

Insight

An educational newsletter
from LBBC



Body Image and Breast Cancer: Tips & Truths

BY NICOLE KATZE, MA

Among the many concerns you may have after a diagnosis of breast cancer is the emotional impact of your changing body.

Body image, what you think of your physical self and how you think others see your body, may play a role in your everyday emotional wellness. For some women, a changing body image has a strong effect on coping with breast cancer in the long-term.

"The weight I've gained since my diagnosis affects every aspect of my life, from my emotional and physical health to my intimacy," shares [Serenity Kisling](#), of Boulder, Colo.

Serenity, now 40 years old, has estrogen receptor-positive stage IV breast cancer. Her treatment included a double mastectomy and *bilateral salpingo oophorectomy*, surgery to remove the ovaries and fallopian tubes. She also takes the medicine anastrozole (Arimidex), an aromatase inhibitor.

Both the surgery and aromatase inhibitors are methods of stopping the body from making the estrogen needed for ER-positive breast cancer to continue growing. But stopping estrogen production can lead to physical changes, including weight gain.

"I'm usually a very positive person, but I have to say, if there's anything about the cancer that I resent, it's this weight gain," she says.

Many women share Serenity's experience, but it is possible to feel good about your body again.

Relating to Your Changing Body

Chemotherapy, hormonal therapy, surgery, and radiation therapy — standard treatments for most breast cancers — all have physical side effects that can visibly change your body. Scarring, lymphedema, weight gain or loss, hair loss, breast removal, and skin changes are some of the most

common. Others, including hot flashes related to early menopause or fatigue that prevents you from being as active as you were before breast cancer, can leave you feeling less confident or in control of your body.

Though these side effects are common, you might be surprised when they arise. You may feel unprepared to deal with emotional reactions to these changes.

[Anne Katz, RN, PhD](#), clinical nurse specialist and sexuality counselor at CancerCare Manitoba, says body image concerns surprise women because the first priority after diagnosis is treating the cancer medically.

"Women make their treatment decisions under duress," Dr. Katz says. "Choosing whether to get a bilateral mastectomy or single mastectomy, for example, requires concentration and rationality, and in the trauma of diagnosis, you often just can't have these."

A woman who has cancer in one breast may choose to have both removed to avoid a cancer in the healthy breast in the future, she explains, without thinking about what it means for body image or sexuality.

"It's not uncommon for women to discover afterward that their breasts were major sources of pleasure. There can be negative feelings because they believe they've significantly altered their own ability to be aroused," Dr. Katz explains.

But body image isn't just about how you react to the loss of or changes to your breasts, your hair, or your physical strength. It's also about how you perceive that your loved ones and strangers view you and your altered body. In our society, a woman's femininity, sexiness and womanhood are often equated with looks. Even in the



Serenity Kisling

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LIVING BEYOND BREAST CANCER®
354 West Lancaster Avenue
Suite 224
Haverford, PA 19041
Breast Cancer Helpline
(888) 753-LBBC (5222)
Tel: (855) 807-6386
Fax: (610) 645-4573
Email: mail@lbbc.org
Website: lbbc.org
Blog: livingbeyondbc.wordpress.com

- facebook.com/livingbeyondbreastcancer
- @LivingBeyondBC
- youtube.com/LBBC1991
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Dear Friends,

In December I had the pleasure of traveling to Texas for the 2013 San Antonio Breast Cancer Symposium. Alongside nearly 9,000 healthcare professionals and advocates, I heard the latest clinical trial findings and cutting-edge research.

Researchers presented hundreds of studies on different aspects of cancer care. Notable results included early findings from the I-SPY2 trial, showing pre-surgical treatment with a type of medicine called a PARP inhibitor might help eliminate some triple-negative breast cancers. APT trial researchers found that targeted therapy with trastuzumab (Herceptin) benefits people with very small HER2-positive tumors. Even trials with "negative" findings — such as one suggesting circulating tumor cells don't help predict effective treatment for metastatic disease — guide future study and teach us more about breast cancer.

These studies reflect the great shift toward personalizing cancer treatment. No longer do we view breast cancer as a single disease, requiring a single cure. Today, we know we need many cures for the variety of diseases we call breast cancer.

This change in the medical treatment of cancer echoes LBBC's longtime approach to programs and services. We believe in providing information that meets the needs of each person coping with the disease. That's why we offer specialized services based on your diagnosis, stage of life or medical circumstance. If you haven't yet, visit lbbc.org to learn more about how we can support you.

Warmly,

Jean A. Sachs, MSS, MLSP



Laurie Beck Photography

P.S. Visit lbbc.org to listen to our podcast and read our news coverage of findings presented in San Antonio.

LIVING BEYOND BREAST CANCER

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

When Cancer Inspires a New Career: Sue's Story

BY ANNA SHAFFER

Sue Bowman, RN, OCN, CBCN, MSW, became a nurse because she always wanted to help others. But after she was diagnosed with breast cancer at age 43, her experience going through treatment inspired a career shift.

"Even when you walk into the chemo room and see it full of other people, it's still a really lonely journey," Sue, now 62, recalls. "There really wasn't anyone my age that was also diagnosed. There were no support groups, no national organizations, no readily available resources for rescuing me from an abyss of despair and information overload."

Though the hospital where she received treatment had a library, it lacked the one-to-one personal touch Sue needed, and there weren't any classes to find out more about what was happening to her. As a patient, she didn't get enough information from her providers to feel as if she was part of the treatment decision process. She decided to meet with a psychotherapist to get the mental and emotional support she wanted.

"I knew there had to be something better to address the holistic needs of women when they are faced with a serious health situation," Sue says. "I thought that if I went into another area of healthcare, that I could make a difference. I wanted to fill that void that I had experienced as a patient. I was looking to counsel women who had breast cancer and pull my nursing experience in."

Sue worked fulltime during the day and went back to school at night, graduating with a master's degree in social work 4 years later. She now works as a breast oncology nurse navigator at a community cancer center in York, Pa., where she provides clinical support and education to people diagnosed with breast cancer. When people come in to get biopsy results, Sue explains the results in layman's terms and works with them to break tasks down into manageable chunks. She develops a rapport with patients, encouraging them to call her with questions and concerns at any time throughout treatment.

The questions she receives center on topics ranging from HER2 status and chemotherapy treatments to relationships, communication and self-esteem.

"Many people are very well-educated and have gone online if they've had any inkling they might have breast cancer," Sue says. "I give them medical information and address their quality-of-life concerns. Because breast cancer affects the whole woman, it's important to address all those things up front."



Sue shares her breast cancer experience if she feels it may help others to know she too was diagnosed with the disease and is now doing well. Going through diagnosis, treatment and recovery has prompted her to take a holistic approach to helping others.

"My breast cancer journey has never really ended, and that helps me truly understand their experiences," Sue says. "Seeing other women affected by breast cancer realize their strengths and cope well with adversity is the tonic I need to pursue my career. It's a perfect fit for me."

Sue acknowledges it can sometimes be difficult to remain objective, especially when women are young and have children the same age as hers were, or have marital difficulties like she did when she was diagnosed.

"There are certain patients who touch parts of my heart and trigger emotions in myself," she says. "By being aware of this, I am less likely to say something that may not be helpful. I guard what I say and remain in the here and now."

Caring for those with breast cancer comes with challenges. When people decide not to undergo treatment against the advice of their doctor, for example, and Sue has to respect that choice, it can be very difficult.

But helping people make evidence-based decisions about their treatment makes it worthwhile. "It's rewarding when you work with someone and see the light bulb go on, when something you have done or said makes their job as a recovering patient a little easier," Sue says.

In the future, Sue hopes to see the movement to make traditional medical care more personalized gain momentum, so each person is given all the information needed to make the best decisions.

"I hope that physicians will be able to take the time necessary to answer questions, and not stand with their hand on the doorknob ready to run to [the] next patient," she says.

She also hopes that breast cancer will no longer be an all-consuming, frightening experience. "Women are strong and have everything they need inside them to deal with this catastrophic disease. With encouragement and support, they can do quite well, and I hope they can be given permission to do that."

How Far We've Come: Treating HER2-Positive Breast Cancer With Targeted Therapies

BY JOSH FERNANDEZ

In February 2004, twenty years after **Claudia Feigner**, of Westport Wash., was diagnosed with early-stage breast cancer, scans revealed she had metastases in her lung and lymph nodes.

Advances in tumor testing since her initial diagnosis showed the cancer was HER2-positive. This meant she could take the medicine trastuzumab (Herceptin), developed to treat the disease.

"It's like a miracle drug," Claudia, 63, says. "Scans early on showed improvement in my lung and lymph-node mets, and after 1 year I had no active cancer. If it had not been available when I was diagnosed [with stage IV disease], my outcome could have been a lot different."

Claudia is among many people worldwide treated with trastuzumab. The medicine changed how doctors think about and treat HER2-positive disease.



CLAUDIA FEIGNER

History in the Making

About 15 to 20 percent of breast cancers are HER2-positive, meaning the cancer is fueled by over-production of the *human epidermal growth factor receptor 2* protein. HER2-positive breast cancers contain excess copies of this gene, leading to dramatically more HER2 protein on the surface of cancer cells. With more HER2 protein producing signals telling the cells to grow, they do so out of control, causing cancer.

To find out if you have HER2-positive disease, doctors use one of two tests. The *immunohistochemistry* (IHC) test measures levels of HER2 protein on the surface of cancer cells. Another test, *fluorescent in-situ hybridization* (FISH), detects extra copies of HER2 genes. You should receive these tests if you are newly diagnosed, have a recurrence, or have breast cancer that spread to other body parts.

Before the late 1990s, women with HER2-positive breast cancer had poorer survival rates. Today, among those who receive targeted therapy, this is no longer the case. Researchers better understand what fuels HER2-positive breast cancer and the discovery of targeted therapies that interfere with its growth make it a very treatable disease.

Trastuzumab was the first HER2-targeted therapy. The medicine attaches to HER2 receptors on cancer cells, blocking signals that cause growth and alerting the immune system to destroy the cancer.

Studies of trastuzumab showed promising results for treating and improving the survival of those with

HER2-positive metastatic breast cancer. Because of this, in 1998 the U.S. Food and Drug Administration approved the medicine as a therapy for advanced disease. Later research led the FDA to approve the medicine for use by those with early-stage and locally-advanced breast cancers in the mid-2000s.

"Even before its approval, trastuzumab demonstrated that HER2-directed treatment could have a dramatic impact on patients with HER2-positive disease," says **Nancy Lin, MD**, a breast oncologist at the Dana-Farber Cancer Institute. "This led to a number of subsequent trials showing it improves cure rates in patients who present with early-stage HER2-positive breast cancer."

Alexis Sulinski, 48, of Derby, Conn., diagnosed in late 2004 with stage III cancer, was one of the first women to benefit from use of the medicine after its approval for early-stage and locally-advanced disease.

"With Herceptin, I could leave the house and go about my everyday life without a problem," Alexis says, noting the few side effects she had. "This was something I couldn't do with my other treatments."

Alexis also believes, "the fact that I took this medicine is the reason I did not have a recurrence."

Since trastuzumab, there has been so much progress in treating HER2-positive breast cancer that in a lecture at the 2013 Breast Cancer Symposium, **George Sledge, MD**, chief of oncology at Stanford University School of Medicine, predicted we will soon see the end of the "HER2 era" of poorer outcomes.

"We will always have patients relapsing with HER2-positive disease, and this will require novel therapies," Dr. Sledge commented. "But from a public health standpoint, I believe HER2 is almost over."

Paving the Way For New Therapies

The success of trastuzumab opened the door for the development of other targeted therapies. Today, many of these treatments are approved for HER2-positive metastatic breast cancer and are being studied in early-stage disease.

Eva Snitkin, 42, of Minneapolis, participated in MARIANNE, an ongoing study assessing the effectiveness of



ALEXIS SULINSKI

treating HER2-positive metastatic disease with two targeted therapies at once: T-DM1 (Kadcyla) and pertuzumab (Perjeta). She began the study in April 2011, a few months after she was diagnosed with bone metastases, finishing treatment 2 years later once T-DM1 became FDA-approved.

"The cancer went away at the time of my first follow-up scan, which was 6 weeks after I began taking the drug," Eva says. "It was like a targeted cancer bomb."

Targeted HER2 therapies developed after trastuzumab include lapatinib (Tykerb), pertuzumab, and T-DM1.

LAPATINIB (TYKERB)

Approved in 2007, lapatinib, given along with the chemotherapy medicine Xeloda (capecitabine), treats HER2- and hormone-positive metastatic breast cancers. Lapatinib when given with capecitabine also has been shown to lead to tumor shrinkage and stabilization in the brain.

PERTUZUMAB

Pertuzumab was approved in 2012 to treat metastatic breast cancer after clinical trials proved its benefit. It was approved in late 2013 for women with early-stage disease to be given prior to surgery, and is generally considered for treating women at higher risk of the cancer metastasizing. Results of a clinical trial to test its value when given after surgery are pending. The medicine is given by vein, often alongside trastuzumab and docetaxel (Taxotere) chemotherapy.

Like trastuzumab, pertuzumab targets HER2 receptors, but attaches to and targets a different site on the receptors. The medicine blocks them from bonding to other proteins, such as HER3, which normally partners with HER2 to cause cancer growth. Blocking HER2 from binding to these other proteins prevents it from sending growth signals.

T-DM1

T-DM1 is an *antibody-drug conjugate*, meaning it is a targeted therapy combined with chemotherapy. It delivers medicine directly to the cancer, sparing healthy cells.

Studies that led to the approval of T-DM1 in 2013 compared the therapy to lapatinib given with capecitabine in HER2-positive metastatic breast cancer. Results showed T-DM1 significantly increased *progression-free survival*, the time from the start of treatment until the disease grows or worsens. They also revealed T-DM1 had fewer harmful side effects than lapatinib and capecitabine combined. Eva took T-DM1 through a clinical trial.

"I experienced very few side effects and for a period of time, T-DM1 kept the cancer away," she says. "All of us who have the disease hope researchers and pharmaceutical companies keep working on new treatments for us."

Researchers are now studying T-DM1 in early-stage disease.



MARCY FUTERNICK

The Future

Last year, **Marcy Futernick**, 57, of Valley Stream, N.Y., felt nervous toward the end of her treatment with trastuzumab for early-stage breast cancer. Just when fears of the cancer coming back began to weigh on her mind, Marcy read about the FDA approvals of T-DM1 and pertuzumab.

"I try to put fears in the back of my mind," Marcy says. "Knowing more treatment options are available since I was diagnosed in 2012 makes me feel much better."

Multiple treatments in the pipeline show promise in fulfilling Dr. Sledge's prediction of an end to the HER2 era.

Recently, **Sara M. Tolaney, MD, MPH**, of the Dana-Farber Cancer Institute, presented encouraging findings at the 2013 San Antonio Breast Cancer Symposium on the effects of combining trastuzumab with a non-anthracycline chemotherapy (weekly taxol in combination with trastuzumab) to treat 406 women with early-stage HER2-positive disease who had smaller tumors. Results revealed more than 98 percent were alive and cancer-free by a follow-up period of about 3.5 years.

By bypassing anthracyclines, there were fewer acute side effects and the small risks of leukemia and cardiac toxicity linked to anthracyclines were eliminated. There is still some low level risk of heart toxicity with trastuzumab.

"For the majority of patients with stage I HER2-positive breast cancer, I think this is a regimen that is going to be adopted pretty widely," says **Eric Winer, MD**, senior author of the study.

A number of other HER2-targeted therapies are in development, Dr. Lin shares. These include oral medicines like neratinib, afatinib, and ONT-380, which block signals used by HER2 proteins to trigger cancer growth. Beyond this, experts continue to study the effectiveness of combining more than one HER2-targeted therapy to treat the disease.

Another area of interest is the *phosphatidylinositol-3 kinase (PI3K) inhibitor*. Lab research demonstrated that HER2 signals through the PI3K pathway. In addition, about one-quarter of HER2-positive tumors contain a *mutation*, or error, in the PI3K gene.

"Those with tumors that have the PI3K mutation seem to be somewhat more resistant to standard therapies," Dr. Winer explains. "We are testing new inhibitors that reverse those mutations."

Experts believe ongoing *genomic research* based on human tumor tissue samples in the setting of metastatic cancer will also lead to ways to assess risk of recurrence and resistance for HER2-positive disease, as well as ways to better treat brain metastases. This research is devoted to studying a person's genes and the combination of gene mutations that may cause breast cancer. Claudia too is hopeful upcoming research will continue to help.

"I know, in general, HER2-positive metastatic breast cancer is considered to be aggressive," Claudia says. "But I have survived for 10 years very successfully, and I'm hopeful more progress will be made."

LBBC Introduces New VP, Special Topics Brochures and Conference Format

BY NICOLE KATZE, MA

Save the Date

Our **Annual Fall Conference** will take place in a new format to allow for a more personalized experience for attendees. This year, we will offer a "tracking" structure for the plenary sessions, based on your type of breast cancer and stage of diagnosis, as well as workshops. This way, you get the information that is most relevant to you personally.

Scheduled for Saturday, September 27, at the Pennsylvania Convention Center in Philadelphia, we invite people with all stages of breast cancer to learn about the latest medical and quality-of-life updates in breast cancer research.

For more information or to register, visit lbcc.org/Events/Annual-Fall-Conference.

LBBC Introduces Vice President

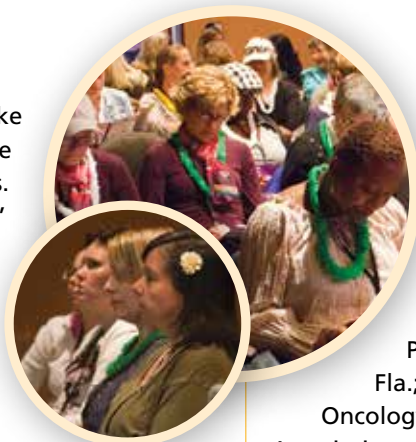
Catherine L. Ormerod, MSS, MLSP, recently joined the LBBC team as our new vice president of programs and partnerships, a role that involves directing and expanding LBBC's resources and programs.

Cathy comes to LBBC from Drexel University College of Medicine, where she directed national programs and relationships for Vision 2020 at the Institute for Women's Health and Leadership. Previously, she was director of educational programs for LBBC.

Cathy is excited to join our team and help further LBBC's mission to connect people with trusted breast cancer information and a community of support.

"Breast cancer is a disease that has impacted many, too many, in my circle of family and friends, and I am passionate about bringing LBBC services to even more people to help them find their way through the maze of information and emotions attached to a breast cancer diagnosis," she says.

Welcome, Cathy!



Research on the Road

LBBC's outreach coordinator, **Katie Creme Henry**, and Young Women's Initiative manager **Arin Ahlum Hanson, MPH, CHES**, are taking our reach further through presentations and exhibits at national conferences. This year, they'll represent the organization at conferences of the American Psychosocial Oncology Society in Tampa, Fla.; the OMG Cancer Summit in Las Vegas; the Oncology Nursing Society in Anaheim Calif.; and the Association of Oncology Social Work, in Baltimore.

YOUNG WOMEN'S INITIATIVE

Young Women's Initiative Update
This February, LBBC's **Arin Ahlum Hanson, MPH, CHES**, manager of the Young Women's Initiative, and **Joanna Fawzy Morales, Esq.**, CEO of Triage Cancer, led a daylong training at **C4YW** for 15 young women who were selected for the Young Advocate Program.

Our Young Advocate Program seeks to engage low-income young women affected by breast cancer and to train them to become more involved in breast cancer advocacy, locally and nationally.

The training covers the topics of breast cancer and young women, breast cancer among ethnic minority women and how to effectively tell one's personal story of breast cancer. Participants complete two outreach activities within their communities between March and October.

Also from the YWI, new Web content was published within the **Learn About Breast Cancer and Young Women** section of lbcc.org focusing on bone health, the use of social media for breast cancer support, anxiety and depression, the unique needs of women under 30, advocacy and communication with providers.

On May 27, YWI will host "Understanding the Unique Needs of Young Women Affected by Breast Cancer," a healthcare provider symposium at the Association of Oncology Social Work 30th Annual Conference in Baltimore. This symposium will help better educate healthcare providers about the unique needs of young women.

Topics to be covered include how to talk about sex and intimacy with patients, fertility preservation options and

how to better care for the psychosocial needs of young women living with metastatic breast cancer. Continuing education credits for social workers and nurses are available. For more information, please email ywi@lbcc.org.

Learn more about breast cancer and young women at lbcc.org/youngwomen.

Don't Forget to Register!

LBBC's **Annual Conference for Women Living With Metastatic Breast Cancer** is just around the corner, but it's not too late to register. Join us for 2 days of presentations focused on your unique needs as a woman living with stage IV breast cancer.

We will offer three plenary sessions and many workshops on topics varying from talking about living well with metastatic breast cancer to the challenges of caregiving. **Julie R. Gralow, MD**, will speak about medical advances and their impact on survival and quality of life in "How Far We've Come: Advances in the Management of Metastatic Breast Cancer" and **Sherry Lebed Davis** will give a presentation on exercise and stress reduction through humor in "Jest for the Health of It." Learn about "Living Fully: Methods for Managing Symptoms and Side Effects" from **Generosa Grana, MD**.

The 2014 conference will be held on Saturday, April 26, and Sunday, April 27, at the Philadelphia Marriot West in West Conshohocken, Pa.

For more information, visit lbcc.org/Events/Metastatic-Breast-Cancer-Conference.

New, Updated Brochures

LBBC's new **Breast Cancer in Focus** series will offer sensitive, medically-reviewed, population-specific information on topics relevant to different groups affected by breast cancer including men, the LGBT community, and African-Americans. The first brochure is planned for release in early summer.

We are also excited to announce a new edition of our **Guide to Understanding Financial Concerns**. This guide offers practical tips on managing the visible and hidden costs of breast cancer treatment and advice on navigating the maze of private and public health insurance plans available to you. This new edition includes information about the Affordable Care Act. Order in print or download it as a PDF at lbcc.org.



Breast Cancer Needs Assessment Survey a Success

LBBC would like to thank the more than 2,500 people who took time to fill out our online breast cancer needs assessment survey. The survey closed January 10.

With your help, we collected information from a diverse group with a range of stages and types of breast cancer. We appreciate your sharing the survey with your friends, family, and breast cancer networks! We'd like to extend a special thank you to our funders, Genentech and Celgene.

Throughout 2014, we will use this data to explore the needs of women with different diagnoses, with an initial analysis focusing on the needs of those with triple-negative, hormone-sensitive and HER2-positive breast cancer.

Look for early results on lbcc.org and our social media networks.

Get Involved!

LBBC is launching a community outreach volunteer program this year. Our goal is to gather volunteers who can help us carry our mission forward by:

- distributing LBBC publications and resources
- participating in events in your community on behalf of LBBC
- hosting LBBC education or awareness programs in your area or helping our staff to plan programs

If you are interested in taking part, please contact **Ashley Burczak, MDiv**, volunteer coordinator, at aburczak@lbcc.org.

Thank You

We want to give special thanks to **Jayne Antonowsky, LCSW, BCD**, whose thoughtful insights as a reviewer of our **Guide to Understanding Your Emotions** enriched our second edition. Ms. Antonowsky is a valued member of our

Medical Advisory Board. Her name was dropped, in error, from our acknowledgments page in the initial batch of the printed guide. We deeply apologize for this error and are grateful for the opportunity to acknowledge her important contributions here.

We would also like to take this opportunity to thank all our reviewers, who help us produce accurate and sensitive programs. Look for our acknowledgment of these individuals at the back of printed materials and on our website.

Photos: Bryan Mead, Laurie Beck Photography, LBBC, Orchard Photography

News and Education Update continued on page 7

LBBC Partner Spotlight: Silpada Designs

BY KEVIN GIANOTTO AND LINDSAY BECKMEYER

In honor of Breast Cancer Awareness Month, LBBC partnered with international direct-selling jewelry company Silpada Designs to raise funds for LBBC programs and services. Silpada introduced an exclusive jewelry piece, the Bravery Bracelet, donating a generous \$10 from the sale of every \$39 bracelet to LBBC.

Dana Mehrer, Chairman of the Silpada Foundation, recently shared an exciting announcement. "The campaign was an incredible success," she said. "We're thrilled to announce that donations totaled more than \$260,540."

If you don't already have a bracelet, it's not too late to purchase one. A limited number of the popular bracelets are still available for order while supplies last. The bracelet features pink quartzite beads, a sterling silver "Courage" tag and support ribbon charm, and an adjustable clasp. Best of all, sales of the Bravery Bracelet will continue to support LBBC. Visit silpada.com, click "Shop" and search "Bravery Bracelet" to get yours.

Founded by two women whose friendship has inspired a culture of women empowering women, Silpada's donations to LBBC have totaled more than \$365,000 since the company's partnership with us began in the summer of 2012.

Last July, Silpada invited LBBC staff to attend the organization's annual national conference, where thousands of amazing women were introduced to the programs we offer. In conjunction with the national conference, Silpada sponsored the first Yoga on the Steps: Kansas City, a group yoga session that allowed LBBC to promote our resources to the community.

Jenny O'Brien, a Silpada representative from Kansas, said of the event, "Yoga was a great way to focus and gather my thoughts after an action-packed conference." Not only was the event relaxing, but also educational and inspiring, she said. "We are a woman-centered business, so it felt good to support the cause. It reminds us not to get so busy that we ignore our health. I think Silpada's involvement with LBBC helps us share this with our representatives and customers as well."

Another major highlight of the conference was the unveiling of the Bravery Bracelet. The piece was an immediate hit among Silpada representatives who were eager to share the bracelet and the cause with their customers.

Jody Lafko, a Silpada representative from Montana, is the top seller of the Bravery Bracelet to date. "I used this promotion as a way to gain as much exposure as possible for the cause," she said. "It really isn't about the bracelet; it's

about educating women everywhere about the disease."

Lafko was inspired and motivated by her own experiences with breast cancer. "I have witnessed several women in my life experience this awful illness," she said. "So I am very driven to help support the cause."

The partnership between LBBC and Silpada gave Lafko and countless other representatives the opportunity to educate, empower and make a difference by holding Silpada parties.

"The purpose of the Silpada party is to give women the opportunity to come together with friends in a setting that is fun and comfortable," she said. "It's my opportunity to educate the women at my shows about the jewelry and what Silpada Designs represents. Women love to help women, especially when there is a strong and growing need for a cure. If I am able to touch even one woman — to make a difference in her life through the tools of my business — then I have done a great job! I am blessed to represent a company that believes in education and community support around this critical issue."

In response to the bracelet's success, Living Beyond Breast Cancer CEO **Jean A. Sachs, MSS, MLSP**, said, "I was blown away. I thought immediately of the incredible women who hosted hundreds of Silpada parties across the country, showing the bracelet and encouraging their girlfriends to support LBBC. I am wearing mine now, as I do every day, with admiration and awe. Thank you so much for embracing our mission and for allowing LBBC to move one step closer to our vision: a world where no one impacted by breast cancer feels alone or uninformed."

It's clear that Silpada shares our passion for connecting people with trusted breast cancer information and a community of support. Through the support of partners like Silpada, resources are available to anyone in need, whether newly diagnosed, in treatment, living with a history of breast cancer or managing metastatic disease.

You can learn more about our friends at Silpada, including how to host your own Silpada party or start your own Silpada business, by visiting the company website at silpada.com.



DONOR PROFILE

Julie Miller: 20 Years as an Advocate and Donor

BY JOSH FERNANDEZ



When **Julie Miller** of Philadelphia was diagnosed with breast cancer in 1993 at age 47, she noticed a concentration of resources on prevention of the disease. Very few resources for women already diagnosed with and treated for breast cancer existed.

Then a patient of **Marisa Weiss, MD**, founder of Living Beyond Breast Cancer, Julie channeled her energy into helping LBBC thrive in its early years. From the onset, LBBC has been committed to serving those diagnosed with, in active treatment for, and living beyond the disease. Julie wanted to be a part of these efforts. Over the years, she wore a myriad of hats, serving as fundraiser, photographer, public relations specialist, office volunteer, honoree at one of our first galas — The Butterfly Ball — and as a member of our first board of directors (then called an advisory board). Julie happily performed all these functions because she wanted women like her to get the support and information they needed to live beyond breast cancer.

"During that time, LBBC was the only breast cancer group out there that specifically helped women after they were diagnosed," Julie, now 67, recalls. "It was amazing reaching out to other women like me, talking with them and sharing with them this terrific resource that also helped me."

Julie does not play all these roles for LBBC anymore, she says, because of how much we have grown under the leadership of **Jean A. Sachs, MSS, MLSP**, our chief executive

officer. Nevertheless, Julie continues to show her love and support of LBBC through her philanthropy. The year 2013 was not only Julie's 20-year "cancerversary," but also marked her 20-year anniversary as a donor. The generosity of people like Julie has allowed us to continue expanding and growing our educational and support resources to better meet the needs of those we serve.

Nearly 600 individuals have been donating to LBBC for 5 years or more and have donated over \$5 million in the last 20 years. Your sustained giving really does make a difference.

"The work LBBC does is wonderful," she says. "If you need someone to talk with, you can call the Breast Cancer Helpline. If you want to know about resources to get help or breast cancer information, you can go online or read the newsletter. There are so many avenues for everyone's needs."

Julie is especially proud of our outreach and commitment to meeting the needs of women under age 45, African-American women and Latina women affected by

breast cancer, especially through publications like *Getting Connected: African-Americans Living Beyond Breast Cancer*.

The Philadelphia-area native hopes others take the time to contribute to LBBC in any way they can to help us further our mission.

"If you can't give money you can certainly give some time and volunteer," Julie says. "It will make you feel good, and you'll be doing so much good for others who are surviving or living with breast cancer."

Thank you to our November 2013 – January 2014 contributors:

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absence of physical changes from breast cancer and its treatment, body image concerns are widespread.

"Women come to me with concerns already set within the context of most of us not liking our bodies anyway. Body image isn't always about being 'heavy' or 'fat,'" says Dr. Katz. "In some cases, 'skinny' is wrong. Many women come in with bad body image to begin with."

It's also true that you could love your body before diagnosis and develop low self-esteem after treatment. Yet, not everyone reacts negatively to an altered body. Your response to change comes from your individual perspective, which is shaped by past experiences, personality and, sometimes, by support from family and friends. These changes could feel different, depending on your age and relationship status. Whether your breasts or hair are important to you and whether you see your scars as unwanted marks or as signs of your strength is unique to you.

Relating to Yourself and Others

Jennifer Pellechio-Lukowiak, 45, of Monmouth County, N.J., wasn't bothered by the way her breast looked after her lumpectomy, and chemotherapy didn't impact her body image.

It wasn't until she finished her course of radiation therapy that she noticed a difference.

Jennifer's breast shrank nearly two cup sizes, and the scar from her lumpectomy sunk in, making it more visible than it was right after surgery.

"We sometimes do a poor job of warning women about certain changes, like the skin effects of radiation or the disfigurement of lumpectomy," Dr. Katz says. "The way a scar looks immediately after surgery sets the stage for how a woman sees it for a while. She may not realize that the big red line will become a thin, white line eventually."

Even though providers often talk about the physical changes that can result from surgery and medical treatment, it can sometimes be difficult to think about them during the stress of a new diagnosis. This, coupled with some providers avoiding sensitive topics — like the loss of pubic hair from some chemotherapies — creates an atmosphere for unexpected negative reactions.

When Jennifer started to feel self-conscious about the way her breast looked and because it felt numb, she saw a



Jennifer Pellechio-Lukowiak

"Even though providers often talk about the physical changes that can result from surgery and medical treatment, it can sometimes be difficult to think about them during the stress of a new diagnosis."



Diane and Ron Grayson

plastic surgeon about reconstruction. Her doctor felt her skin was too damaged from treatment to safely allow an implant to be inserted.

"For 5 years, my breast was a constant reminder of being sick, and that's taxing after a while," Jennifer says.

Her husband was very supportive and reminded her that, for him, the look of her breast wasn't significant. He chose to concentrate on the fact that Jennifer was alive and out of treatment. Even with this support, she struggled.

"It was hard to explain that while I understood it didn't bother him, it really bothered me," she says.

When considering treatments that may cause body image concerns later, especially surgery, Dr. Katz advises: "This is your body, and you get to say who does what to it as long as you are fully informed about your treatment options. Don't rush into anything."

Even when your partner doesn't mind the way your breast looks or feels, it's important to consider what matters to *you*. If you're single, how you see your breasts after surgery could have a strong impact on how confident you feel in future relationships, both physically and emotionally. Whatever your situation, if reconstructing your breasts is important to you, it's worthwhile to seek second or third opinions.

Diane Grayson, 57, of Bellevue, Wash., had two lumpectomies, a mastectomy, and reconstruction with a saline implant that later needed to be removed. She worried about how the changes to her body were affecting her intimate relationship with her husband.

"He would tell me to do whatever made me happy," Diane says. "But I wanted to make *him* happy, too. In the end, though, you should be true to your own feelings and try to focus on yourself, what *you* need."

The challenge has been in deciding on a next step. "I don't have the same feeling of wholeness or sexiness I had before. What I really want is to be able to accept my body and what happened to me, to feel comfortable enough to move forward [with the possibility of another reconstruction]," Diane says.

What Can I Do?

Some women come to embrace their changed bodies. Learning to love and accept the body you have and to forgive it for what might feel like a betrayal may be difficult, but it can be done.

Dr. Katz offers a few simple ways to start:

- Give yourself time to grieve the loss of your breasts, hair, or physical ability before you decide what to do next.
- Wear things that make you comfortable. If you wore "sexy" underwear before, continue. If you feel your best in a t-shirt, wear one.
- Find clothes you're comfortable having your partner see you in. Being naked with your partner can be pleasurable, but if you want to cover up more than usual, that's OK.
- If you've had reconstruction, consider nipple or areola tattoos, if that is important to you.
- Eat healthy and limit alcohol. A good diet can help you maintain weight and make you feel well physically and emotionally. If you need help, consider talking with a nutritionist about your unique situation.
- If you have a partner, talk about how you feel. Open communication is one of the best ways to actively cope with challenges in relationships, and though it may be uncomfortable to bring up sex, talking now sets the stage for later.
- If you're single or dating casually, take as much time as you need to start a physical relationship. You may find yourself wondering if negative experiences are caused by a lack of connection or by your partner's feelings about your body or the cancer. Who you choose to share your body with is your decision.



Kellie Green

Photo Courtesy of Laura Gordillo Photography, www.lauragordillo.com

- Find a support group, or seek professional counseling. Sometimes all it takes is extra understanding from people who've been there or who know what to say or ask.

It may be that you come through treatment and see your changed body as a reminder of all you've been through and the challenges you've faced. **Kellie Green**, 53, of Warner Robins, Ga., who found a lump through a breast self exam she did while lying on her side, had this experience after being treated for stage III triple-negative breast cancer in 2008. "I never thought about reconstruction, I just wanted the cancer to be gone," says Kellie. "It took me 2 weeks to look at myself after surgery, and at the time it didn't look too bad. A few weeks later I saw myself in the bathroom mirror, just as I was passing by it. My shirt was unbuttoned halfway and I just thought 'Wow, I am so sexy right now.'"

Kellie had both breasts removed in separate surgeries, chemotherapy and radiation. After her treatment, she started telling herself she was beautiful, went back to working out regularly, and experimented with tops that accentuated her chest. How she came to see her body so positively she can't quite say.

"It just kicked in for me. Beauty is not all about the breasts. We're all beautifully made," Kellie says. "We're not ugly. Cancer is ugly."

WANT TO LEARN MORE?

Check out these FREE podcasts and presentations on topics ranging from how to cope with changes to self-esteem, body image, and intimacy after a breast cancer diagnosis. They're all available at lbcc.org/Event-Archive:

"Body Image: Breaking Through the Looking Glass" – During her illuminating presentation, **Anne Katze, RN, PhD**, a clinical nurse specialist and sexuality counselor at CancerCare Manitoba

- explores how you relate to and feel about your body
- helps you understand how your personal views and society's values may impact your feelings
- provides you with practical tools for accepting your new body and managing body-image issues that may impact your relationships

"Sex and Intimacy After Breast Cancer" – Hear **Beverly Vaughn, MD**, a specialist in gynecology with more than 20 years of experience,

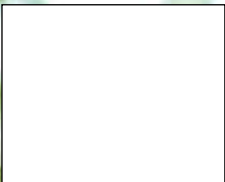
- share how you may experience your body and interest in sex differently after breast cancer treatment
- offer effective solutions for managing side effects that can impact intimacy and pleasure
- explore strategies for increasing desire and talking with healthcare providers about your concerns

"Rediscovering Yourself: Improving Self-Esteem and Body Image" – Listen to **Liz Russo, MSW, LCSW**, a psychotherapist who was diagnosed with breast cancer at age 29, as she:

- explains how a breast cancer diagnosis and treatment impacts the way we view ourselves and our bodies
- offers methods to help quiet the negative messages we receive from ourselves, others and society

Insight

An educational newsletter
from LBBC



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Calendar

Educational Programs

Webinars

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

MARCH 25, 2014
✦ **Breakthroughs in Neoadjuvant Treatments**

APRIL, 2014
✦ **2-Part Series: Triple-Negative Breast Cancer**

Conferences

APRIL 26 – 27, 2014
✦ **Annual Conference for Women Living With Metastatic Breast Cancer**
West Conshohocken, Pa.

SEPTEMBER 27, 2014
✦ **Annual Fall Conference**
Philadelphia, Pa.

Special Events

MAY 18, 2014
Yoga on the Steps: Philadelphia, Pa.

JULY 20, 2014
Yoga on the Steps: Kansas City, Mo.

SEPTEMBER 13, 2014
Yoga on the Steps: Denver, Colo.

OCTOBER 18, 2014
The Butterfly Ball
Philadelphia, Pa.

Check lbcc.org for the latest program information



Photo: Bryan Mead

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