

Insight

An educational newsletter
from LBBC



Breast Cancer After 60: Knowing Your Needs

BY NICOLE KATZE, MA

After a routine mammogram in 2005, **Marcia Messing**, 81, received a message from her imaging center.

Then 73 years old, Marcia didn't think much of it, delaying a return call until the center reached out again and insisted on speaking with her. After follow-up appointments, she learned the radiologist saw what looked like a tumor in each breast.

"I never thought they'd tell me I had breast cancer," says Marcia, of Los Angeles, who once managed an MRI center herself. "When you're that age, you're at a point in your life when you think you've made it through. And then, wham-o! I was totally shocked."



MARCIA MESSING

Your overall health, family support, marital status, financial ability, health insurance coverage and role in your community all may impact your treatment decision-making. "[Often] an older woman isn't just caring for herself; she's caring for her grandchildren, her spouse or her siblings. It's essential that for as long as possible, she remain vital and independent," Ms. Cooper says.

As you undergo treatment or make decisions, consider the following issues you may face, and be sure to ask your providers questions.

Diagnosis at a Later Age

Most people diagnosed with breast cancer are older than age 60; the average age at diagnosis is 62. According to the National Cancer Institute, 1 in 28 American women will be diagnosed with breast cancer between ages 60 and 70. As we approach 80, this number drops to 1 in 26.

Despite the greater chance of diagnosis at a later age, many women are surprised. Some find the physical and psychological effects of breast cancer diagnosis and treatment less bothersome than the more tiring or painful health-related issues they already face. **Linda Cooper, LCSW, OSW-C**, a licensed clinical social worker at Rocky Mountain Cancer Centers in Denver, says medical professionals should be aware of and prepared for the diversity of reactions older women have at diagnosis.

"Older women are not all the same," Ms. Cooper explains. "In considering just women over age 60, there's a spectrum from the 'young-old' to the 'very old,' and they each experience a diagnosis individually."

Health, Aging and Breast Cancer

When treated with standard therapies, early-stage breast cancer and ductal carcinoma in situ (DCIS) diagnosed in older women usually don't shorten life. But you may have other health issues—what doctors call *comorbidities*—that may impact your treatment options. Trouble with everyday movement, for example, may make treatments that require frequent trips to the hospital difficult; other chronic illnesses, like heart conditions, may limit cancer medicines that can be combined with those prescribed for the heart.

It's important that all your providers communicate with one another and that you maintain a record of your medicines, including dose and frequency, to share with any new doctors.

Mara Schonberg, MD, MPH, assistant professor of medicine at Beth Israel Deaconess Medical Center, Harvard Medical School, says clear communication is key to getting the right treatment for you.

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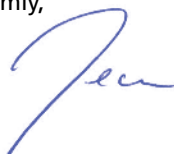
Dear Friends,

In this issue, our medical information story focuses on a noninvasive breast cancer called *ductal carcinoma in situ*, or DCIS, that affects more than 64,000 women each year.

Due to the widespread use of mammography screening, doctors are seeing a significant increase in DCIS cases. Mammograms often pick up noninvasive disease, but because we don't yet have validated tests to predict which DCIS cases will never harm us versus develop into invasive breast cancer, some women may undergo treatment they might not need—along with the related side effects and emotional upset. Journalist Peggy Orenstein explored these issues in her *New York Times Magazine* article, "Our Feel-Good War on Cancer," published in the spring, and healthcare professionals continue to debate the most effective treatments for this condition.

At LBBC, we are aware of the controversy and understand it may be hard to know what to do if you are faced with a DCIS diagnosis. LBBC seeks to provide you with tools to help you take an active role in your treatment and recovery and make informed choices that are right for you. As with any form of breast cancer, DCIS presents you with challenging treatment decisions—and we hope our free programs and services can help you effectively communicate with your providers about your options and the potential outcomes. And we pledge to be here for you, no matter what the stage of breast cancer, to help you manage the emotional impacts of treatment.

Warmly,



Jean A. Sachs, MSS, MLSP

P.S. I welcome your thoughts on how we can improve our programs and services. Take our online survey at surveymonkey.com/s/2013LBBC, and enter to win a \$25 gift card for your participation (U.S. residents only).



Laurie Beck Photography

LIVING BEYOND BREAST CANCER

*Empowering all women affected by breast cancer
to live as long as possible with the best quality of life.*

Paddling to Support and Sisterhood: Betty Solley's Story

BY JOSH FERNANDEZ

Struggling to catch their breath, **Betty Solley**, of Philadelphia, and her teammates paddled furiously on the Potomac River in Washington, D.C., pushing themselves to the limit under the scorching sun in their red and gold dragon boat.

"Crossing that finish line was a huge challenge," Betty, 69, recalls of her first race in 2004. "It was an awesome experience, but it was also when I realized that I really had to train for this sport."

Almost 10 years later, Betty is an accomplished dragon boat athlete. She is a member of Against the Wind, a crew of the Philadelphia Flying Phoenix dragon boat team made up entirely of women who have been diagnosed with breast cancer, and a member of the PFP's premiere red crew. In 2012 she paddled on the River Thames in London at the Queen's Diamond Jubilee Pageant. Now Betty has been selected as a member of Team USA's senior C division, which will represent the United States in July 2013 at the World Dragon Boat Racing Championships in Szeged, Hungary.

The former health and physical education teacher's dragon boating career began after she was diagnosed with stage I breast cancer in winter 2003. After undergoing a lumpectomy, chemotherapy and radiation, Betty looked for a way to restore and build her physical fitness.

The opportunity presented itself during a workshop she attended at the Abramson Cancer Center of the University of Pennsylvania's annual conference, "Life After Breast Cancer." A workshop attendee talked about the physical and emotional benefits of *dragon boating*, a racing sport in which 20 paddlers synchronize their strength, endurance and technique to power a 41-foot-long canoe through the water. Betty was invited to try paddling with Against the Wind, and she enthusiastically accepted.

Betty met the team for the first time in fall 2003, a few weeks after she finished treatment. That day, she got in the boat and watched the women around her, eventually paddling one side while the team member next to her paddled the other. Before she knew it, the boat went quickly forward.

"It felt like something unique and different, and it wasn't like anything I had done before," Betty says.

The summer following her first race, Betty started working out on a rowing machine and lifting weights. Recently, Betty began joining her peers at a paddle pool to perfect her technique in a stationary boat. She now goes to the gym

twice a week to strength train, using machines to condition her entire body.

As a result of her hard work, Betty can now perform seated dip repetitions with a resistance of 200 pounds. She has also drastically improved her running distance: Before joining Against the Wind, Betty couldn't run a quarter mile; now she's training for a 5k race.

"It's an amazing feeling to be able to get out there and run without pain," she says. "It wouldn't have happened if I wasn't training with the team."

This is why Betty encourages women who have completed breast cancer treatment to try dragon boating—it's an aerobic activity that builds endurance, increases flexibility and fosters a sense of community among teammates.

"I'm of two minds—dragon boating and actively promoting breast cancer awareness through dragon boating," Betty says.

Betty is active in Against the Wind's "Survivors In Sync," an outreach program the crew runs in partnership with local hospitals. The program aims to bring women who have completed breast cancer treatment to the Schuylkill River to try dragon boating and meet other women who have also experienced the disease.

As someone who sought a more physically active outlet than a support group, Betty says what she loves most about dragon boating is the camaraderie.

"The focus is not on cancer, but if someone has a recurrence, then they become a magnet for support—when you are on Against the Wind, we have your back," she says.

Betty says the team is looking to expand, and she hopes women who have been treated for breast cancer will consider a test drive with Against the Wind or a team near them.

"It's a sisterhood," Betty says. "It's a way for you to belong to a group that is beyond cancer." 🍷

To learn more about Survivors In Sync, visit PhiladelphiaFlyingPhoenix.org or email info@philadelphiaflyingphoenix.org. For more information about Against the Wind, visit facebook.com/pfpattw or meetup.com/AgainstTheWind.

Visit ibcpc.com/members for a list of dragon boat teams near you.

"It's a sisterhood," Betty says. "It's a way for you to belong to a group that is beyond cancer."



Understanding DCIS

BY JOSH FERNANDEZ

Stacy Goldsby, 49, of Burlingame, Calif., was told by her doctor that she had breast cancer after a lump was discovered in her breast during a routine mammogram in August 2012.

It was not until she received her biopsy results and sought a second opinion that Stacy discovered she had a noninvasive form called *ductal carcinoma in situ*, commonly referred to as DCIS.

"I felt displaced and confused at first because I didn't know what it was," Stacy says. "I had to reread everything, including one book in particular that had a full chapter on DCIS. I had read everything but that chapter."



STACY GOLDSBY

Diagnosing Noninvasive Breast Cancer

According to the American Cancer Society, about 60,000 women were diagnosed with noninvasive breast cancer in 2011. About 85 percent of these cases were DCIS, a stage 0 cancer in which abnormal cells are found in the lining of milk ducts. Unlike invasive disease, the cancer in DCIS has not broken through the walls of the milk ducts to surrounding healthy breast tissue. DCIS is considered stage 0 because it is "in situ," meaning the cancer remains in the spot where it began.

Although it is not life-threatening, DCIS that is inadequately treated can progress to invasive breast cancer. Having DCIS can also increase your risk of developing invasive breast cancer later in life.

If DCIS is found in addition to an invasive breast cancer diagnosis, you will be treated based on the stage of the invasive cancer.

David Euhus, MD, professor of surgery in the division of surgical oncology at U.T. Southwestern Medical Center at Dallas, says more than 80 percent of women diagnosed with invasive breast cancer have DCIS as part of their diagnosis.

"DCIS is never invasive, but it can be associated with invasive cancer," he says.

DCIS is different from *lobular carcinoma in situ* (LCIS), abnormal cell growth that does not spread beyond the breast's milk-producing glands, or *lobules*. LCIS is much less common than DCIS. According to the American Cancer Society, it accounted for about 11 percent of in situ diagnoses from 2004–2008. Although LCIS is not considered cancer, having it increases your risk of developing invasive breast cancer in the future.

If you are diagnosed with LCIS after a needle biopsy, your doctor may recommend an open surgical biopsy to make sure DCIS or invasive cancer are not also present.

LCIS is not an immediate threat to your health. You and your doctor might have follow-up visits every six to 12 months to watch for any signs of invasive breast cancer. Your doctor might also advise that you make lifestyle changes, take medicines or undergo preventive surgery to reduce your risk of developing invasive breast cancer.

The Overtreatment Debate

Dr. Euhus says that mammography has become so common that doctors are seeing a significant increase in the number of women diagnosed with DCIS.

"We do this screening because we want to catch these more aggressive cancers when they are very early so we can interrupt their natural history and stop them from becoming fatal," Dr. Euhus says. "The downside is that [screening] picks up cancers that aren't life-threatening."

Peggy Orenstein recently addressed this issue in her article, "Our Feel-Good War on Cancer," published in *The New York Times Magazine*. Because there are no available tests to differentiate DCIS that will not progress from those that could develop into invasive breast cancer, some women may undergo treatment they might not need.

Treating DCIS

Dr. Euhus says there is a lot of overlap between treatment for DCIS and invasive breast cancer. "Just like invasive breast cancer, you have the option of breast conservation, which is a lumpectomy to remove the DCIS with a margin of normal tissue around it, followed by radiation," he says. "Or you can have a mastectomy, removing the entire breast, and not have radiation."

A lumpectomy with radiation is usually recommended when DCIS only appears in one area of the breast and can be removed along with a clear margin of healthy tissue.

Doctors may recommend a mastectomy if the DCIS covers a large area, or if there is more than one area of DCIS in the breast. If you receive a lumpectomy, you may choose to forgo radiation if you have a very small, low grade DCIS and feel the side effects outweigh the benefits. The genomic test called Oncotype DX may be able to identify DCIS with such a low recurrence risk that radiation may not be necessary after lumpectomy.

After surgery and radiation, you may receive hormonal therapy, like tamoxifen, if the DCIS is hormone receptor-positive.

Lumpectomy plus radiation reduces the risk of recurrence between 15 and 30 percent in DCIS. Studies suggest that radiation followed by tamoxifen after surgery reduces risk of recurrence in hormone-sensitive breast cancers by half within five years. Dr. Euhus says the risk of recurrence after mastectomy is about 2 percent.

After she was diagnosed with DCIS in August 2008 at age 54, **Susan O'Neill**, of Orlando, Fla., received a lumpectomy followed by radiation. Since the DCIS was ER positive, her doctor recommended tamoxifen to lower the risk of recurrence, which she turned down.

"It came down to the fact that it wasn't mandatory, so I choose not to take tamoxifen, especially given the side effects," she says. "I have been very diligent in my follow-up care, and I'm still cancer free, so I feel I made the best decision for myself."

Stacy opted to undergo a double mastectomy. Her mother died of metastatic breast cancer in 1984, when Stacy was 20 years old. Given her family history, this treatment decision made her the most comfortable.

"My mother was 44 when she was diagnosed, and the breast cancer hit her like a tsunami—it took her out hard and furious," Stacy says. "To honor her legacy and life as her daughter, I had to make bold decisions."

Emotional Impact

If you have been diagnosed with DCIS, you may feel confused or frustrated. Even though it is not considered life-threatening, you still experience the same treatments and side effects as women with invasive breast cancer—including surgeries that change or disfigure the breast, reconstruction, radiation and hormonal therapies—without really knowing whether you needed them.

When **Janet Glover-Kerkvliet**, 50, of Baltimore, learned she had DCIS, she felt conflicting emotions.

"I had something on the breast cancer scale and it was scary, but there was this sense in my own mind that somehow it was less, or not as bad, or not as important. Then there was the question, 'Do you really call this cancer?'" Janet recalls.

Stacy asked herself the same question. In late 2012, Stacy and another woman diagnosed with DCIS attended a breast cancer support group. After the woman introduced herself, another group member said within earshot, "DCIS? Oh, I wish I had that," causing the woman to get up and leave.

"I was shocked," Stacy says. "That moment made me feel like there was not a real sense of identity—where do I fit in with this group? I didn't quite know, and in a way the incident made me feel like I did not have 'enough' cancer."

Because there was no history of cancer in her family, Susan didn't know what to expect. She joined a breast cancer support group to alleviate her anxiety.

Susan learned a lot, but because most of her peers had invasive breast cancer and had much more extensive treatment, she developed feelings similar to Stacy's.

"It's a personal challenge for someone with DCIS—sometimes you didn't feel worthy to be part of the group because [others] seemed to suffer so much more than what you did," Susan says.

Fear of recurrence or of developing an invasive breast cancer can also take an emotional toll.

Susan tries to put her fears at ease by reminding herself of the lifestyle changes she made to reduce her risk and the careful screening schedule she and her doctor created. Her follow-up care included a mammogram and MRI every six months for the first three years after treatment. Now she receives just a mammogram every six months.

Stacy will see her doctor for her first-year follow-up appointment this August. "I feel more confident from the changes I've made for my health and with my follow-up care," Stacy says.

Janet has routine screenings and works on improving her health with exercise, maintaining a healthy weight, lowering stress and eliminating caffeine. She deals with fears of recurrence through therapy, her faith and building a support network of family and friends.

"DCIS is not trivial," Janet says. "It does affect your life, even if it's stage 0."

The Future

Researchers are working to discover a way to predict risk of DCIS recurrence or progression. Until then, many women may choose more treatment rather than risk DCIS recurrence or invasive breast cancer.

Stacy says she never wanted to look back and wish she had done more, especially after watching what her mother went through.

"I know a lot of people questioned my boldness, and I know that a mastectomy doesn't eliminate the risk of recurrence," she says. "It was for my comfort and my peace. I needed to know that I did everything I could to reduce my risk." 🍷

ASCO UPDATE

Get updates reported at the annual meeting of the American Society of Clinical Oncology by listening to a podcast of our June webinar, **ASCO Update**, at lbcc.org/Event-Archive. You can also get more news at lbcc.org/Understanding-Breast-Cancer/Breast-Cancer-News, including a follow-up on ATLAS, a study that has shown that tamoxifen treatment for estrogen receptor-positive breast cancer is even more beneficial when taken for 10 years instead of five.



SUSAN O'NEILL



JANET GLOVER-KERKVLiet

Fall Conference Spotlights Changing Landscape of Cancer, Features Siddhartha Mukherjee

BY JANINE E. GUGLIELMINO, MA

Prize-winning Author at Fall Conference

Our fall conference, [News You Can Use: Breast Cancer Updates for Living Well](#), has been expanded to two days and will be held Oct. 26 and 27 at the DoubleTree by Hilton Philadelphia Center City.

Siddhartha Mukherjee, MD, author of the Pulitzer Prize-winning *The Emperor of All Maladies: A Biography of Cancer*, serves as our opening plenary speaker. In "The Changing Landscape of Cancer," he will discuss the history of cancer and how the past influences the present. Dr. Mukherjee practices at Columbia University, in New York.

Two other plenary sessions cover hot topics in breast cancer care, navigating the healthcare system and eating healthfully after diagnosis. **Hollye Jacobs, RN, MS, MSW**, creator of The Silver Pen blog, is a pediatric and adult palliative care nurse and social worker. Diagnosed with breast cancer last year, Ms. Jacobs speaks frequently about managing life-threatening illness. **Suzanne Dixon, MPH, MS, RD**, a registered dietitian and epidemiologist, is recognized internationally for her expertise in nutrition and cancer.

The conference features 18 workshops, a yoga class, and ample time to meet and make new friends.

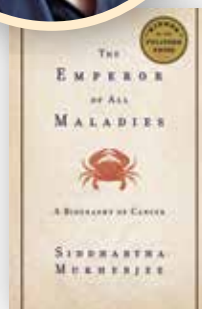
For the agenda and details about travel grants and fee waivers, visit [lbbc.org/Events/Annual-Fall-Conference](#).

Cheers, Volunteers!

We want to thank the nearly 1,000 volunteers from 37 states who last year donated time to LBBC. Your efforts helped us better serve the 80,000-plus individuals who rely on our programs and services.

To expand our footprint, in January LBBC held our first volunteer training webinar. Speakers discussed the organization's history and explored ways to get involved. To hear the recording, visit [lbbc.org/Get-Involved/Volunteer](#).

With the expansion of our [Survivors' Helpline](#), we need more volunteers to staff the phones from 9 a.m. to 5 p.m. ET. Fourteen women joined LBBC's team after an April



orientation. In late July we will train more than 20 women of various ages, backgrounds and diagnoses. Later in the summer, we will train an additional 11 volunteers. To learn more about volunteering on the Helpline, contact Lynn Folkman at [lynn@lbbc.org](#).

Stretch Yourself

Our [Guide to Understanding Yoga and Breast Cancer](#), the latest title in LBBC's brochure series, introduces you to this popular form of exercise.

Whether you have practiced yoga for years or are simply curious about it, you will learn how to use yoga for fitness, coping and spirituality. Find out what the research says about yoga and breast cancer, and discover safe poses and practices for those with lymphedema and in treatment for early-stage or metastatic disease. This guide was written with help from providers, instructors and women affected by breast cancer.

Our next title, due in October, will focus on genetic testing, counseling and family risk assessment. To learn more about all our publications, please visit us at [lbbc.org/Understanding-Breast-Cancer/Guides-to-Understanding-Breast-Cancer](#).

Video, Podcasts Available

Webcasts and podcasts from our [Annual Conference for Women Living with Metastatic Breast Cancer](#) are online now at [lbbc.org](#).

In April, about 250 women with stage IV breast cancer gathered in Philadelphia for a weekend of education, information and connection. **Wendy G. Lichtenthal, PhD**, a psychologist at Memorial Sloan-Kettering Cancer Center in New York, drew praise for her presentation on "Living Life with Cancer: Finding Meaning," as did **Linda and Bob Carey** of The Tutu Project, who discussed how Linda's stage IV diagnosis changed their lives. Go to our website to stream videos of both plenaries and to access podcasts of up to 17 workshops.



News and Education Update continued on page 7

LBBC Staff Named to Federal Advisory Committee

Elyse Spatz Caplan, MA, LBBC's director of programs and partnerships, was recently appointed to the federal Advisory Committee on Breast Cancer in Young Women.

The committee assists the U.S. Centers for Disease Control and Prevention in developing evidence-based methods to grow understanding and awareness of breast cancer among women diagnosed younger than age 40. The ACBCYW was established after passage of the EARLY Act, legislation spearheaded by Florida representative **Debbie Wasserman Schultz**.

Elyse was diagnosed with stage IIB breast cancer 22 years ago, at age 34. Since then she has dedicated her career to assisting women with the disease. Her term lasts through November 2014. Congratulations, Elyse!



and partnerships. "When you post your concerns, they can point you to LBBC resources relevant to your needs. This personal, high-touch approach will help LBBC reach more women who need us."

In addition to using the resource online, you can download mobile apps for your iPhone or Android. Watch a video and learn more about the resource at MyBCTeam.org.

Spreading the Word

The 14 graduates of our first **Young Advocate Program** are raising awareness nationwide of the impact of breast cancer in premenopausal women.

Selected for training at **C4YW**, the Annual Conference for Young Women Affected by Breast Cancer, the women learned skills to help them advocate and become more involved in breast cancer activities locally and nationally. Among the group's accomplishments so far:

- Distributing materials and raising funds at **Laconia Motorcycle Week** in New Hampshire
- Encouraging healthcare providers to share LBBC's educational guides
- Applying to participate in the **National Breast Cancer Coalition's** Project LEAD
- Blogging about what they learned at C4YW
- Speaking publicly at local health fairs and community events

LBBC will hold another advocate training in 2014. To stay updated on all activities of our Young Women's Initiative, visit lbbs.org/Audiences/Young-Women.



Conference Roundup

LBBC's booklet **Getting Connected: African-Americans Living Beyond Breast Cancer** was the subject of a 50-minute oral presentation earlier this month at the 29th **Association of Oncology Social Work** Annual Conference in San Diego.

Katie Creme Henry, our outreach coordinator, co-presented with **Arin Ahlum Hanson, MPH, CHES**, manager of the Young Women's Initiative. Arin also presented a poster with findings from our national needs assessment of women diagnosed before age 45.

Both women presented posters at the **Oncology Nursing Society** 38th Annual Congress, held in Washington, D.C., in April. Such events help LBBC share our programs and resources with healthcare professionals and advocates. Email us at publications@lbbs.org to let us know of opportunities in your area.

LBBC Partners with MyBCTeam

A new social media network offers a private space to meet and connect with others coping with breast cancer.

MyBCTeam.org will partner with LBBC to link its members to our extensive resources. MyBCTeam allows you to safely get to know other women, even matching you with people with similar diagnoses. Build your own team of women and providers, and track your interests on pinboards.

"The beauty of MyBCTeam is that moderators assist members," says **Elyse Spatz Caplan, MA**, director of programs

Thumbs Up—or Down?

Let us know what you thought of this issue of *Insight* by visiting surveymonkey.com/s/2013LBBC. Complete our survey, and enter to win a \$25 gift card (U.S. residents only). 🍀

Photos: Bryan Mead, Laurie Beck Photography, Orchard Photography

Ways to Give: The Options Are Endless

BY LINDSAY BECKMEYER

Did you know that every year, about 65 percent of Living Beyond Breast Cancer's programs and services are supported by donations from corporate partners and grassroots fundraisers?



Tiffany Mannino (right) held Paint it Forward, an event to benefit LBBC, at her local painting studio during Breast Cancer Awareness Month

Without these gifts, LBBC could not provide programs and services at little or no cost to those in need.

Corporate partners such as **5-hour ENERGY**, **Chico's**, **Cline Cellars**, **essie**, **Everything But Water**, **jane iredale—THE SKIN CARE MAKEUP**, **Soma** and **White House | Black Market** donate a portion of product sales or make a donation to LBBC each year and help bring awareness of the organization by displaying our logo on their websites, products and catalogs. If you are interested in exploring a partnership with LBBC, please contact us at (610) 645-4567 or development@lbcc.org.

Equally important is the contribution of individuals wishing to further LBBC's mission. Grassroots fundraisers organize and host special events, donating a portion of proceeds to help support our programs and services. LBBC is fortunate to be the beneficiary of more than 20 grassroots fundraising events that raise almost \$100,000 annually.

Want to bring your unique talents and interests to LBBC? Host a fun and interactive event to raise money for women affected by breast cancer! Events can range from hosting a happy hour at your local pub to asking your boss to let you and your coworkers pay \$5 to dress down on a Wednesday to throwing a painting party at a new art studio.

Last year **Tiffany Mannino**, a 39-year-old teacher who was diagnosed with breast cancer three years ago, reached out to **Tara Smith**, owner of **The Uncorked Artist**, a painting studio that teaches classes and hosts parties. Tiffany asked to hold an event for Breast Cancer Awareness Month

and donate half the proceeds of an art class to LBBC. Tara agreed, and together they raised \$545 for LBBC in one night.

"I absolutely love art, so when I heard about The Uncorked Artist, I knew that would be a perfect thing to do to raise money for LBBC," Tiffany says. "We had so much fun that night! Not only did I get to enjoy quality time with those I care about, but we were also able to support a cause we all hold near and dear to our hearts. And did I mention we had a blast doing it?"

In November 2012, **Glynis Rhodes** hosted a "cancer-versary" party at her local fire hall, celebrating the anniversary of her breast cancer remission. The evening included raffle drawings and a silent auction, and all proceeds went to LBBC.

"LBBC was so great to me during my journey with cancer. They helped me stay positive and have fun even though I was going through treatment, so I really wanted to give back to them in some way," Glynis says. "A raffle and silent auction seemed like the perfect opportunity."

If you're interested in hosting an event but aren't sure where to begin, visit lbcc.org/Events for our community fundraising event guidelines. Fill out our online form so we can help you in your planning process. Once you complete the form, you will have the option to create a personal page for your event. You can send the link to anyone you'd like to invite or ask for a donation. 🍷

PLANNED GIVING AND YOUR LEGACY

You can help LBBC continue to provide education programs for free or at little cost by making a planned gift. We offer a number of opportunities that can be tailored to meet your needs.

One of the easiest ways to make a planned gift is to include LBBC in your will or revocable living trust. It is not necessary to rewrite your entire will to make a bequest to LBBC. You can simply instruct your attorney to prepare a *codicil*, an amendment, to your current will or living trust.

One sentence in your will or trust ensures that future generations will benefit from LBBC's services and programs. For example:

"I give to Living Beyond Breast Cancer, a nonprofit corporation organized and operating under the laws of the Commonwealth of Pennsylvania, the sum of \$_____ (or ___ percent of the rest, residue and remainder of my estate) for its general purpose as an unrestricted gift."

For more information, please contact Becky Mills at mbmills@lbbsc.org or (484) 708-1806.

SUPPORT LBBC THROUGH THE COMBINED FEDERAL CAMPAIGN AND UNITED WAY



This September, federal workers can support LBBC through the Combined Federal Campaign, the world's largest and most successful annual workplace payroll deduction giving program. The CFC promotes and supports philanthropy by providing federal employees with the opportunity to improve quality of life for those in need. Designate giving code #78012 to make a gift to LBBC through the CFC.

You can also support LBBC through your United Way workplace giving program. If you give through the United Way of Southeastern Pennsylvania, choose #10172 during this year's campaign!

For additional information, contact development@lbbsc.org.



(top photo)
Paint it Forward
participants

(bottom photos)
Artwork created at
Paint it Forward, a
fundraiser held to
benefit LBBC

Thank you to our January 2013 – April 2013 contributors:

\$100,000+



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"Not many clinical trials include women who have comorbidities, so we often don't conclusively know how effective or ineffective a treatment will be for someone who [has them]," Dr. Schonberg explains. "Treatment decisions should always be based on the question of 'how will I benefit?'"

At the same time, breast cancer calls for many doctor visits, which means more care, more eyes on you, and sometimes, more underlying conditions found and treated.

"The screening level involved in a breast cancer diagnosis might distract you from symptoms of other illnesses, but breast cancer care by necessity means you're getting more of everything, and that can be a good thing," says Dr. Schonberg.

Gretchen Kimmick, MD, MS, associate professor of medicine and a medical oncologist at the Duke Cancer Institute in North Carolina, stresses the importance of screening for other syndromes before beginning treatment.

"There are new tools for physicians to use to determine risk of side effects from treatment and that help determine where other support services, such as physical therapy or nutrition counseling, or consultation with a doctor who specializes in geriatric syndromes, might be useful," says Dr. Kimmick.

Making treatment decisions

After her diagnosis, Marcia met with a breast surgeon who recommended a double mastectomy. The treatment plan felt too aggressive to her. "He was very professional but not comforting in any way," Marcia remembers. She decided to get a second opinion with a surgeon she knew, who agreed the tumors could be treated with lumpectomies.

"He scared me less, and I trusted him," she says. "With my age and tumor size, I didn't need chemo, just radiation."

Not all women seek a second opinion. Dr. Schonberg notes a trend toward women following the first recommendation a doctor makes.

"There don't seem to be very many conversations about the pros and cons of treatment, and what other treatment options are available," she says. "But you should push your doctor and be informed. Ask your surgeon the challenging questions."

More and more medical schools and facilities train doctors in shared decision-making that allows you to decide on treatment paths that suit your personal needs. It's OK to let your oncologist know if you don't understand a treatment path, or you think a certain treatment might disrupt

your lifestyle. Being open and honest with your healthcare team is the best way to ensure you get the treatment you need, while living the life you want.

Balancing your specialists

Many people develop health issues with age, such as diabetes, high blood pressure and problems with *mobility*, the ability to move well. If you have age-related or other chronic conditions, you may see several specialists to manage them. You might even see your specialists more often than your primary care physician (PCP).

The role of the PCP in your breast cancer care varies depending on where you live, your health insurance plan and your familiarity with your doctor. In some rural areas, where cancer centers are farther away, PCPs may be more involved in coordinating your care. You might even choose to have your PCP coordinate your care simply because you've known the doctor for so long.

Oncologists, PCPs and other specialists such as social workers often need to communicate after assessing how to maintain your independence. In some cases they may ask you to sign a document that gives them permission to talk with other members of your healthcare team. A social worker or nurse navigator at your treatment center can help you

find ways to facilitate communication among your providers.

If you want your family members or caregivers to have access to your doctors or medical records, ask for a copy of the Health Insurance Portability and Accountability Act (HIPAA) at your next appointment. HIPAA is a federal law that protects your privacy and gives you control over who can access your health information.

Your provider's office may communicate with you by email between appointments. If you are comfortable using computers, this can be a quick and easy way to get your questions answered. But if you don't have access to a computer or are uncomfortable using one, you have a right to get your questions answered over the phone or in person.

The Internet can be a great resource for medical information, but it can sometimes be unreliable. If you choose to research online, always check what you find with your doctors.

Health Insurance and Medicare

At any age, health insurance can be complex. It can be especially difficult if you are new to Medicare or have supplemental insurance, or both, and you are just learning how

"There don't seem to be very many conversations about the pros and cons of treatment, and what other treatment options are available. But you should push your doctor and be informed. Ask your surgeon the challenging questions."

to manage your plans. If you or your spouse or partner continues to work, you may have several plans, including private insurance through your employer, Medicare and supplemental insurance.

Understanding your benefits plans, and what medical expenses they cover, is an important part of managing your breast cancer care. Talk to your insurance companies and ask for details; your cancer center may also have a financial counselor who can help you. If managing your bills during treatment becomes too much, ask a trusted friend or family member to help you.

When you have private insurance through an employer, your plan may cover a significant portion of breast cancer expenses after you fulfill the *deductible*, a set amount of money you must pay out-of-pocket before your insurance starts to cover costs.

If you are over age 65, you are likely enrolled in Medicare, a federal healthcare program for older adults that covers hospital stays, doctor visits and some cancer medicines after a deductible. Some medicines may require you pay for additional coverage through Medicare Part D. Changes to the government budget in 2013 may affect where you can get treatment and what prescriptions are covered. Visit medicare.gov, call (800) 633-4227 or talk to your healthcare team for more information.

Some women, especially those under 65, may be uninsured. **Chris Schrader**, 64, runs a daycare from her home in Indianapolis and didn't have access to insurance through an employer. She and her husband were too young for Medicare, but they couldn't afford private coverage, so they decided to go without health care.

"It was a tough decision, but we were the picture of health at the time," Chris says.

Chris had her annual mammogram through Little Red Door Cancer Agency, an Indianapolis-based nonprofit. When cancer was found, Little Red Door referred Chris to Project Health of the Indianapolis Medical Society, which serves poor and uninsured residents.

"Project Health paid for everything and didn't make us feel small about it," says Chris. "It's important to remember that no matter what, help is available."

Chris could not go back to a private plan because her diagnosis is a *preexisting condition*, a health issue she had before she applied for new health coverage. Today, insurance companies may legally deny coverage for such illnesses. But as of 2014, the Affordable Care Act prevents insurance companies from denying coverage for past breast cancers.



CHRIS SCHRADER



LINDA TIMMONS

If you've been diagnosed and do not have health insurance, ask to speak with a patient navigator or social worker who can help you find and apply for affordable coverage.

Managing Your Relationships

Support from family and friends may be strong; it can also be a source of stress and anxiety. You may be the caregiver for a family member, or you may be caring for someone else with a chronic illness. The role you fill may impact your treatment decisions as you work to balance what you want for yourself with what others want for you.

"If a woman is a caregiver, she'll often delay her own treatment to continue caring for her relative, or she'll go with a more aggressive treatment option to ensure that she'll continue to be able to care for them," says Dr. Schonberg. "At the same time, some families push for the woman to take a more aggressive route because they want her to be OK. You have to take a step back and consider all sides. Don't take everything at face value."

Romantic relationships may also play a role in your decisions. If you aren't partnered, you may consider how treatment could affect your future, or whether reconstruction is important to your intimate life.

Linda Timmons, 62, was diagnosed with stage I breast cancer in 2011. Divorced with adult children, she opted for reconstruction after a bilateral mastectomy. Soon after, complications from the surgery forced her to have the implants removed. Now she is having a second reconstruction.

"People might wonder why someone would go through extra surgeries for reconstruction, but I wanted to," says Linda. "The hardest part is feeling confident enough to go out there and date."

Though single, Linda's children, as well as her ex-husband, cared for her during treatment and after the surgeries that followed. Beyond her family, she found support in her friends and Bosom Buddies, a group at the Cancer Support Community in her Miami hometown.

"Strong friendships are an important part of getting well," she says. "And knowing other women with breast cancer is just as essential. If you're only dealing with family, you don't understand that there are people out there with you who have been through it, too." 🍷

For peer support and information in a confidential setting, call our Survivors' Helpline toll-free at (888) 753-LBBC (5222). Your call will be answered by a woman who has experienced breast cancer.

SUMMER 2013

Insight

An educational newsletter
from LBBC



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information@lbbsc.org.

Calendar

Educational Programs

Webinars

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

JULY 15, 2013

✦ **Breast Reconstruction:
Tissue Flap Procedures**

JULY 25, 2013

✦ **Newly Diagnosed: Using
Complementary Therapies
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JULY 30, 2013

✦ **Breast Reconstruction: Implant
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AUGUST 15, 2013

✦ **Breast Imaging and Screening
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Conferences

OCTOBER 26–27, 2013

✦ **Annual Fall Conference**
Philadelphia, Pa.

FEBRUARY 21–23, 2014

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

Special Events

JULY 28, 2013

Yoga on the Steps: Kansas City, Mo.

SEPTEMBER 15, 2013

Yoga on the Steps: Denver

OCTOBER 12, 2013

The Butterfly Ball
Philadelphia, Pa.

Check lbbsc.org for the latest
program information



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