

# Insight

An educational newsletter  
from LBBC



## Supporting Each Other: Peer Support Throughout Your Journey

BY JOSH FERNANDEZ

**Teresa Li** of Chicago, Ill., was shocked to learn she had stage III breast cancer.



TERESA LI

A 39-year-old mother of two children who were younger than 8 at the time of her diagnosis, she felt troubled by the treatment decisions she had to make, the uncertainty of her future and how to tell her children about her diagnosis.

"It all seemed so overwhelming, and I knew I couldn't handle it all by myself," Teresa, now 41, remembers.

Then she discovered a breast cancer hotline. Speaking with a volunteer with a similar diagnosis eased her worries. From there, she became involved in a monthly in-person support group for women with cancer and, soon after, discovered the extensive network of online and social media resources available to her for peer support. The more *peer emotional support* Teresa received, the better she felt.

### What Is Peer Emotional Support?

According to Peers for Progress, a program of the American Academy of Family Physicians Foundation, peer emotional support is when "people with a common illness are able to share knowledge and experiences — including some that many health workers do not have."



DOREEN BAILEY

This type of support can take the form of phone calls, electronic messaging through online chat rooms or forums, one-on-one or group in-person meetings, and through social media sites including Facebook.

**David Spiegel, MD**, director of the Center on Stress and Health and professor of psychiatry and behavioral sciences at Stanford University, says this type of support is important because people are social creatures and a cancer journey can be isolating, especially if you feel you are burdening family and friends with your worries.

"Part of what is helpful with peer emotional support and counseling is that you feel less alone with your disease," Dr. Spiegel says. "It helps you learn to treat your emotions as friends rather than enemies, and that your feelings are not something to be suppressed for your family and friends. Furthermore, you learn that you can give as well as receive advice and support — your cancer experience can become an asset, not just a problem."

At times, **Doreen Bailey**, 50, of Clarkson, Mich., withheld her feelings not just to protect her loved ones, but also because she did not think they could relate to what she was experiencing.

"My family and friends were very supportive, but it's difficult for someone who hasn't gone through a breast cancer diagnosis to completely understand what you're feeling," Doreen says.

Peer support differs not only from the kind of support that loved ones can offer, but also from the type of support healthcare providers can extend. **Rosa Canosa, MSW, MPA, LCSW-R**, program

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#### LIVING BEYOND BREAST CANCER®

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*Dear Friends,*



I am pleased to share exciting news of a milestone. Last month we celebrated the 1-year anniversary of live answering hours, Monday – Friday, 9 a.m. to 5 p.m ET, on our Breast Cancer Helpline. Throughout the past year, we at LBBC have seen the positive way in which the expansion of answering hours brought comfort and support to an increasing number of people, demonstrated by an 87 percent increase in call volume compared with calls received 1 year ago today.

To date, 99 dedicated volunteers affected by breast cancer have been trained to offer callers peer emotional support, as well as practical information, through caring and confidential telephone exchanges. As part of our commitment to actualizing our vision — a world where no one impacted by breast cancer feels uninformed or alone — a caller can be matched with a Helpline volunteer who shares similar characteristics including age, stage of diagnosis, or treatment type.

Whether you are newly diagnosed, in active treatment, or years beyond treatment, one thing is constant: We will continue to be here for you through our Helpline so you never feel alone.

With this commitment comes news of further expansion. I am thrilled to share that you can now call (888) 753-LBBC (5222) Monday – Friday, from 9 a.m. up until 9 p.m. ET and will be connected to a live volunteer. We look forward to serving many more people through those four additional hours of live support each weekday.

As 2013 draws to a close, please make a donation to LBBC and know it is through your generosity that we can continue to expand our support services, just like our Breast Cancer Helpline, to better serve all people affected by breast cancer. Secure donations can be made online at [lbbc.org/gift](http://lbbc.org/gift) or sent to our office.

Warmly,

Jean A. Sachs, MSS, MLSP



Laurie Beck Photography

#### LIVING BEYOND BREAST CANCER

*To connect people with trusted breast cancer information  
and a community of support.*

# Young Advocate Speaks Up for Herself and Other Women

BY ROBIN WARSHAW, FOR LBBC



TeMaya Eatmon is still surprised by her role as an advocate for, or supporter of, those diagnosed with breast cancer, and by her willingness to talk with others about her breast cancer experience.

An operations manager from Atlanta, TeMaya could not have imagined 1 year ago, when diagnosed, how central advocacy work would be in her life today. At the time she thought, “I want everything to be over and my life to go back to the way it used to be,” she says.

Her view now is much different. “I want it to be over with, but until breast cancer is eradicated, it won’t be over with.”

At age 36, TeMaya was married for about a month when she noticed discharge from her breast. She contacted her OB/GYN who sent her for tests. They didn’t reveal the problem, but she discovered TeMaya was pregnant. The discharge continued, but TeMaya was told it was associated with pregnancy.

A few weeks later, she miscarried. When TeMaya mentioned the continuing discharge to her doctor, she was sent to a breast center. A mammogram and ultrasound showed she had a *papilloma*, a *benign* (non-cancerous) breast growth. Surgery that had been scheduled to remove a uterine fibroid believed to have caused the miscarriage would now also involve removing the papilloma.

During the procedure, the surgeon discovered the papilloma was covering widespread *ductal carcinoma in situ*, cancer confined to the breast ducts. TeMaya then had two lumpectomies because the surgeons could not get clear *margins*, areas of healthy tissue around the DCIS. Still, after the second lumpectomy, the margins were not clear.

## Finding Connections at C4YW

Knowing she had decisions to make, TeMaya accessed [lbbs.org](http://lbbs.org), our website, to look for information. There she learned about **C4YW: Conference for Young Women**, hosted by LBBC and Young Survival Coalition. She attended the annual event only 2 months after her diagnosis. It was the first time she had been around women affected by breast cancer like herself.

“For me to go and see other women who were young and hear the stories, that was amazing,” she says. “Even going to the breast center was overwhelming because I never saw other young women and, specifically, African-Americans.”

Conference presentations helped her understand how important a role she had in her own care.

“When I went to C4YW, I realized I didn’t have to just listen to my [first] doctor. I could get a second opinion,” says TeMaya. “If I hadn’t been to the conference, I wouldn’t be as comfortable with where I am now.”

Part of an inaugural group of 15 women at C4YW participating in **LBBC’s Young Advocate program**, TeMaya received training on ways to speak up for breast cancer issues and concerns — both personally and publicly.

“We were charged with what we could do when we got home. And I said the first thing I would do was advocate for myself,” TeMaya says.

True to her word, she went home and sought a second opinion about next treatment steps, assembling an entirely new medical team, except for her medical oncologist. She decided to have both breasts removed.

Through advocating for herself, TeMaya realized inequities in care exist. Although she has health insurance, she began thinking about the uninsured or underinsured and those without disability coverage. “How would they fight to beat the disease?” she asks.

TeMaya also was acutely aware of the reluctance to discuss breast cancer among African-Americans, having experienced that unwillingness in her own family.

“My mother was shocked with the diagnosis and reluctant to share her daughter had breast cancer with other family members,” she says.

Her advocacy efforts have now expanded from speaking up for herself to advocating for others. She is helping revive an Atlanta affiliate chapter of the **Sisters Network**, a national organization of African-American women affected by breast cancer. The group’s credo, “Stop the Silence,” reflects TeMaya’s own commitment to increasing breast cancer awareness and acceptance among African-Americans. She also participates in the local Young Survival Coalition’s **Face 2 Face** network.

TeMaya received science-based advocacy training in 2013 from **Project LEAD**, a program of the **National Breast Cancer Coalition**, and wants to participate in more research-focused activities.

“It’s a whole different world when you start getting into the research. You learn so much more information you can share with people,” she says. “If they’re not pleased with their medical care, you can give them hope to see where there’s a possibility.”

She is using that training to help her sorority, Delta Sigma Theta, work on breast cancer awareness. Her goal: “to get young African-American women talking about the disease, planning for prevention and getting out of the denial stage.”

TeMaya has other plans as well. “I hope to start a family in 2014,” she says. 🍀

# Recognizing the Unfamiliar: A Survey of Less Common Breast Cancers

BY NICOLE KATZE, MA

The American Cancer Society estimates 232,340 new cases of *invasive breast cancer* — cancers able to travel to distant parts of the body — will be diagnosed by the end of 2013.

Many cancers will be found after a woman discovers a hard, uneven lump during a breast self-exam or an annual mammogram shows a suspicious shadow.

Yet for women who develop some of the breast cancers highlighted in this article, which account for roughly 2 to 14.5 percent of all diagnoses each year, these common stories may not hold true.

"These rare cancers can take many women by surprise because they aren't garden-variety," says **Anees Chagpar, MD**, an associate professor of surgery at the Yale School of Medicine and director of the Breast Center at Smilow Cancer Hospital at Yale-New Haven.

## Paget Disease of the Breast

"We women believe we have good knowledge of breast cancer with the amount of information that's available today," says **Ivy Szematowicz**, 63, of Brandon, Fla. "But so often we're hearing broad generalizations and we could be ignoring serious symptoms."

Ivy first noticed a flaking of the skin of her nipple during a breast self-exam. At first she was unalarmed. The sore left by the flaking seemed unremarkable. But when it didn't heal with time, she went to her gynecologist.

"He seemed unconcerned and told me to use Eucerin cream to moisturize the dry areas," Ivy recalls. "I felt a little foolish for being there because I thought I was worrying for no reason."

After an annual mammogram came back clear, Ivy still had no answer as to why the skin around her nipple was flaking. Several months later, her gynecologist sent her to a dermatologist who ordered a biopsy. The biopsy confirmed Paget disease of the nipple — also called Paget disease of the breast — nearly a year after she first noticed symptoms.

In Paget disease of the nipple, cancer cells travel from a tumor inside the breast — most often from the *ducts*, or pathways that carry milk, but also from the *lobules*, or milk glands — to the skin of the nipple and the *areola*, the dark circle around it. This can cause symptoms similar to many skin conditions including itching, tingling, redness or flaking skin. In some cases, a yellowish or bloody liquid may leak from the nipple, or the nipple might invert and become flat.

Some experts believe in other cases cancer cells form

in the nipple or areola itself, which explains why a small number of women with Paget disease of the nipple do not have a primary tumor in the breast or have a separate, unrelated tumor from the disease in the nipple.

By the end of 2011, Ivy had surgery to remove the nipple and areola — sometimes called a *central lumpectomy* — and radiation. Because Paget disease can be hormone receptor-positive or HER2-positive, treatment plans follow the standard of care for those subtypes and are influenced by whether the cancer has traveled to lymph nodes.

"People automatically think that breast cancer presents as a lump," says Ivy. "I walked around with cancer for a year without knowing. If you have a sore, no matter how small, see a doctor and ask them to rule out Paget."

## Malignant Phyllodes Tumor

**Carey Persico**, 52, of Massapequa Park, N.Y., is one of the estimated 500 to 1,000 women living in America each year who are diagnosed with a malignant phyllodes tumor, according to **Richard J. Barth, Jr., MD**, associate professor of surgery and section chief of general surgery at the Geisel School of Medicine at Dartmouth.

Two weeks before an annual mammogram and ultrasound, Carey felt something unusual but dismissed it because, like many women, she has *fibrocystic breasts* — naturally lumpy due to the way tissue grows.

"When the radiologist told me there was 'something' on my scan, I assumed that 'something' would be defined," says Carey. "It was only after a core-needle biopsy was performed and [a tumor sample was] sent to [The] Mount Sinai Department of Pathology for further [analysis] that I was informed of this rare phyllodes tumor."

While malignant breast tumors usually feel jagged and hard, a phyllodes tumor is unique in that, whether malignant or benign, it feels smooth and moveable — like a benign breast tumor called a *fibroadenoma*. Pathology tests must confirm the lesion as phyllodes, because it looks similar to a fibroadenoma on imaging tests.

Unlike most other breast cancers that grow in the lobules or ducts of the breast, phyllodes tumors arise in the connective tissue. Tumors often grow so quickly that they



IVY SZEMATOWICZ



CAREY PERSICO



can be as large as 3 or 4 centimeters when first found. They must be promptly removed through surgery, along with a wide margin of surrounding healthy tissue, to prevent them from traveling beyond the breast if malignant.

Given the low number of people diagnosed each year, clinical trials are difficult to pursue, so there are some unknowns about the disease.

"Pathologists know what phyllodes tumors look like and can identify them," says Dr. Barth. "Sometimes they are estrogen receptor-positive or progesterone receptor-positive, but we don't have the clinical evidence to know what treatments are most likely to work as we [do] with other breast cancers."

Phyllodes tumors don't respond well to chemotherapy or hormonal therapy, so surgery is the primary treatment. Radiation therapy may also be offered. Yet, whether it is necessary is still a controversy, one Dr. Barth is studying in phase II clinical trials.

## Medullary Breast Cancer

Medullary breast cancers are soft, well-contained masses that are usually triple-negative. Under the microscope, their cells appear *poorly differentiated* — unlike normal breast cells that are well developed and specialized — and are arranged in sheets without glands.

Linked to a mutation in the *BRCA1* gene, medullary breast cancers are often associated with better outcomes than more common invasive *ductal cancers* — those that begin in and travel beyond the milk ducts. This is because they are usually found before cancer has traveled to the lymph nodes. Only 10 percent of individuals with medullary disease have cancer in the lymph nodes at diagnosis.

**Nichole Daegele**, of New Haven, Conn., was diagnosed with medullary triple-negative disease in 2011 at age 26.

"I learned I had triple-negative breast cancer, but nothing about it also being medullary," says Nichole. "It's not only rare. There's not a lot of information about it, and what there is, you have to look for."

Criteria for identifying this cancer are "not necessarily standardized," says **Karen L. Smith, MD, MPH**, medical oncologist and clinical associate of the breast cancer program at Johns Hopkins Kimmel Cancer Center. "However, there's no evidence that treatment decisions should be made differently than for other forms of breast cancer."

Nichole had a double mastectomy, 6 months of chemo, and 5 weeks of radiation in 2012. She underwent genetic testing due to her young age and because the tumor was both triple-negative and medullary, but tested negative for mutations to both *BRCA1* and *BRCA2*. The negative result left her with more questions.

"Mine really seems to be a sporadic case. No one knows how or why it formed this way," she says. "No matter what, you should be proactive and persistent about your health. No matter how young you are."

## Inflammatory Breast Cancer

Inflammatory breast cancer affects approximately 4,000 people each year, says **Ricardo H. Alvarez, MD, MSc**, assistant professor in the department of breast medical oncology at the University of Texas MD Anderson Cancer Center and in the Morgan Welch Inflammatory Breast Cancer Research Program and Clinic in Houston. Like Paget disease of the nipple, it is marked by symptoms a woman might notice but not attribute to cancer.

"IBC usually appears in younger women, and the symptoms come on in a very short period of time, in as few as 3 to 4 weeks," he says. "Not all physicians are familiar with it, so in many cases women are told it may be mastitis."

*Mastitis*, an infection of breast tissue, causes the same redness, swelling, warmth and tenderness as IBC. However, if a doctor prescribes an antibiotic and the symptoms don't go away, the issue is unlikely mastitis.

**Joshlyn Earles**, 62, of Rialto, Calif., felt some of these symptoms before her own diagnosis. Yet it was a scan done by a chiropractor for unrelated back pain that showed an abnormality, suggesting she might have cancer. At his direction, she made an appointment with an internist but, even then, felt her concern was unaddressed.

"He didn't think a chiropractor could find cancer with a digital picture," Joshlyn remembers.

Before her regular visit to her PCP, Joshlyn had pain in her right breast and a small lump above her nipple. Her doctor ordered a mammogram, but all it showed was a spot slightly denser than the rest of the breast.

She eventually had a *coned down mammogram*, a test able to check one portion of the breast more thoroughly. A biopsy later confirmed IBC.

In the cancer world, IBC is what Dr. Alvarez calls an "orphan" disease — one that doesn't have a specific molecular signature, clear targeted treatment options or means of prevention. It's also aggressive and diagnoses seem to be on the rise.

Dr. Alvarez and colleagues at the Morgan Welch Inflammatory Breast Cancer Research Program and Clinic are working toward a better understanding of IBC and how to treat it. To date, they believe there may be as many as 10 subtypes of IBC, all different from one another.

"Clinical trials are the best way for IBC to be treated," he says. "Subtyping has brought about a new era for the treatment of not only common and rare breast cancers, but all cancers."

For a list of resources about these four breast cancers, visit this article's "Resources List" within our newsletter archive online at [lbbc.org/About-LBBC/LBBC-Newsletter-and-Publication-Archive/National-Newsletter](http://lbbc.org/About-LBBC/LBBC-Newsletter-and-Publication-Archive/National-Newsletter). 🐾



JOSHLYN EARLES



NICHOLE DAEGELE

# LBBC Presents at Major Conferences, Updates Publication and Expands Helpline

BY JOSH FERNANDEZ

## Save the Date – Sunny Florida!

LBBC and [Young Survival Coalition](#) invite you to ditch the snow and 30-degree temperatures and join us in sunny Orlando, Fla., for our Annual Conference for Young Women Affected by Breast Cancer ([C4YW](#))!

The conference takes place [Friday, February 21 – Sunday, February 23, 2014](#), at the [Hilton Orlando Lake Buena Vista Hotel](#) in the Walt Disney World Resort. Our general sessions are Armchair Discussion with the Medical Experts, Resiliency after Breast Cancer and Cooking with Fit and Flair. For more information about the general sessions and our workshop offerings, visit [c4yw.org](#).



## New Edition of Emotions Guide Now Available



LBBC is excited to inform you that a new edition of our [Guide to Understanding Your Emotions](#) was produced this fall and can be ordered in print or accessed in PDF format online at [lbbc.org](#).

*Guide to Understanding Your Emotions* will help you make sense of and learn ways to successfully manage the range of complex emotions you might experience whether you are newly diagnosed with breast cancer, beginning treatment or about to begin your "new normal" after your initial treatment ends. Learn how treatments can impact your emotions, how to recognize the signs of anxiety and depression, where to go for community and professional support, and strategies for coping with and responding to your emotions.

## Triple-Negative Update

In the fall, we finished phase II of our triple-negative breast cancer research initiative. After interviewing our four focus groups totaling 30 women, we launched the [Survey of Breast Cancer Information and Support Needs](#) online in early November — which stayed open through early

December. This survey engaged both women with triple-negative breast cancer and women with hormone-positive breast cancer.

The goal of the online survey was to gather information from nearly 1,000 women nationwide to learn about the gaps in resources, support and information for women living with early-stage and metastatic triple-negative breast cancer.

Results are being compiled and analyzed. LBBC anticipates publishing our findings by early spring 2014.

## Conference Round Up

LBBC's [Arin Alum Hanson, MPH, CHES](#), manager, Young Women's Initiative, attended the Advanced Breast Cancer Second International Consensus Conference, also called [ABC2](#), in Lisbon, Portugal, from November 7 – 9 to present "[Defining the Unique and Persistent Needs of Young Women in the U.S. Living With Metastatic Breast Cancer Through a Multi-Phased Needs Assessment](#)."

The abstract, based on the YWI needs assessment research, was presented to hundreds of medical professionals from more than 60 countries worldwide. The biannual conference is the only event that brings together international experts to develop a set of established guidelines for metastatic breast cancer. LBBC presented its research report *Silent Voices* at the first ABC conference in 2011.

Two of our research posters were accepted at the fourth annual [Academy of Oncology Nurse Navigators Conference](#) in Memphis, Tenn., from November 15 – 17. "[What Young Women Want: A National Needs Assessment of Young Women Affected By Breast Cancer](#)" is an overview of the YWI needs assessment. "[Developing Culturally Relevant Breast Cancer Resources: Getting Connected: African-Americans Living Beyond Breast Cancer](#)" showcased LBBC's publication by the same name, and raised awareness of the importance of culturally-specific resources for women with breast cancer. LBBC's [Catherine Creme Henry, MA](#), outreach coordinator, presented both posters at the AONN conference.

We thank Arin and Katie for all their hard work in representing us at these events!

News and Education Update continued on page 7



## Featured Podcasts: Fall Conference

Did you miss our annual fall conference, **News You Can Use: Breast Cancer Updates for Living Well**? Do not worry — podcasts and transcripts of numerous workshops are now available online.

Learn the latest in breast cancer research and updates from the nation's leading breast cancer experts specializing in treatment and quality-of-life issues. Access the presentations at [lbbs.org/Events/Annual-Fall-Conference/2013-10-26-Annual-Fall-Conference](http://lbbs.org/Events/Annual-Fall-Conference/2013-10-26-Annual-Fall-Conference).

## Young Women's Update

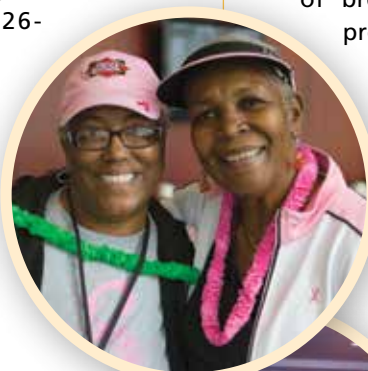
Our **Young Women's Initiative** kept busy this fall:



- Since their debut in summer 2013 through early October, the first three installments of the Young Women's Initiative's **"Let's Talk About It"** video Series have been viewed by many! "What Young Women Should Know About Bone Health" and "Hear Me: Communicating With Your Healthcare Team" have been watched by several hundred viewers and the most popular video, "Let's Talk About Sex (and Breast Cancer)", has been viewed by thousands. The video series features interviews with young women and healthcare providers. Check them out yourself by visiting [lbbs.org/Audiences/Young-Women/Let-s-Talk-About-It-Video-Series](http://lbbs.org/Audiences/Young-Women/Let-s-Talk-About-It-Video-Series)
- LBBC will host a YWI symposium for healthcare providers on May 27 in Baltimore. This event will be held prior to the Association of Oncology Social Work annual conference. The symposium aims to help providers build their skill sets to work with young women affected by breast cancer. All healthcare providers are welcome! E-mail [ywi@lbbs.org](mailto:ywi@lbbs.org) for more information.
- We have entered our third and final year of our cooperative agreement with the Centers for Disease Control and Prevention as of October 2013. You can expect many new programs and resource enhancements

in the upcoming year, including new videos, publications, projects, website content tailored to young women and to healthcare providers and more recruitment and training of women for the YWI's Young Advocate Program.

- **Arin Ahlum Hanson, MPH, CHES**, manager of the YWI, continues to represent LBBC as liaison member to the Centers for Disease Control and Prevention's **Advisory Committee on Breast Cancer In Young Women (ACBCYW)**, established by the Education and Awareness Requires Learning Young (EARLY) Act, to develop evidence-based approaches to advance understanding and awareness of breast cancer among young women through prevention research, public and health professional education and awareness activities, and emerging prevention strategies.



## Volunteer and Helpline News

November was a big month for our volunteer programming and **Breast Cancer Helpline**.

Late this year, LBBC launched the **Community Outreach Volunteer Program**, an initiative in which volunteers make their communities aware of the programs and services LBBC offers. Each outreach volunteer is given a kit, which contains LBBC publications, brochures and promotional material, to help us reach more women affected by breast cancer.

November also marked our one-year anniversary of live answering hours, Monday – Friday, 9 a.m. to 5 p.m. ET. Our Helpline expanded even further, as we now answer calls live until 9 p.m. ET! LBBC will host a second National Helpline Volunteer Training in the first quarter of 2014. The recruitment and selection process for the training begins in January.

The **Breast Cancer Helpline** is free and confidential; Spanish-language speakers are available. If you have questions, need to talk, or just need someone to listen, call (888) 753-LBBC (5222). We can help. 💖



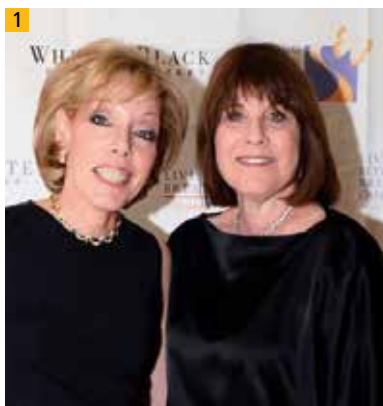
Photos: Bryan Mead, Zachariah N. Orchard, Lynn Folkman



# Highlights From LBBC's Annual Gala, The Butterfly Ball

BY KEVIN GIANOTTO AND LINDSAY BECKMEYER

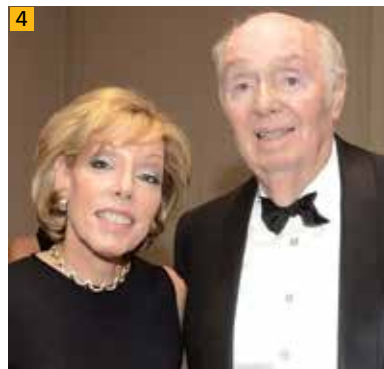
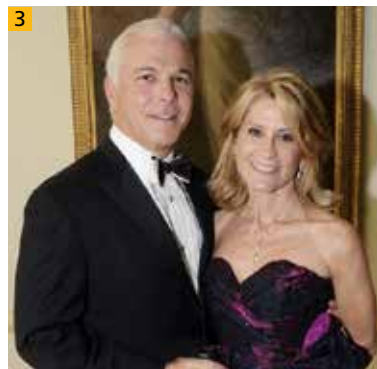
On Saturday, October 12, Living Beyond Breast Cancer hosted its annual gala, The Butterfly Ball, presented by White House | Black Market. By the end of the evening, over \$700,000 was raised in support of LBBC's programs and services!



During the event, **Amy Lessack**, **Marni Manko**, **Rev. Dr. Lorina Marshall-Blake** and **Susannah Wolf** were each presented with LBBC's Going Beyond Award, given to recognize individuals who have used their personal experience with breast cancer to help others.

Among the highlights of the evening was the presentation of our highest honor, The Founders Award, to **Ellyn Golder Saft** and her father, **Robert Golder**, recognizing their philanthropic support of women recovering from or in treatment for breast cancer.

Ellyn and Robert established the Cis B. Golder Quality of Life Grant in memory of mother and wife Cis B. Golder who passed away in May 2006 from complications of breast cancer. Grants of up to \$2,000 per applicant are awarded to help individuals in the Philadelphia area who are diagnosed with breast cancer with immediate financial needs, with the goal of supporting a better quality of life. ♡



1 Founders Award recipient Ellyn Golder Saft (left) and gala committee co-chair Donna Feinberg.

2 LBBC CEO Jean Sachs (third from left) and White House | Black Market president and event mistress of ceremonies Donna Noce Colaco (far right) with Going Beyond Award recipients (from left) Amy Lessack, Susannah Wolf, Rev. Dr. Lorina Marshall-Blake and Marni Manko.

3 Dr. Steven Copit with 2012 Founders Award recipient and wife, Dr. Debra Somers Copit.

4 2013 Founders Award recipients Ellyn Golder Saft and father, Robert Golder.

5 Co-chairs John McDonald and wife Kristin are joined by their children Jack and Annie.

6 2013 event co-chairs Jeanne Marren Egan and husband Michael Egan.

7 Guests bid during the live auction.





## Donor Spotlight: Zac and Elizabeth Goldberg, MD

BY JOSH FERNANDEZ

Eager to make a donation to an organization serving those affected by breast cancer, **Zac and Elizabeth Goldberg, MD**, of Providence, R.I., carefully sifted through the organizations listed on Charity Navigator's website until they found Living Beyond Breast Cancer.

"It became clear that LBBC focused not just on research news and updates, but more on immediately helping people who are newly diagnosed, currently living with breast cancer or are on the road to recovery," Zac, 31, says. "That appealed to both of us."

The Goldbergs generously donated **\$5,000** to us by the time their year-long pledge ended in the summer of 2013, helping us continue to fund comprehensive programs and resources for those affected by breast cancer. LBBC makes it easy to give by accepting donations in monthly installments. Providing this donation was especially important to Elizabeth, who recently finished her residency in emergency medicine at Rhode Island Hospital. At age 47, her mother was diagnosed with triple-negative breast cancer, which eventually became metastatic. She died when Elizabeth was 20 years old.

"I was able to spend her last 6 weeks of life with her in Berlin, Germany, where she had been living at the time," Elizabeth, now 30, says. "She was one of the major reasons I always knew I wanted to give back to people affected by breast cancer and their families."

Zac and Elizabeth appreciated the range of programs and resources we offer — our community meetings, webinars, conferences and publications — and, especially, our current triple-negative breast cancer research initiative to expand our programming for women affected by triple-negative disease. The couple was especially fond of our website, [lbbc.org](http://lbbc.org), which showcased all this information.



"My mother never had this kind of support when she was diagnosed in the 1990s. Resources and information such as what you offer would've been a major comfort for her," Elizabeth says.

Zac and Elizabeth encourage others who are affected by breast cancer, or who know someone dealing with the disease, to consider donating to LBBC because of the support we offer.

"There's a lot a physician can do to help, but one of major things you can do to improve your happiness and ability to live with the disease is become an advocate for yourself," Elizabeth says. "LBBC does an excellent job of helping women do that." 💚

## Thank you to our August 1, 2013 – October 31, 2013 contributors:

### \$100,000+

Centers for Disease Control and Prevention

### \$25,000–\$99,999

Eisai Inc.  
Novartis Oncology  
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17th Annual Paddle Rally  
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### \$10,000–\$14,999

Ann N. McDonald Memorial Basketball Tournament

AstraZeneca  
Comcast-Spectacor  
Donna and Barry Feinberg  
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The Jewish Women's Foundation of Greater Philadelphia: Women of Vision  
Kristin and John McDonald  
The Plastic Surgery Foundation

### \$5,000–\$9,999

5th Annual Rally for Life  
Abramson Cancer Center of the University of Pennsylvania  
Albert Einstein Healthcare Network

Andrea and Abraham Morris Charitable Fund  
Cline Cellars  
Lauren and John Colabelli  
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Louise and Peter Havens  
The Hylton Charitable Golf Tournament  
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Retail Resource Group, LLC  
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Muriel Robinson  
Roxborough Memorial Hospital  
Nancy and Phil Siegel  
David R. Trinkley and Kevin M. Gianotto  
Valley Green Bank  
Judith and David Wachs Family Foundation

**Continued from cover**

division director of CancerCare, oversees online, telephone and group peer support programs and says that although healthcare providers can certainly be compassionate and warm with those affected by breast cancer, the empathy and bond between peers who share a similar diagnosis is very powerful.

"A peer, for example can feel freer to refer to specific providers whereas a medical professional may be more inhibited to do so," Ms. Canosa says. "The bond among peers provides a safe place for someone newly diagnosed to communicate and grapple with gritty issues."

This desire to connect with other women affected by breast cancer is precisely what led **Ronda Walker Weaver**, 54, of Orem, Utah, to actively seek support from peers even though she was already blessed with the support of family and friends.

"I was looking for someone who could speak the language of breast cancer and mentor me," Ronda says. "I think everyone who goes through breast cancer treatment can benefit from having a 'breast cancer sponsor.'"

## Obtaining Peer Support

Peer emotional support is commonly associated with telephone helplines and with one-on-one or group meetings that take place face to face.

When Ronda was about to undergo treatment, she reached out to a support group offered by her local chapter of the American Cancer Society. In addition to providing her an outlet for her emotions, this support group offered themed meetings and workshops, one of which taught women who experienced hair loss from chemotherapy how to wear wigs or hats. Another support group Ronda attended allowed women to learn and practice mindfulness meditation and yoga together.

Ronda also credits peers she met in the hospital setting with offering her support.

"My best support came from the chemotherapy room. The other women and I were able to share tips and discuss so much," Ronda says. "We gave each other a tremendous amount of support."

**Susan Seymour**, 44 of Hopewell, N.J., found solace in the peer support she received from discussions over the telephone. She spoke with peers by accessing a few organizations' phone support services, including LBBC's Breast Cancer Helpline, for the first 6 months after she was

diagnosed with stage II breast cancer in November 2012. Additional screening in May of 2013 determined the cancer had become metastatic.

"A lot of times you feel very lonely, like a dark cloud is following you around," Susan says. "I didn't really know anybody that had breast cancer, so it was important for me to be able to talk to anyone who would listen."

Of course, in today's technology-driven world, peer emotional support encompasses more than just in-person support groups and telephone helplines for those diagnosed with breast cancer.

According to a recent study published in *Patient Education and Counseling*, 31.5 percent of women affected by breast cancer used an online breast cancer community at some point in time, and about 17.8 percent used social media, specifically Facebook, to connect with peers also facing the disease.

Seeking support via the Internet and social media was especially important to Doreen, who lived in a rural area with no local in-person support group for women with breast cancer.

"The closest support group for me was about an hour away," Doreen says. "I don't think I could've gotten through my experience without online support."

Ms. Canosa thinks the prevalence of breast cancer in the United States and the limited resources in areas such as Doreen's means social media and the Internet will continue to flourish as avenues for accessing peer support and information.

"A good peer support program that provides training and oversight to its members can be a very effective tool to help people connect to each other and reduce that sense of isolation," Ms. Canosa says.

Support gained from interacting with women through social media sites complemented in-person or face-to-face support for both Ronda and Teresa.

"I needed online support when I was not healthy enough to have face-to-face support," Ronda says about obtaining support through Facebook during her chemotherapy treatment.

Blogging also gave Ronda an outlet to express herself and receive support. Teresa started a private blog on CaringBridge for her close family and friends to follow her journey.

"People were cheering me on," Teresa says. "It felt great to get that kind of support."



RONDA WALKER WEAVER



SUSAN SEYMOUR

## The Benefits of Talking With Someone Like You

Many women with breast cancer enjoy the camaraderie that comes from giving and receiving peer emotional support — including the opportunity to serve as cheerleaders for one another and to discuss issues that loved ones and healthcare providers may not be able to relate to.

For Doreen, the benefit of talking with someone facing similar health challenges was also the wealth of knowledge she received about treatment decisions, follow-up care and overall practical tips.

Doreen discovered her online group, “Knitters for Breast Cancer,” through ravelry.com, a website and online community for people who enjoy knitting and crocheting. In addition to talking about knitting, the women in the breast cancer subgroup start threads when they have questions or concerns and wait for responses.

“Since there are members across the globe, there is always someone up at every hour of the day to respond to a question or concern,” Doreen says, “For me, it was like someone was always there to hold my hand, even though they weren’t physically there with me.”

Teresa feels the same way about her in-person, phone and social media connections. A weekly ritual she enjoys is the popular Twitter chat hashtag, #BCSM, which stands for “Breast Cancer Social Media.”

Started in 2011, BCSM has a popular weekly following on Monday evenings. During the hour-long Twitter chat, users — and sometimes medical professionals — interact with one another to discuss the latest breast cancer information and to swap personal stories.

Teresa observes the #BCSM chat exchanges, but she sometimes shares her stories or asks questions of her fellow breast cancer tweeters.

“I got to ask about reconstruction, which was such a big decision for me,” Teresa says. “Just chatting with others who had been through it was extremely helpful.”

Though she has experienced success engaging with others through Twitter, Teresa acknowledges that it is not always the easiest tool to use to communicate, especially with the 142-character limit.

Dr. Spiegel says that though it may be popular, social media and online peer communities may not be ideal for people who are not comfortable putting their life out there in cyberspace. He adds that without facilitation of some kind, social media could sometimes lead to misleading information being shared.

“I think this kind of platform has great potential for connecting people, but also the potential for trouble,” Dr. Spiegel says.

That said, peer support acquired offline is not immune to challenges. Sometimes, you might get advice and opinions from peers that do not sit well with you.

While in a hospital waiting room, Doreen heard perspectives from people that she wishes she had not.

“If people have a negative attitude and I don’t want to deal with it, I tell them they’re allowed their opinion, but that I don’t feel that way,” Doreen says. “I then don’t discuss it with them any further.”

Susan says she has heard everything. She once openly expressed a craving for a cupcake, and another woman advised her against it because she claimed it would worsen the cancer.

“When you put yourself out there, people feel free to comment,” Susan says. “I try to ignore these comments when they aren’t helpful, and instead focus on living my life.”

Despite some challenges that might arise, peer emotional support in all its forms is important to Ronda because of the potential such bonding has to improve the life of someone who is newly diagnosed.

Ronda encountered this first-hand, but the first time it happened was the day after her diagnosis. She went to the gym and began talking with a woman she had not seen before. During their conversation, Ronda learned the woman was 9 months from her own breast cancer diagnosis.

The coincidence moved Ronda, and the two became friends. The woman listened to Ronda’s concerns, shared information and stories of her own, and even gave Ronda hats in case she experienced hair loss from chemotherapy. The woman was her role model and guide, and it inspired Ronda to want to be that peer for another newly diagnosed woman.

Ronda is now a Helpline volunteer for LBBC.

“It’s something I must do,” she says. “When I can support someone the way the survivors I have met supported me, it’s a good feeling.”

*If you need emotional support, LBBC is here to help. In addition to our resources available on [lbbs.org](http://lbbs.org), you may find practical information from the updated edition of our [Guide to Understanding Your Emotions](#). Go to [lbbs.org/guides](http://lbbs.org/guides) to download or order a copy.*

*Do you want to talk with someone who cares and knows what you’re feeling? Our [Breast Cancer Helpline](#) can connect you with a peer for support today or when you’re ready. Call (888) 753-LBBC (5222). We can help. 🍪*

**“A good peer support program that provides training and oversight to its members can be a very effective tool to help people connect to each other and reduce that sense of isolation.”**



# Insight

An educational newsletter  
from LBBC



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Calendar

## Educational Programs

### Webinar

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

DECEMBER 19, 2013

✦ **Update From the San Antonio  
Breast Cancer Symposium**

### Conferences

FEBRUARY 21 – 23, 2014

✦ **C4YW—Annual Conference  
for Young Women Affected  
by Breast Cancer**  
Orlando, Fla.

APRIL 25 – 26, 2014

✦ **Annual Conference  
for Women Living With  
Metastatic Breast Cancer**  
Philadelphia, Pa.

## Special Event

MAY 18, 2014  
**Yoga on the Steps:  
Philadelphia**

Check [lbcc.org](http://lbcc.org) for the latest  
program information



Photos: Bryan Mead

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