



## Coping With Menopausal Symptoms After Breast Cancer Treatment

BY ANGELA KNIGHT, FOR LBBC



Wendie Pahor

**M**enopausal symptoms caused by breast cancer treatment can be challenging for anyone of any age. They are a common side effect of many types of chemotherapy treatment as well as surgery to remove the ovaries and hormonal therapy medicines.

Simply speaking, menopausal symptoms such as hot flashes, night sweats and vaginal dryness occur when the ovaries no longer make normal levels of estrogen. Many breast cancer treatments can affect menopausal symptoms.

**Janet S. Carpenter, PhD, RN, FAAN**, director of the Center for Enhancing Quality of Life in Chronic Illness at Indiana University, says women can experience a variety of menopausal symptoms and related health problems. These include:

- Hot flashes
- Night sweats
- Sleep troubles
- Mood swings
- Bone loss
- Changes in sexual desire
- Problems with vaginal dryness

Menopausal symptoms vary by person and in strength, and what bothers one person might not bother another.

**Wendie Pahor**, 49, of Las Vegas, Nevada, was diagnosed with stage I breast cancer in January 2011.

"I experienced hot flashes, night sweats, vaginal dryness, total lack of [sexual] desire, painful intercourse and weight gain," Wendie says. "I can handle the hot flashes and such, but the [impact on] intimacy with my husband is what has affected our quality of life the most."

Changes in estrogen levels can disrupt your comfort during sex. "The vagina has more estrogen receptors per square inch than probably anywhere else in the body," says **Ann Honebrink, MD**, a gynecologist at Penn Health for Women at Radnor of the University of Pennsylvania School of Medicine. "When breast cancer treatment deprives the body of estrogen, the walls of the vagina thin, the opening narrows, and combined, this causes discomfort that's very noticeable."

A health issue often related to loss of estrogen and menopause is bone loss. Osteopenia, or lower than normal bone density, occurs naturally as women age. When treatment causes early menopause, the drop in estrogen can make it happen faster.

Understanding what causes menopausal symptoms and related health concerns may help you find ways to combat their effects—and to talk with your providers about actions you can take.

### Natural vs. Medical Menopause

It's important to remember that experiencing *menopausal symptoms* and being *in menopause* are different. Menopausal symptoms after breast cancer treatment can be temporary.

"We don't say someone is *in menopause* until they've gone a year without a menstrual period," says **Patricia Ganz, MD**, director of cancer prevention and control research and of the patients and survivors program area at UCLA's Jonsson Comprehensive Cancer Center.

*Continued on page 8*

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40 Monument Road  
Suite 104  
Bala Cynwyd, PA 19004  
**Breast Cancer Helpline**  
**(888) 753-LBBC (5222)**  
**Tel: (855) 807-6386**  
**Fax: (610) 645-4573**  
**Email: [mail@lbcc.org](mailto:mail@lbcc.org)**  
**Website: [LBBC.ORG](http://LBBC.ORG)**  
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## Dear Friends,

Many of you may already know about the promise of immunotherapy in treating cancer. Clinical trials have begun to show its effectiveness in some forms of breast cancer. To keep you up-to-date, we talk with several leading experts about immunotherapy in this issue of *Insight*.



Photo: BECK Photography

Just as it's an exciting time in breast cancer research, it's also an exciting time at LBBC. We are in the first year of implementing a three-year strategic plan with a bold goal—to substantially grow the number of people we reach. Our plan is to enhance and expand our services while staying focused on our mission of providing you with trusted breast cancer information and a community of support.

We are experimenting with new technology: perhaps you already virtually “attended” a plenary session at an LBBC conference, or texted your question during our new Breast Cancer 360 programs that examine issues from every angle. We'll soon launch a texting service for the Young Women's Initiative and a chat feature for our Breast Cancer Helpline. And later this year, look for a fully redesigned LBBC.ORG, with more content and interactive features.

In September, you'll find us in Denver, Colorado, where we will hold our Annual Fall Conference during what we've named a Wellness Weekend. We'll top it off with Yoga on the Steps, LBBC's take on grassroots fundraising. Look for community meetings in Philadelphia, Kansas City (Missouri), and Denver, as well.

But just like progress in medical research, nothing can move forward without your help. To achieve our goals, we need (more than) a few good volunteers. We have a variety of opportunities, from joining our social media SHARE team to getting intensive training through our Young Advocate Program or Hear My Voice metastatic outreach program. Learn more at LBBC.ORG.

Thanks for being part of LBBC's community and let us know what topics you want to learn more about.

Warmly,

Jean Sachs, MSS, MLSP  
CEO

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# Recognizing Our National Volunteers

BY ERIN ROWLEY

*Since the beginnings of Living Beyond Breast Cancer, volunteers have been a vital part of the organization. Today we could not do what we do without our many dedicated volunteers across the country, who donate their time, energy and talent to help us carry our mission forward. For that reason, we present awards each April to a few special volunteers who have gone above and beyond. These awards are named after three dedicated volunteers whose service moved the organization forward and who are sadly no longer with us. We owe a big thank you to this year's honorees and to all our volunteers—they double our impact!*



## Reesa Gavin

**The Ann Klein Volunteer Award**  
Plymouth Meeting, Pennsylvania

I've been volunteering for LBBC for about 2 years. I wanted to give back, so I started to look for volunteer opportunities on the Internet, and I found information about LBBC.

As a volunteer, I do whatever is asked of me, including entering information into the computer, filing paperwork and stuffing envelopes. Being recognized with this award means to me that people have recognized how important my volunteer work is.



## Linda Wallace

**The Ann Klein Volunteer Award**  
Newtown Square, Pennsylvania

I think I started volunteering in 2003. I took two or three years off at one point and came back about a year-and-a-half ago. I think the reason volunteering with Living Beyond Breast Cancer is important to me mostly has to do with the fact that when I got diagnosed with breast cancer, LBBC was one of the places that I went to for information.

As a volunteer, I come in to the office once a week for a few hours, and I help with just about anything that is needed. I really appreciate that LBBC thought to give me this award.



## Peggy Valdez Olivas

**The Lee Plamondon Volunteer Award**  
Lakewood, Colorado

I have volunteered with LBBC, as a Helpline volunteer and at events in Denver, since July 2013. My best friend of 23 years, Jane Johnson, and I were diagnosed with breast cancer within a few months of each other in 2007 and 2008. We muddled our way through learning about the disease. Jane found LBBC and the organization helped us, as Jane would say, "learn to speak cancer."

Sadly, Jane passed away in early 2013, just weeks before LBBC put out a call for Helpline volunteers. I imagined volunteering

was something we would have done together. Initially I thought I couldn't start this journey without her, but I quickly realized that volunteering is a wonderful way to honor her.

I want to make a difference and getting feedback that I'm doing just that is an incredible honor. Each time I volunteer, I'm reminded of what a joy it is to be part of this incredible organization.



## Charmaine Chan

**The Community Vision Award**  
Philadelphia, Pennsylvania

I got hooked on LBBC after going to Yoga on the Steps: Philadelphia and attending the annual conference in Philly. Volunteering to give back was important to me because I got such wonderful free support when I was going through the worst of my cancer experience. Being a healthcare provider, I know there are people who are not as lucky. It's tough to face cancer alone, and LBBC not only provides wonderful information that is accurate and up to date, but helps women feel supported emotionally as well.

My main volunteer activity has been on the LBBC Helpline, but I have done many other volunteer activities as well. I was so surprised when I heard that the staff voted for me. There are so many people who put so much time and love into this organization; I don't feel as if I'm doing anything extraordinary. I volunteer because I believe in what LBBC does and because people need to know about this amazing organization.



## The Shipley School

**The Paula A. Seidman Volunteer Award**  
Bryn Mawr, Pennsylvania

**Betsy Leschinsky:** Shipley has supported LBBC for more than 7 years. Everyone is involved in our efforts, from the littlest students all the way up to our seniors!

We first began by supporting Yoga on the Steps: Philadelphia (Team name: The Shipley Sweethearts). Then when some of our teachers were diagnosed with breast cancer, we started having "dress down days" to raise money for LBBC, and bringing in speakers to help inform our students and faculty. LBBC gave unconditional support to several of our faculty and families as they navigated their journey. We will never forget how much that meant and how much it helped.

It is very special to be recognized, but to be honest we were surprised. We all just love and support the amazing work LBBC does! 🌟

# Helping the Immune System Treat Cancer

BY ERIN ROWLEY



Shauntell Cullen

Immunotherapy, also called biologic therapy or biotherapy, uses the body's own defenses to fight cancer. Clinical trials of immunotherapy are now accepting people with breast cancer; they are small and in early phases, and focus on metastatic disease.

Though immunotherapies are not likely to change practice in breast cancer in the near future, they are an exciting area of research that could have an impact on treatment down the road.

"I think patients have always been interested in immunotherapy," says **Douglas Yee, MD**, a medical oncologist and a professor and director of the Masonic Cancer Center at the University of Minnesota. "Women are very interested in the idea that maybe we can try a different strategy to treat their breast cancer besides our conventional targeted therapies or chemotherapies."

When she first learned about immunotherapy, **Shauntell Cullen**, 35, from Boise, Idaho, was excited. Shauntell was diagnosed with metastatic breast cancer in 2012. She received different chemotherapies and tamoxifen, but the disease grew despite these treatments. After two-and-a-half years, Shauntell asked her doctor to help her find clinical trials that might halt the cancer's spread.

## A Hot Topic

The immune system is a complex group of organs and cells that defend the body against infections and other foreign substances.

Its complicated nature, and the difficulty it has noticing cancer cells, which are often similar enough to healthy cells to stop it from reacting, made breakthroughs difficult in the past.

But excitement surrounding immunotherapy has appeared again in the last decade or so because of a new idea that has gained momentum about how the immune system may respond to cancer.

Think of the immune system as a car with brakes. Brakes are useful, because they stop the car from crashing. They keep the immune system from attacking substances that aren't harmful. But the brakes can also stop the car from going full speed, keeping the immune system from using its power to fight cancer cells. Dr. Yee says the idea that doctors may be able to help the immune system fight cancer by "removing the brakes" is a big part of the new buzz around immunotherapy.

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"We've learned that tumor cells are very efficient at applying the brakes to the immune system," Dr. Yee says. "We're learning how to overcome some of those brakes with new molecules that really help us have a more effective immune response against tumor cells."

Today, immunotherapy shows the most potential in diseases like lung cancer and a kind of skin cancer called melanoma, Dr. Yee says. That's because those cancers have many complex mutations, or changes in cell DNA. More mutations mean a better chance of helping the immune system recognize and respond to cancer.

Breast cancer, especially hormone receptor-positive breast cancer, tends to have fewer mutations than those other cancers, so it "has been a little slower to come to immunotherapy," Dr. Yee says.

Research continues into immunotherapy for all types of breast cancer, but there is especially great potential for triple-negative breast cancer. That's because of all of the subtypes, triple-negative has the highest number of mutations.

In October 2014, Shauntell started receiving treatment as part of an immunotherapy study that includes people with a variety of metastatic cancers. Shauntell was the first person with breast cancer to enter the trial.

"It's pretty exciting to be the first—and scary at the same time to be the first," Shauntell says.



## Types of Immunotherapy

Researchers are looking at different types of immunotherapies. These treatments all use the power of the immune system, but do it in different ways. They include:

### CHECKPOINT INHIBITORS

Medicines that work by removing the brakes that stop the immune system from fighting cancer are called checkpoint inhibitors. They interact with substances that appear on cancer cells, especially the PD-1 and PDL-1 proteins, to rev up the immune system. Checkpoint inhibitors being studied in breast cancer include pembrolizumab (Keytruda), MPDL3280A and indoximod.

### VACCINES

Vaccines, whether for the flu or for cancer, have the same goal: create an immune response to help the body fight a harmful substance. In breast cancer, though, because the disease is not known to be caused by a virus, vaccines are used for treatment rather than prevention. Vaccines can be made from the person's own tumor cells or from the tumor cells of someone else. Once an injection is given, the vaccine can strengthen the immune system and help it recognize cancer cells as harmful, foreign substances. Vaccines being studied in breast cancer include NeuVax, GVAX and GP2.

### T-CELL THERAPY

T cells, a kind of white blood cell, protect the body from disease. T cells can be removed and grown in a lab to make more than the body could make on its own and make them better at fighting cancer. Then, they are put back inside the body.

One T-cell therapy technique involves putting chimeric antigen receptors, or CARs, on the T cells. These receptors attach themselves to proteins on cancer cells, killing the cancer.

Another technique involves tumor-infiltrating lymphocytes, or TILs, white blood cells that may exist deep inside tumors. This is the technique involved in Shauntell's treatment. The cells were taken out of her body and adapted in the lab, with the hope that when put back in, they would help her immune system fight the cancer. The treated white blood cells, given the nickname "cancer fighting ninjas," were returned to Shauntell's body in February.

### MONOCLONAL ANTIBODIES

You may be familiar with monoclonal antibodies. That's because trastuzumab (Herceptin), used to treat HER2-positive breast cancer, is from this family of medicines. Monoclonal antibodies are proteins made in a lab. They treat cancer in a variety of ways. Trastuzumab, for example, attaches to HER2 proteins and blocks the signals that tell cancer cells to grow.

Some monoclonal antibodies also help the immune system see cancer it may not have noticed otherwise. So far, trastuzumab has not been used with that purpose in mind. But recent research suggests some people who benefit from trastuzumab may have an immune response to the treatment.

"That's very interesting and it's an area that we as breast cancer physicians are just starting to understand," Dr. Yee says.

## Joining a Trial

It can be a challenge to enter an immunotherapy trial. The trials need people whose cancers have specific traits, and there are limited trials in only a few places.

Shauntell's trial is held at the National Institutes of Health, in Bethesda, Maryland. She travels the more than 2,000 miles from Boise every few weeks for checkups. Preparing for the procedure, which involves chemotherapy treatment, receiving her new white blood cells and getting her white blood cell counts high enough to prevent infection, once required a 30-day stay in the hospital.

Though she feels lucky to be able to make the journey, Shauntell says it's still hard. She has to leave her young son behind. And though she has not yet had serious side effects, her treatment comes with a risk of high fever and dangerously low blood pressure immediately after the white blood cells are put back inside the body.

Shauntell also had to accept the idea of stopping other, more well-known treatments to start a treatment whose value is unknown. But she feels taking part in the trial is the right decision for her—whether the treatment works or not.

"There's a big part of me that honestly feels like I was just meant to be here, [participating in this trial]," she says. After so many other treatments, "I felt that I needed to shock my cancer. Standard chemotherapies ... they just weren't working. So for me to have something completely different—if my body can fight this off, I just have that much better of a chance of living longer."

At the end of March, Shauntell learned the liver tumors had shrunk by 5 to 10 percent. 🍌

*If you are interested in learning more about joining a clinical trial for immunotherapy, talk to your doctor and visit [ClinicalTrials.org](https://ClinicalTrials.org) or [cancerresearch.org/cancer-immunotherapy/clinical-trial-finder](https://cancerresearch.org/cancer-immunotherapy/clinical-trial-finder).*

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Shauntell says.***

***After so many other treatments,  
"I felt that I needed to shock my cancer.  
Standard chemotherapies ... they just weren't working."***

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# News & Education

BY NICOLE KATZE, MA

## We've Moved!

In late March, LBBC moved to new offices in Bala Cynwyd, Pennsylvania. Our mailing address is:

40 Monument Road, Suite 104  
Bala Cynwyd, PA 19004

## Annual Fall Conference on the Way

Our Annual Fall Conference is back September 18 – 20, this year in Denver, Colorado. The fall conference will feature prominent experts to give you the latest medical and quality of life news during tracks on triple-negative, ER- and HER2-positive, and metastatic breast cancer. It's all part of **Wellness Weekend: Information and Inspiration for You**. The weekend concludes with **Yoga on the Steps: Denver**. Visit [lbbc.org/fallconference](http://lbbc.org/fallconference) to register or learn more. To learn about Wellness Weekend, visit [lbbc.org/wellnessweekend](http://lbbc.org/wellnessweekend).

## Join Us for Yoga on the Steps

Help raise awareness and support LBBC's programs and services by joining hundreds of other yogis and fitness fans at **Yoga on the Steps: Kansas City** and **Yoga on the Steps: Denver**. The all-levels outdoor yoga classes are paired with live music and a Healthy Living Expo. Visit [yogaonthesteps.org](http://yogaonthesteps.org) to start a team, or join on your own in either city.

## See the Issue From Every Angle

Last November, we held our first **Breast Cancer 360**—a program featuring an expert panel discussion on a specific topic and a live Web stream.

This year, we held a Breast Cancer 360 event on breast cancer in young women in Philadelphia, Pennsylvania, and we will host one on triple-negative breast cancer in Denver, Colorado, on July 22. A third is planned for November in Kansas City, Missouri. To learn more, visit [lbbc.org/events](http://lbbc.org/events).

## Apply to Become a Young Advocate!

The **Young Advocate Program** provides the tools and training to help you use your personal breast cancer experience to make a difference in your community. If you had breast cancer before age 45, have limited income and were diagnosed within the last 3 years or are living with metastatic disease, you're eligible to apply. The fall program will take place in Denver during **Wellness Weekend**. To learn more, visit [lbbc.org/Audiences/Young-Women/Young-Advocate-Program](http://lbbc.org/Audiences/Young-Women/Young-Advocate-Program).



## Hear My Voice

Our first cohort of **Hear My Voice** outreach volunteers was trained at the **Ninth Annual Conference for Women Living With Metastatic Breast Cancer**, April 11 – 12 in Philadelphia. The volunteers, all people living with metastatic disease, will work in their home communities to connect others with metastatic breast cancer to psychosocial services and information. The group was comprised of 31 women, ages 24–68.

## Do You Blog?

We're looking for people interested in sharing their stories on the **LBBC Blog** during Breast Cancer Awareness Month in October. Email [jfernandez@lbbc.org](mailto:jfernandez@lbbc.org) for more information.

## Conference Roundup

LBBC has been on the road this spring. Here's where you may have seen us:

- CancerCon, Denver, Colorado
- FORCE 2015 Annual Conference, Philadelphia, Pennsylvania
- SURVIVORville, Nashville, Tennessee
- YSC Summit, Houston, Texas
- AOSW 31st Annual Conference, Seattle, Washington
- NCCN 20th Annual Conference, Hollywood, Florida
- 2015 ASCO Annual Meeting, Chicago, Illinois
- ONS 40th Annual Congress, Orlando, Florida
- 2015 World Congress of Psycho-Oncology, Washington, D.C. 🐾

# Beyond These Pages

Like what you've read?  
Learn more at [LBBC.ORG](http://LBBC.ORG)

BY NICOLE KATZE, MA



Listen to our 2-part series of podcasts, or read the transcripts, about breast reconstruction

[lbbc.org/Events/2015-02-11-Reconstruction-Implants](http://lbbc.org/Events/2015-02-11-Reconstruction-Implants)

[lbbc.org/Events/2015-02-25-Reconstruction-Tissue](http://lbbc.org/Events/2015-02-25-Reconstruction-Tissue)



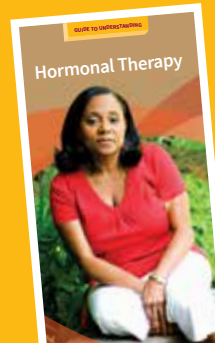
Register for Yoga on the Steps: Kansas City or Yoga on the Steps: Denver

[Yogaonthesteps.org](http://Yogaonthesteps.org)



Save the date for our Annual Fall Conference, **Breast Cancer Today: Individual Treatments, Shared Experiences** taking place in Denver this September

[lbbc.org/events](http://lbbc.org/events)



Learn about hormonal therapies and menopausal symptoms in our *Guide to Understanding Hormonal Therapy*

[lbbc.org/guides](http://lbbc.org/guides)



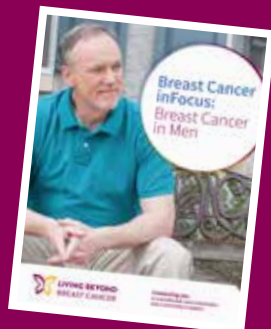
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Read about breast cancer in men in our latest *inFocus* guide

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Natural menopause is a much more gradual process than medical menopause. “The average age of natural menopause is 51,” Dr. Ganz says. “In the 5 to 10 years preceding that when ovulation tapers off, a woman may notice hot flashes, sweating and irritability from time to time, but it’s very gradual. Women will typically experience a 2–3 year period where the intensity of symptoms pick up, around the time of the last menstrual period, as the body gets acclimated to the changes in hormone levels.”

Medical menopause, on the other hand, is sudden, may be permanent, and its symptoms can be more severe than natural menopause. In breast cancer treatment, medical menopause is caused by some anticancer therapies that damage or remove the ovaries, stopping estrogen production.

### IMPACT OF MEDICINES

Chemotherapy can cause menopausal symptoms as soon as the first treatment cycle, but it’s also possible to develop them later in treatment. Your periods may suddenly stop or become irregular. Either way, the estrogen levels in your body may or may not be low, and symptoms like hot flashes and night sweats can vary.

Hormonal therapies that interfere with the body’s estrogen can have the same effects. Menopausal symptoms from chemotherapy and hormonal therapy can also permanently or temporarily affect fertility in younger women.

“It’s tricky for younger women who may want to get pregnant or want to utilize some form of birth control,” says Dr. Honebrink. “Keep in mind that [treatment] doesn’t go on forever, and ovarian function may or may not return. It’s hard to predict.”

To learn more about medical menopause and fertility, visit [lbbc.org/Learn-About-Breast-Cancer/Receiving-a-Breast-Cancer-Diagnosis/Fertility-and-Future-Pregnancy](http://lbbc.org/Learn-About-Breast-Cancer/Receiving-a-Breast-Cancer-Diagnosis/Fertility-and-Future-Pregnancy).

**Stephanie Joseph**, 51, of Germantown, Maryland, was diagnosed with stage II breast cancer in 2011. She took an aromatase inhibitor, a type of hormonal therapy, which caused severe hot flashes.

“I was having them almost 24 hours a day, feeling nauseous and almost flu-like,” Stephanie says. Her oncologist suggested integrative therapies, nonmedical therapies used alongside cancer treatment. “For now,” Stephanie says. “It is under control.”

Your doctor might offer standard medical therapies. These include gabapentin (Neurontin), an anti-seizure medicine that has been shown in studies to reduce hot flashes, and the antidepressant medication venlafaxine (Effexor). You can take practical steps, such as avoiding spicy foods and drinks with caffeine that may trigger hot flashes. Some women have success using acupuncture or deep breathing.

Stephanie also focuses on things she loves. “I have a great job and am able to work, I have four Chihuahuas I adore, and very often, I listen to music. [There’s] nothing better than spring time, opening the windows and blaring Madame Butterfly... Hang in there, it does get better,” she says.



Susan Rosen

Stephanie Joseph

### SURGERY AND OVARIAN SUPPRESSION

If you are premenopausal and have estrogen receptor-positive breast cancer, or you test positive for a *BRCA1* or *BRCA2* mutation, your doctor may recommend surgery to remove your ovaries, called oophorectomy. This causes surgical menopause, permanent menopause that begins immediately after surgery. With surgical menopause, symptoms may start suddenly, and may be more severe than those from natural menopause.

**Susan Rosen**, 50, of Franklin, Massachusetts, was diagnosed with stage III breast cancer in 2010. She tested positive for a *BRCA2* mutation, so she had her ovaries removed.

“Surgery truly causes forced menopause—it ends your periods for good,” Susan says. “I was at an age where I was done having children. Even though I am not on any hormone therapy [medicines] at the moment, I continue to have hot flashes.”

Ovarian suppression is a possible alternative to surgery. These medicines stop the ovaries from making estrogen, which causes temporary menopause. It can cause the same menopausal symptoms as other treatments but allows you to keep your ovaries.

### What You Can Do

There are many different ways to manage menopausal symptoms and find some relief. You may need or want to try several things to address your concerns.

“It may be comforting to know that hot flashes and night sweats will [often] go away on their own—and to keep in mind that however long they do last, they won’t last forever,” says Dr. Honebrink. In the meantime, she suggests:

- dressing in layers you can quickly remove to cool down
- avoiding hot drinks, smoking, spicy food, caffeine and alcohol
- asking your doctors about low doses of certain antidepressants. They may be helpful if symptoms are severe



## SEXUAL SIDE EFFECTS

For vaginal dryness, Dr. Honebrink suggests using a water-soluble lubricant during sex. Avoid those that affect sensation or contain spermicide—they can irritate the skin. Also stay away from petroleum jelly-based products that can harbor bacteria in your vagina and lead to infection. Consider regular, ongoing use of a vaginal moisturizer 2–3 times a week.

It's common to be less interested in sex during and after treatment for breast cancer. If you find your desire for sex waning, talking with your partner about your concerns can be very helpful.

**Cheryl Clark**, 66, of Lake City, Florida, was diagnosed in 2010 with stage I, HER2-positive breast cancer.

“No matter how understanding or supportive a partner is, they have needs. Be creative. Communicate. Engage their help,” Cheryl says.

Wendie agrees and adds, “You need to find other ways to be intimate, such as cuddling, back rubs [and] holding hands.”

For many more tips on improving your sexual health and talking with a partner or future partners, download our *Guide to Understanding Intimacy and Sexuality* on LBBC.ORG.

## BONE HEALTH

Bone loss can happen during natural or medical menopause. In some cases your doctors might order a DEXA scan, a test to measure your bone mineral density, before you start certain treatments. Your vitamin D level may also be checked.

Dr. Honebrink also suggests several methods to slow or prevent bone loss:

- perform weight-bearing exercise and eat foods rich in calcium
- consider trying foods like bok choy, broccoli, collard greens, salmon, sardines and anchovies
- find out if taking vitamin D or calcium supplements is safe for you. Too much of either could have negative effects, like kidney stones

Your doctors should tell you if tests show you have osteoporosis, a very low level of bone density. They would offer prescription medicines called bisphosphonates to treat it and lessen your risk for bone breaks.

For more tips on maintaining bone health, read our *Guide to Understanding Bone Health*, available on LBBC.ORG. 🐾



Cheryl Clark

# Ask Your Peers

*“What is most important to know when planning breast reconstruction?”*



### Jana Mitchell, Sparta, Wisconsin

“I had a TRAM flap [breast reconstruction surgery in which a flap of tissue is moved from the abdomen to the chest]. If I did it all again, I'd choose to be flat and fabulous because of the discomfort the procedure caused. I suggest

asking how reconstruction will affect your quality of life. Finding a comfortable bra or even lying on your stomach can suddenly seem impossible.”



### Elisa Guida, Erie, Pennsylvania

“It's OK to say ‘no.’ After my second diagnosis, I had a mastectomy. I researched reconstructing a radiated breast area and decided against it. Before surgery, I checked out a prosthesis. I haven't looked back—and that was 10 years ago.”



### Susan McMillan, Metairie, Louisiana

“The first thing you should know about reconstruction is options! Women need to be given all the options available. They need to learn about using their own natural tissue versus implants, and other possibilities. The MOST important thing they should know is to get the right doctor—someone who has been doing reconstruction for a long, long time.”

🐾 *How did you cope with hair loss? Let us know at [editor@lbbc.org](mailto:editor@lbbc.org).*

# The 2015 Going Beyond Honorees

BY JESSICA BETTS



Lynn Folkman Auspitz, Dana Donofree, Jewel Adjabe, Deb Strauss

Every year, LBBC honors several women with the Going Beyond Award who use their personal experiences to help others. Each honoree has her own unique story, but these remarkable women share the desire to impact others.

*"[W]ith hardship comes the opportunity to grow as a person and expand your perspective. Who would have guessed that, in some ways, metastatic breast cancer would make me a stronger person?"—Jewel*

**Jewel Adjabe's** family history of breast cancer meant she met her diagnosis of stage II breast cancer with some knowledge, but also lots of questions. When she developed metastatic disease, as her mother had before her, she was scared—but knew she needed more information. She discovered LBBC's combination of information and community was just what she needed. As an LBBC Ambassador, she introduces other women to the programs, services and support that have helped her stay positive and look forward.

*"For me, it's important to listen and connect to people and be there for them, to respect where they are in their journey and*

*just be present with them. Being able to do that for others makes everything I have gone through worth it. That's why I am here: to be present and share that gift."*—Lynn

**Lynn Folkman Auspitz** was about to leave for a conference in Miami when she found out she had breast cancer. She was scared of how she would manage and pay her bills, but her friends and family rallied around her. After a year of active treatment, Lynn took stock: She felt different on the inside and did not want to return to the status quo. She learned about LBBC soon after her diagnosis, and became a Breast Cancer Helpline volunteer in 2011. Lynn now serves as our manager of community engagement.

*"The message is changing and it's getting louder. For the first time, people are really speaking out with truth and honesty. Don't tuck away what's happening under your blouse. Talk about it!"*—Dana

It was one day before **Dana Donofree's** 28th birthday—and two months before her wedding—when she learned she had breast cancer. She soon realized there was no beautiful lingerie for women who had reconstructive surgery, and decided it was up to her to do something about it. In 2014, **AnaOno Intimates** was formally launched, offering comfortable and alluring bras for women who have had reconstruction. A percentage of her sales benefits LBBC.

*"I hope we can all celebrate what we have, right now, right this minute, without looking back with regret or looking forward with fear. Today might be difficult, but this one moment can be wonderful. Maybe that's the best celebration of all."*—Deb

When **Deb Strauss** was first diagnosed with breast cancer in 1987, she was a busy mother of small children. When she discovered she had metastatic disease 5 years later, she attended an LBBC community meeting and realized there were many ways she could give back. As a Helpline volunteer, Deb has connected with many women facing uncertainty and fear, and her calm and positivity have helped many women navigate difficult times. 🌟

## TO GIVE AND RECEIVE:

## An Interview With Donna Noce Colaco

BY KEVIN GIANOTTO

**W**hite House | Black Market president **Donna Noce Colaco** tells LBBC's **Kevin Gianotto** about her connection to LBBC, being honored with the Founders Award, and why WHBM continues to support our programs and resources.

**How did getting your WHBM team and customers involved in fundraising for LBBC evolve?**

*We all have an opportunity to impact those around us and the world we live in. I live my personal life and conduct my professional life with the belief that what you put forth in this world is what comes back to you. My WHBM family means everything to me and many of us have been together for almost 8 years now. We share a passion to make a difference.*

*LBBC is very special to all of us. The courageous women whose photos grace our walls are a constant reminder of the power we have to make a difference. I think it's easy to bring people along on such a journey when you do it not for the recognition, not for the publicity but simply because you care.*



Donna Noce Colaco

### How did you first learn about LBBC?

*I joined WHBM in 2007 and at that time, LBBC had been a partner for about 3 years. When I attended my first LBBC fundraiser two months later, I knew that this partnership was perfect. Our organizations aligned around a mission to empower women. LBBC was still small then, but their heart was big. Bigger than anything I had been involved in. There was never a question that this relationship would grow!*

### How does it feel to receive LBBC's 2015 Founders Award?

*It's not often I find myself speechless! I actually read the letter four times before I picked up the phone and asked [LBBC CEO] Jean Sachs, "Are you sure?" I am humbled by such an honor and to be recognized with the caliber of individuals who have received the Founders Award before me.*

*I cried when I accepted, I cried when I shared the news with my family and I still get choked up every time I think about it.*

### You're friends with many women who've used LBBC programs. Can you share a story about what these friendships mean to you?

*There are so many beautiful, strong women who have come into my life because of LBBC. Perhaps the woman I think of most often touched my life for the shortest amount of time but will be in my heart forever.*

*I met Lori Bauer in the summer of 2010 when we recognized 25 breast cancer survivors to celebrate WHBM's 25<sup>th</sup> anniversary. We were in New York City for two days celebrating. Lori was so full of life, love and gratitude. I didn't realize at the time how ill she was. Her eyes danced with happiness, and she was filled with generosity and warmth.*

*At The Butterfly Ball, she gave me the most precious gift – a scrapbook with photos, notes and cards from all the women I spent the day with in New York. She hugged me and the tears of joy ran down my face and landed on her shoulder. How ironic, I thought when I later learned how ill she really was, that my tears fell on her shoulders. Shoulders so strong they carried the weight of her illness with courage and strength. I think of her often. I pass her photo in my office 10 times a day and when I stop and look into her eyes, I feel a peace and humility that will forever be her gift to me.*

*When someone like Lori blesses your life, the generosity of her soul stays with you. I feel nothing but gratitude for the brief time we shared this world together. 🍌*

# Donor Spotlight

BY ADVANCEMENT STAFF



### Camille Enkeboll

*Founder and Owner, Consciously Cool Chick*  
**National Yoga on the Steps Incentive Donor**

Artist Camille Enkeboll started her yoga line, **Consciously Cool Chick**, to inspire and empower women—and she also wanted to give back. When she learned about Living Beyond Breast Cancer and Yoga on the Steps, she knew she found the right organization. “It’s hard to find anyone who has never seen a loved one battle cancer,” she says. “For me, it was my father. As a woman and mother of a 7-year-old daughter, it scares me. Fortunately, LBBC is here to inform, encourage and support women. As an advocate for women and children’s causes, I am moved by their positive impact and nurturing ways. I’m proud to lend my support.”

Camille designed and donated this year’s Yoga on the Steps tank top and created a special yoga mat for our top fundraisers.

“The yoga mat was inspired by the courageous women who have faced breast cancer, to encourage peace and empowerment while on their transformative journey.” Camille donates a portion of every sale at CCoolchick.com to LBBC.



### Marisa Gefen, 34

**First Time Yoga on the Steps Participant**

After 10 months of treatment, Marisa saw an ad online for the Yoga on the Steps Kickoff event. At the event, “We formed a circle and introduced ourselves to the group, [and] I instantly felt connected to the survivors and their supporters in that room. As part of my healing, I knew I needed to give back—and now I had found the way.” She raised funds by sharing her personal fundraising page on social media and by emailing letters to friends and family. For YOTS 2015, she raised \$4,200. To date, she has personally raised almost \$3,000 and her team has raised nearly \$8,700 for Living Beyond Breast Cancer’s programs and services to help others who have been diagnosed with breast cancer.



### Valley Green Bank

**Yoga on the Steps Corporate Sponsor**

**Valley Green Bank**, a division of Univest Bank and Trust Co., began supporting Living Beyond Breast Cancer in 2010. Committed to and celebrating the vibrancy of the communities it serves, the bank takes great pride in providing nonprofit organizations the unique financial support they need.

“Supporting Living Beyond Breast Cancer, a nationally recognized organization, has been a true privilege. LBBC plays a critical role in the lives of thousands of affected women and their families by delivering quality education and support services, and energetic, fun events like Yoga on the Steps,” says Jay Goldstein, president of Valley Green Bank.

VGB has been a loyal sponsor of Yoga on the Steps for many years, in the past hosting a yoga event at their branch office in the Mt. Airy neighborhood of Philadelphia, Pennsylvania, and regularly advertising the event through local channels. This year, the bank took an even more prominent role by becoming a major sponsor and putting together a team of over 20 people, Valley of the Uni Yogis, to fundraise and participate in Yoga on the Steps: Philadelphia. 🍌



**LIVING BEYOND  
BREAST CANCER**

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](mailto: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.



**LIVING BEYOND  
BREAST CANCER**

### IN PERSON

Conferences  
Community meetings  
Yoga on the Steps  
Helpline

### ONLINE

Webinars  
Videos  
Twitter Chats

### IN PRINT

Brochures  
Newsletters  
Understanding Guides



**SUMMER 2015**

# Calendar

## Educational Programs

### WEBINARS

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

**JULY 14, 2015**

**Metastatic Breast Cancer: Understanding and Finding Clinical Trials**

**AUGUST 2015**

**Environmental Health and Breast Cancer**

**SEPTEMBER 2015**

**Neoadjuvant Treatments for Early-Stage Breast Cancer**

### BREAST CANCER 360s

*Online and in person!*

**JULY 22, 2015**

**Breast Cancer 360: A Look at Triple-Negative Breast Cancer From Every Angle**

*Sky Ridge Medical Center Auditorium, Lone Tree, Colorado*

### COMMUNITY MEETINGS

**AUGUST 2015**

**Building and Restoring Physical Wellness After Breast Cancer**

*Kansas City, Missouri*

**SEPTEMBER 2015**

**Bone Health**

*West Conshohocken, Pennsylvania*

## Conferences and Special Events

**JULY 19, 2015**

**Yoga on the Steps: Kansas City**

**SEPTEMBER 18 – 20, 2015**

**Wellness Weekend: The Annual Fall Conference and Yoga on the Steps**

*Denver, Colorado*

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

THANK YOU TO

# Our Donors

## **\$60,000 and up**

AstraZeneca  
Celgene  
Eisai  
Novartis Oncology  
U.S. Center for Disease  
Control and Prevention  
Yoplait

## **\$40,000 to \$59,999**

Alexandra Samuels TTEE  
Charitable Remainder Trust  
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CBS Radio  
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## **\$20,000 to \$39,999**

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Pfizer

## **\$10,000 to \$19,999**

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Merrimack Pharmaceuticals  
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## **\$5,000 to \$9,999**

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the Cure Event  
Susan G. Komen  
Valley Green Bank, a Division of  
Univest Bank and Trust Co.

## **\$2,500 to \$4,999**

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*February to April 2015*