Initiative

LBBC's Young Women's Initiative will host a number of events in the coming months, including:

- Healthcare Provider Symposium: Understanding the Unique Needs of Young Women Affected by Breast Cancer, on Tuesday, May 19, in Seattle. The symposium will help providers work more effectively with young women.
- a Young Advocate training, which will train 15 young women to use their personal experience to make a difference in their communities. This will be held in Philadelphia from June 12–14.
- a 360 program, held on June 13, in the Philadelphia area, which will focus on young women affected by breast cancer. This event will be available nationally via web stream.

For more information about these events, or to register, visit lbbc.org/Events or call LBBC at (855) 807-6386.

Beyond These Pages

BY NICOLE KATZE, MA

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



Listen to a podcast about chemobrain given by Arash Asher, MD

lbbc.org/Events/2014-09-17



Read more about the financial impact of breast cancer in our Guide to Understanding Financial Concerns

lbbc.org/guides



Save the date for Wellness Weekend: Information and Inspiration for You, September, 18–20 in Denver.

lbbc.org/wellnessweekend



Register for Yoga on the Steps: Philadelphia, our signature fundraising event

yogaonthesteps.org



Learn more about body image and sexual concerns in our "Let's Talk About It" video series

lbbc.org/Audiences/Young-Women/ Let-s-Talk-About-It-Video-Series



Find out how to become a Helpline volunteer or join our Share Team

lbbc.org/Get-Involved/Volunteer



Read the latest updates in breast cancer research from the San Antonio Breast Cancer Symposium on our Breast Cancer News site

lbbc.org/Understanding-Breast-Cancer/Breast-Cancer-News/ Updates-from-San-Antonio-Breast-Cancer-Symposium



Help support our programs by making a donation

lbbc.org/gift

CHEMOBRAIN: Getting Through the Fog (continued from page 1)

that controls whether something can enter the brain. Many people considered it unlikely that chemotherapy could lead to problems with thinking. Yet research shows some kinds of chemotherapy can cross the barrier, at least in small amounts. But even if the chemotherapy can't cross that barrier, Dr. Asher says, toxic chemicals that may be made in the blood in reaction to the treatment CAN cross it.

Chemobrain is seen in people of all ages. But, Dr. Jim says, older women may be more at risk. Treatment may speed up normal aging, causing thinking problems that are stronger and show up sooner than they would in a person without cancer. This is called the "accelerated aging hypothesis."

Still, Dr. Asher says, there's no reason to believe that people who have chemobrain have a higher risk of getting diseases like Alzheimer's later in life.

"Certainly your brain ages, but I can guarantee you the chemo was a factor and the chemobrain was definitely different. It felt like [I was] just walking around in a complete fog," says **Susan McMillan**, a social worker from Metairie, Louisiana. Susan was diagnosed with stage III breast cancer about 8 years ago, at age 52.

She had eight rounds of chemotherapy—one round every 2 weeks. After about three rounds she began noticing memory issues and had trouble focusing and reading.

Carmen Rivera, 50, from Miami, experienced chemobrain after being treated with a double mastectomy, chemotherapy and *tamoxifen*, a hormonal therapy that can be used to prevent *recurrence*, or return, of hormone-positive breast cancer.

After taking tamoxifen, Carmen had intense symptoms that she called "chemobrain on steroids."

Carmen's experience highlights the fact that "chemobrain" may not be the best word to describe this condition. Research shows symptoms may also be caused by other treatments, not just chemotherapy. Dr. Asher suspects that the more treatments—including chemotherapy, surgery, radiation and targeted therapies—the more likely a person may be to experience chemobrain.

Talking to Your Doctor

Carmen says hardly anybody talks about chemobrain, which frustrates her, since the condition had a big impact on her breast cancer journey.

"You have your oncologist; you have the surgeon; you have the nurses. It's a huge team and nobody talks about it," she says. "Maybe if they tell you about it ahead of time, you wouldn't think there was something wrong with you."

Don't be afraid to bring chemobrain up yourself. Your doctor may be able to change your treatment plan or help you manage the side effects you're having. If you think your doctor isn't taking you seriously, or you want to see someone more experienced in treating chemobrain, ask to see a specialist, such as a speech therapist or a *neuropsychologist*, a doctor who focuses on the relationship between the brain and behavior.



Dr. Asher says it's important to consider other factors that could make chemobrain worse, but can be treated or changed. Those factors can include:

- · Poor sleep, chronic stress and loneliness
- · Pain, depression and anxiety
- · Lack of exercise, loss of muscle mass and poor nutrition
- Side effects of medicine for other health problems
- Menopause

In the year after Gail's diagnosis, her mother, sister and her brother-in-law passed away and she took in her nieces for a few years. She also moved into a new home, which made it even harder for her to remember where she put things. The stress and the treatments made it hard for her to sleep, which made the side effects worse.

"There are people who go months and months having cumulative poor sleep. We're learning that it can have tremendous effects on [thinking]," Dr. Asher says.

You don't need to deal with these problems alone. Talk to a member of your healthcare team about how you feel and how they can help you feel better.

Ways to Cope

Chemobrain can interfere with your work, relationships and daily life. But there are steps you can take to lessen side effects and cope with them. Dr. Asher gives these tips for managing chemobrain:

- Get moderate exercise. Look into practices such as yoga and tai chi.
- Get enough sleep—8 to 9 hours per night for most people.
- If you're feeling depressed or anxious, talk to your doctor about medical and non-medical ways to manage those symptoms.
- Make to-do lists on a notepad; cross off items when they're done.
- Mark important appointments on a calendar.
- Organize your surroundings; keep things like keys or glasses in a specific place.
- Reomve distractions when you need to get things done; have conversations in quiet places.
- Don't multitask; focus on one thing at a time.
- Note when chemobrain is taking place.

Carmen noticed her symptoms were worse when she was stressed. To help, she started doing yoga and meditating. Doing so calmed her and reduced her symptoms. She also relied on family and friends, who were understanding—like her sister, who took care of her during treatment.

"I consider myself extremely lucky to be surrounded by so many supportive co-workers and family members," Carmen says.

One thing that many people with chemobrain swear by is laughter.

Susan couldn't help but laugh when symptoms of chemobrain led her to put out raw shrimp on a block of cream cheese and serve it to guests at a party.

Gail sometimes makes up words as a lighthearted way of dealing with not finding the word she wants. She also lowers stress in her life by listening to music during dinner, rather than putting on the news. She crochets and stays in touch with old friends—her memories from that era are very clear; it's newer memories that she has the most trouble with. She tries to stick to a routine to make her memory issues less of a problem.

Lifestyle changes may help you think more clearly. Some people see big improvements after making changes; others do not. It's not known why some respond better than others.

Susan began eating better and drinking more water, but mostly, she says, she just had to wait out the chemobrain.

"There are [people who make changes] and are still troubled, and I think those are the ones who are more purely affected by the chemotherapy alone," Dr. Asher says. "We take it on a patient-by-patient basis."

How Long Will It Last?

Every person's experience with chemobrain is different. Dr. Asher says most people see their problems slowly go away within 6 to 9 months of ending treatment. But some will continue to feel the effects longer than that. It is estimated that less than one-third of people who are treated for cancer have long-term cognitive changes.

Most of Carmen's chemobrain symptoms disappeared after she finished taking tamoxifen. After Susan finished chemotherapy, she started to notice chemobrain less and less. Within about a year of finishing treatment, her symptoms were mostly gone. She, like Carmen, wants people to know that what they're feeling isn't likely to last forever. Susan suggests embracing the power of positive thinking. She says, "worry is like a rocking chair. You rock and rock and you go nowhere."

Unlike those with early-stage disease, whose treatment ends, having metastatic breast cancer means that Gail continues to have regular treatment. After more than 4 years of therapy and almost that much time living with chemobrain, she says the condition is more noticeable than ever. It's a constant source of frustration but she has learned to accept it.

"I could cry over it at times, and I do when I'm alone. But if I cry through this illness, I'm not living and I'm wasting time." she says.

Research Continues

Dr. Jim looks forward to a day when doctors better understand which cancer treatments are most likely to cause chemobrain and which people are most at risk. That way, doctors can do a better job of tailoring treatment to specific people's needs.

Dr. Asher says he's seen much more research being done on chemobrain in the last 5 to 7 years than was done in the decades before, and he expects it to continue.

"I'm grateful that this topic's getting more attention," Dr. Asher says. "It's been a real source of distress for many of our patients for a long time." ~

Ask Your Peers

"Where did you go for financial information or support?"



Heidi L. Rankin, Ozark, Missouri

"I turned to my local resources for support. The Breast Cancer Foundation of the Ozarks paid our mortgage, utilities, etc. for 3 months. My local American Cancer Society and gave me 2 wigs, bras and prosthesis after my surgery FOR FREE.

At the local hospital where I was receiving treatment, I learned that every 2 weeks I was able to receive a free case of Ensure to replace meals if treatment were to make me ill. I also asked the hospital about financial assistance for the amount I owed after insurance paid and they gladly set up a payment plan that I could afford."



Stephanie Barr, Salina, Kansas

"We have a program in Kansas called 'Early Detection Works' that provides women with free mammograms and biopsies. I didn't have insurance, so my case worker there also got me started on my application for Medicaid. My cancer

center also had a financial aid staff member who was able to help me apply for assistance. She was able to get me approved to get several of the therapies and prescriptions I needed, and helped me get approved for Medicaid."



Sheryl DeHaven, Daleville, Virginia

"I was fortunate enough to have a breast cancer navigator at my oncologist's office. She was able to help me contact the utility companies to work out a payment plan so that I did not lose any utilities. I also did online research and found some great

resources, and reached out to the American Cancer Society. LBBC also provided several resources that helped with the finances."

What is most important to know when planning breast reconstruction? Let us know at editor@lbbc.org.

THREE CITIES, ONE GOAL:

Yoga on the Steps

BY ADVANCEMENT STAFF



Stephanie Haynes Kansas City, Missouri

Stephanie Haynes got involved in Yoga on the Steps: Philadelphia in

2011, without a strong connection to LBBC or to breast cancer. "I just thought the idea of gathering with hundreds of people to do yoga was inspiring," Stephanie says. "That day I learned how deeply breast cancer touches so many lives."

That same year, Stephanie left Philadelphia to move back to Kansas City. Then, one of her coworkers was diagnosed with breast cancer.

"When I saw that Yoga on the Steps was coming to Kansas City, it meant something more to me because of my coworker," she says.

Her team, Pound Puppies, was a "mishmash of coworkers, yogi friends and survivors from all over the city" and the second-highest fundraising team for Yoga on the Steps: Kansas City in 2014.

"I support LBBC not just because of their resources and community but because they provide a space for women to share their story," she says.



Theresa Ely Golden, Colorado

"Seven years ago when I heard the words 'you have cancer' I couldn't see the

road ahead," says Theresa Ely of Golden, Colorado.

After treatment ended, she made exercise a priority and established new routines to help lower her risk of recurrence. Last year, while discussing the benefits of yoga with a friend, she decided it was time to "get yoga back" into her life. She also decided 2014 was the year she would give back to LBBC.

Theresa registered for Yoga on the Steps: Denver, set a fundraising goal and emailed friends and family asking them for donations. In the end, she exceeded her fundraising goal.

For 2015, she plans to work with her yoga instructor to contact other yoga studios and continue to raise money for LBBC.

and why they'll do it again in 2015. Register for Yoga on the Steps at yogaonthesteps.org

Julie Wolfe

Yoga team captains from our three yoga

locations share how they became involved

Julie Wolfe
Hamilton, New Jersey

In 2013, Julie Wolfe participated in Yoga on the Steps: Philadelphia in honor of

her sister-in-law, Dawn. "It was rainy, cold and really fun," she remembers. So much so that she decided to do it again in 2014. The 2014 event meant even more to her, though, because she had recently been diagnosed with stage IIIB triple-negative breast cancer.

"When I was diagnosed, I committed to be at YOTS even though I did not fully understand the effects of chemo and how hard it might be to do yoga during my ninth week of Taxol treatment," Julie says.

Even though she felt "sick and fluffy" and could not be in the sun for long periods, she attended the event and raised \$7,000. "It was a sunny day with lots of family, friends and me in a big floppy hat," she remembers.

"We Can Survive"

CONCERT HIGHLIGHTS LBBC

BY KEVIN GIANOTTO

here was no shortage of highlights at the second annual CBS Radio We Can Survive concert, which took place at the Hollywood Bowl in Los Angeles on Saturday, October 24, 2014. Sponsored by Living Beyond Breast Cancer corporate partner 5-hour ENERGY, We Can Survive featured concert headliner Taylor Swift who was joined by Pharrell Williams, Gwen Stefani, Ariana Grande, Sia, Paramore, Jennifer Lopez, Alicia Keys and Lady Antebellum for a night of amazing music to benefit LBBC programs and services.

"The visibility LBBC gained through the association with these performers was amazing," says **Sandy Martin**, LBBC's vice president of advancement. "We increased awareness of LBBC on a national scale, and our social media presence through Facebook and Twitter, two platforms that have proved to be a significant way of reaching people about our resources."



The concert, honoring women diagnosed with breast cancer, featured headlining act Taylor Swift, the country-gone-popsinger who had the entire Bowl on their feet.

Earlier in the evening the concert's performers led musical sets interspersed with words of hope and encouragement for women in the audience who had been diagnosed with breast cancer. Paramore singer Hayley Williams wore a lightning bolt-emblazoned top with a pink cape, explaining the choice was for "those that are surviving a tough battle," and saying, "you're superheroes."

The show ended with Pharrell Williams, who touched on the female-forward nature of the evening throughout his set. Pharrell ended a medley of his hits with "Happy." The song's positive message rang especially true as a shower of confetti decorated the crowd.

Why LBBC: The Donor Connection

BY ADVANCEMENT STAFF



Terry Frangiosa Harleysville, Pennsylvania *Guardian Angel*

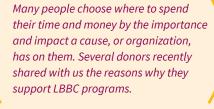
"I attended my first LBBC conference with my sister.

who was diagnosed with breast cancer at the age of 33. We were both shocked and frightened by the diagnosis, especially because she was so young. We left feeling empowered by the information we learned at that conference. As our knowledge grew, our fear decreased and the conference became a part of my sister's healing process. Donating to LBBC's Guardian Angel program, a service that offsets conference registration fees for those experiencing economic hardship, is my way to help others access the information and support they may need and to make a difference in their lives. I know attending that conference years ago did exactly that for my sister and family."



Sydney Licht
New Orleans, Louisiana
Founder of
Yoga on the Quad

"LBBC is a community that has supported my friends and family and allowed me to grow as a leader on campus and as a professional, and empowered me to make a difference. I am reminded of this each year when I join thousands of LBBC supporters at Yoga on the Steps: Philadelphia. The event is so powerful and inspiring that I brought it to Tulane so I could share the message with my peers. We have successfully held four Yoga on the Quad events to support LBBC. As an LBBC fundraiser, volunteer and former intern, I am grateful not only for their educational and support programs but for the opportunity to be a part of something larger than myself."





Angela & Roi

Boston, Massachusetts Angela Lee, Co-Founder Shop to Support Partner

"Angela & Roi gives to LBBC

because we want to partner with a breast cancer organization that provides assistance and programs to women and men throughout the entire diagnosis process. We were extremely impressed that LBBC holds Charity Navigator's highest ranking for sound fiscal management. As a 'shop by color' charity handbag company, we wanted to work with an organization that makes a positive impact, has a follow-through mentality and doesn't put their financial gains first. LBBC definitely fits that bill and because of this, we chose to not only partner with LBBC for the month of October, but to join their Beyond October program and donate a portion of proceeds from our pink collection year-round."

"I give to LBBC because I want others to gain that same hope and sense of community."



Eileen LaufgrabenPalm Beach Gardens, Florida *Annual Donor Since 1998*

"When I write my annual check to LBBC, it truly gives

me joy. My family supports other causes but I do this for me because LBBC means the world to me. I was diagnosed in 1995 and as I look back over the past 20 years I can honestly say that the most empowering moment in my breast cancer experience was in the spring of that year when I attended my first LBBC conference. I walked in and saw a thousand other women. I knew no one in the room, but I knew we were all connected and I no longer felt alone. I felt hopeful. I give to LBBC because I want others to gain that same hope and sense of community."



Meredith and Dylan Maltin

Blue Bell, Pennsylvania DIY Fundraisers

"I was diagnosed with

invasive ductal carcinoma in August 2013 and had a double mastectomy with reconstruction. Diagnosis was definitely lifealtering, but finding LBBC and their services helped me and my family a great deal. Last year, my son Dylan decided to combine his love for baseball and his desire to support a cause for his 'mitzvah project,' a community service endeavor many synagogues require of young people approaching their bar or bat mitzvah. Using the DIY tools on the LBBC website, Dylan created an online fundraising page and invited his baseball team, friends and family to participate in a Home Run Derby. He raised \$1,700 for LBBC. In his words, 'this event proves when people come together and do something positive, you can make a change in the world."



Lisa D. Kabnick

Philadelphia, Pennsylvania Cis B. Golder Quality of Life Grant Donor

"I joined the LBBC board in

1995 after my first experience with breast cancer and have continued to support LBBC since then. I support the Cis B. Golder Quality of Life Grant because I share the Golder family's vision and understand how important the grants are to the recipients. I was fortunate, as was Cis, when I went through treatment. I had excellent health insurance and family to help with my then young children. There is so much money in research for new treatments (and there should be more!), but the Golder Grant helps people when they are most vulnerable—when they have no other source of funds. It is a unique program and I'm proud to support it." -

There are many ways for individuals and companies to support LBBC. To learn more about how you can help, visit lbbc.org/donate.



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

LBBC

Our vision

is a world where no one impacted by breast cancer feels uninformed or alone.



IN PERSON

Conferences Community meetings Yoga on the Steps Helpline

ONLINE

Webinars
Videos
Twitter Chats

IN PRINT

Brochures Newsletters Understanding Guides

Calendar

Educational Programs

WEBINARS

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

APRIL 2015

Triple-Negative Breast Cancer Series:

April 17 Part 1: Reducing Risk of Recurrence Through Healthy Lifestyle Choices

April 29 Part 2: A Medical Update

MAY 28, 2015

Managing the Financial Impact of Breast Cancer

JUNF 2015

Annual Update from ASCO (American Society of Clinical Oncology)

COMMUNITY MEETINGS

APRIL 16, 2015

Fear of Recurrence Kansas City, Missouri

JUNE 13, 2015

360: Young Women and Breast Cancer

Philadelphia, Pennsylvania

Conferences

APRIL 11 – 12, 2015

9th Annual Conference for Women Living With Metastatic Breast Cancer

Philadelphia, Pennsylvania

Special Events

MAY 17, 2015

Yoga on the Steps: Philadelphia

Coming This Fall

SEPTEMBER 18 - 20, 2015

Wellness Weekend: Information and Inspiration for You *Connect. Learn. Support. Denver, Colorado*

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

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November 2014 - January 2015