



## DEBUNKING THE MYTHS OF Clinical Trials

BY NICOLE KATZE, MA

**C**linical trials, research studies in humans, are the main way new anticancer medicines and prevention and diagnosis techniques are tested and approved for use. Yet the number of adults who join cancer clinical trials is quite low. Concerns about safety and getting the best care, as well as unclear ideas of how research is done, may prevent people from enrolling.

Despite the popular belief that medical research in humans is unsafe or scary, some people find the structured care offered through clinical trials comforting. They also may see benefit in having access to new study treatments to try.

“Joining a clinical trial was the best thing I ever did,” says **Fran Kamin**, 51, of Lake Worth, Florida. “It’s amazing to me how many misconceptions there are.” Fran took part in BOLERO-3, a study of everolimus (Afinitor) for treating HER2-positive metastatic breast cancer. Researchers found that participants treated with everolimus lived for longer spans of time without the disease growing or spreading.

Deciding whether a clinical trial is right for you is a personal choice, but your healthcare team can help you make an informed decision.

### How Trials Work

“Everybody wants the best possible care,” says **D. Lawrence Wickerham, MD**, associate chairman of the National Surgical Breast and Bowel Project. “Participation in trials is how we ensure that high quality care.”

Before a new therapy or approach reaches the point of being tested in a large group of people, it must go through testing in animals or test tubes and through two rounds of research in small groups of people. A treatment must be found safe and effective in these steps, or *phases*.

If a treatment is found safe and of benefit through a large phase III trial, the U.S. Food and Drug Administration may grant approval for it to be used outside of trials. The FDA monitors trials and must give researchers permission to move from one phase to the next.



Fran Kamin

“The reality is that trials are highly regulated, with an institutional review board checking protocol and reviewing participant consent forms before and during the study,” says Dr. Wickerham.

### TRIAL TYPES

There are four types of trials:

- **Interventional trials** compare new treatments or therapies with standard therapies
- **Prevention trials** test methods of preventing cancer from forming or returning. If a trial is studying recurrence, you may be able to participate after you finish treatment
- **Diagnostic trials** explore whether imaging or other methods help doctors find breast cancer earlier or learn more about the cancer faster
- **Follow-up trials** monitor people who have used a certain treatment or therapy over a long period to watch for changes in quality of life and side effects

### TRIAL PHASES

New study medicines and treatment techniques go through three phases of testing before they may gain FDA approval. They must be successful in one stage to move to the next. These phases are:

- **Phase I.** Researchers test a new treatment in a very small group of people to find out how to give the medicine, what kinds of side effects it causes, and how safe it is to use. Fewer people are eligible to join phase I trials, and they are not disease-specific.

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## Dear Friends,

In this issue of *Insight*, we feature an article on the important topic of *clinical trials*—research studies with people, which help us learn more about the causes, prevention, diagnosis and treatment of breast cancer.

Only 3 percent of U.S. adults with cancer take part in clinical trials. Yet trials are the only way to advance our understanding of the disease. You might be surprised to learn that clinical trials are not a method of last resort. In fact, the earlier you and your care team talk about clinical trials, the more likely it is you'll find a good match for your situation.

There are many options to take part in breast cancer clinical trials. As of mid-May, [clinicaltrials.gov](http://clinicaltrials.gov) lists more than 1,500 studies that need participants. Many are for people in active treatment, but some focus on post-treatment care and follow-up. Our article will help you understand when and how to ask about clinical trials, and what your providers might consider when recommending them for you.

We hope you enjoy the cleaner, leaner look of *Insight*. Our new layout eliminates section titles and offers us more flexibility to include emotional support and practical tips alongside medical information. Check out "Beyond These Pages" (page 7) to explore other LBBC programs on the topics covered in this issue and "Ask Your Peers" (page 9), where you'll read perspectives from others coping with breast cancer. As always, we welcome your feedback. Write to us at [editor@lbbc.org](mailto:editor@lbbc.org).

Warmly,

Jean A. Sachs, MSS, MLSP  
Chief Executive Officer

**P.S.** Visit [lbbc.org](http://lbbc.org) to listen to our podcast and read our news coverage of updates from ASCO.



Photo: Laurie Beck Photography

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# MY STORY: A Birthday Gift to Cherish

BY MARLENE SNYDER, FOR LBBC

Marlene Snyder



I am a stage I breast cancer survivor. On June 6, 2011, my 56th birthday, I learned I had cancer and now consider that diagnosis the best birthday present of my life.

I was diagnosed with breast cancer after having a routine mammogram. At the time, I felt fine and life was good. I was heading out on a vacation with my son to celebrate his 21st birthday.

Before my breast cancer diagnosis, I had three other cancers and a bone marrow/stem cell transplant. I knew the routine, so I put on my big-girl panties and off I went for care. My chin was up as tears fell from my eyes. I was in kill-the-cancer mode, but had no idea what would follow.

Although scared for my life, I knew I had to be strong. I rounded up my support team and off we went to the many scheduled oncology and surgery appointments. My support team took notes, listened closely when my ears felt as if they were closed up, and asked the questions necessary to proceed through this frightening ordeal. They held my hand when I was afraid.

I had a hard time understanding how I could be in remission for almost 13 years from the last cancer, a Hodgkin's lymphoma, and now be dealing with breast cancer. Yet, I moved forward, through an 11-hour bilateral mastectomy with reconstruction and six more surgeries to finally get my reconstructed breasts. It seemed that complications arose each time the plastic surgeon tried to fix the existing problem. I was scared of being anesthetized each time, since I was so weak. Dying was not an option.

I've always had a silly sense of humor that helps get me through tough times in life. I also always look at the glass as half full. Now was no exception. I focused on moving forward and envisioned all the things I would do when I was well again. This gave me an incentive to get well and motivation to stay well.

I love giving of myself and helping others. This is my way of saying thank you for the opportunity to be well again. I am now done with all my treatment. Pain from the surgical sites remains, but I love to show off my new 'girls' as they look very flattering under my swimsuit. To help ease pain, I do aqua exercises.

Throughout my experience of being treated for breast cancer, I gained a real sense of satisfaction that I hung in there even though the pain during healing was unbearable at times. Before each surgery I prayed and attended services at my synagogue to ask G-d to watch over me during these challenging times. I amazed myself at my strength, not only while dealing with breast cancer, but throughout my entire cancer journey since 1992.

My birthday is quite a special day to me, and I celebrate each year by doing what I love most, taking a sewing or quilting class and having dinner with my family. I am blessed to be alive. I stay on top of my appointments and tests so I will be able to enjoy each birthday for many years to come.

➤ *Would you like to share your story? Email [editor@lbbc.org](mailto:editor@lbbc.org) to find out how.*

*“Although scared for my life, I knew I had to be strong. I rounded up my support team and off we went to the many scheduled oncology and surgery appointments.”*

# What if? Coping With Fear of Recurrence

BY NICOLE KATZE, MA



Carol LaRegina

**C**arol LaRegina, 60, of Raleigh, North Carolina, was diagnosed with triple-negative breast cancer at age 47. She would be diagnosed with a second new breast cancer 4 1/2 years later.

“The first time around, my ‘what ifs?’ weren’t as strong as the second,” she says. “But I was so worried about the cancer coming back that I was constantly doing self-exams. When you’re in treatment, life goes on and you see the light at the end of the tunnel. Then, all of a sudden, you’re done. It’s like being a child thrown out into the streets.”

Carol’s ‘what ifs?’—commonly called *fear of recurrence*—are a normal part of coping with breast cancer diagnosis and treatment. It’s natural to worry about breast cancer coming back or getting worse, and also for those concerns to last months to years after treatment.

Though fear can be strong at times, you can take actions to get through it in the moment, keeping it away for periods of time.

## About Fear of Recurrence

Fear of recurrence is not only normal but is to be expected, says **Hester Hill Schnipper, LICSW, BCD, OSW-C**, chief of oncology social work at Beth Israel Deaconess Medical Center in Boston and author of *After Breast Cancer: A Common Sense Guide to Life After Treatment* (Bantam, 2006). It can begin the moment you are diagnosed or at any time during treatment.

“It’s appropriate to feel this way,” says Ms. Schnipper, who was diagnosed with breast cancer in 1993 and 2005. “It’s also important to realize you’re not crazy. No doctor can ever say someone is cured of cancer. No one gets a guarantee.”

How fear of recurrence impacts you, and how often, can depend on your cancer experience as well as on your emotional health before diagnosis, Ms. Schnipper explains.

If you have a more advanced cancer or cancer that spread to the lymph nodes, had difficult side effects from treatment or have a type of cancer that doesn’t respond to ongoing therapies like tamoxifen, you may fear cancer coming back more strongly than others. Watching family members go through multiple rounds of cancer treatment, being a generally anxious person, having young children and other life factors also may lead to greater fear.

But fear should never be so strong that it overtakes your daily life, Ms. Schnipper says. Anniversaries of cancer milestones, birthdays, family gatherings or certain smells or tastes may spark fear, but that feeling should be less severe as time goes on. Triggers will likely remain, but you may not react as strongly to them as you once did.

“Look at yourself and remember: you’ve gone through treatment and lived,” Carol says. “What’s the point if you’re going to live your life in fear?”

“Look at yourself and remember: you’ve gone through treatment and lived.”



Emily Bahne

## What You Can Do

**Nykisha Gaines**, 38, of New Castle, Delaware, says, for her, keeping the fear at bay is about managing the messages around her. Diagnosed in 2012, she tries not to worry too much after finishing a year of chemotherapy.

“We tend to neglect our minds,” she says. “We tend to follow popular trends such as ‘be fit, be healthy’ that only focus on the body. The mind is just as important and needs attention as much as, if not more than, the physical body.”

Nykisha keeps a circle of positive people in her life and relies on her faith to help prevent negative feelings from arising. Like many people after a cancer diagnosis, Nykisha says she wants to end negative relationships and to take steps toward achieving emotional balance.

“You need people around you who will have a positive outlook on the situation. That’s the kind of vibe that you’ll benefit from,” she says.

But it’s not all about controlling how we think. As with breast cancer treatment, coping with fear of recurrence is personal, and everyone handles it differently. Ms. Schnipper offers this advice:

- Talk about your fears with someone you trust. Don’t suffer in silence.
- Learn more about the kind of breast cancer you have. For some people, having a deeper understanding of what’s happening to your body can be calming.
- Find the right people. Sometimes your friends or family won’t understand your worries, especially if you’re through treatment and doing well. A “cancer buddy”—someone who has gone through cancer, too—may be a better person to talk with.
- Follow the “2-week rule.” Everyday pains, cold symptoms or fatigue may lead you to worry that the cancer is back. Most of the time these issues are nothing serious, but the fear can be intense. The rule suggests you wait 2 weeks to see if a symptom goes away on its own. If it doesn’t, make an appointment to see your doctor to find out more.
- Try stress reduction techniques, such as exercise, meditation, yoga and getting more sleep. Reducing everyday stress can make you feel stronger and more confident.

Knowing the triggers—events, sensations, memories—that bring back your fears can also help. Ms. Schnipper says being aware of your them allows you to anticipate the start of fear, instead of being surprised by it.

Learning more about the cancer helped **Emily Bahne**, 33, a pediatric nurse practitioner and past oncology nurse in Fresno, California, handle her worries more easily.

“I deal with reading and statistics,” she says. “The Internet can be a scary place, but I needed to prepare myself before I went into my provider’s office. The most amazing thing is how people cope so differently.”

## When Is the Fear Too Much?

If you find you’re thinking about cancer all the time, crying most days, waking up at night with your heart pounding or not sleeping, you may be experiencing anxiety, not fear of recurrence.

“It shouldn’t be an intensely negative experience,” says Ms. Schnipper. “If you get to the point where you wonder if you should be talking with a professional, you probably should be.”

Talk therapists and social workers are good people to seek out for professional help. Your cancer treatment center may have these experts on-site. If it doesn’t, staff may be able to recommend professionals in your community.

In some cases, your health insurance provider will only pay if you choose from a list of professionals it provides. Try to select someone with experience working with people with cancer, or breast cancer specifically.

You may also consider joining a peer support group hosted by nonprofit organizations, hospitals, community centers or faith groups. Talking with people who relate to your experience can be empowering.

“Although science has come far, our stories are still the same. We’re all going through the same thing,” says Carol.

Ms. Schnipper recommends joining a group with a professional leader or moderator. In some peer-led groups it’s easy for conversations to take a negative turn and stay there. A moderator’s job is to steer the conversation back toward practical things you can do to move forward.

In most cases, fear of recurrence does not become true anxiety. The chances of developing it are greater if you have a medical history with anxiety or depression. If you haven’t experienced them before, it’s most likely that your own fear will fade and only resurface when something triggers it. Over time, other things in life may take the place of worry.

“I spend my time doing things that are meaningful and significant to me,” says Emily. “You can live a pretty good life in 6 years, and a pretty crappy one in 60. What’s most helpful to me is doing what I need to do to live well and up to my own standards.” 🌟

“Fear should never be so strong that it overtakes your daily life.”



Nykisha Gaines

# News & Education



BY JOSH FERNANDEZ

## Fall Conference: Just for You

Our revamped **Annual Fall Conference, Breast Cancer Today: Individual Treatment, Shared Experiences** features three tracks focusing on your unique experiences with breast cancer. The tracks are: hormone receptor-positive and HER2-positive, triple-negative, and metastatic breast cancer. Participate in one of the tracks or mix and match the sessions of your choice. The **Triple Negative Breast Cancer Foundation** partnered with LBBC to develop the TNBC track.

The event, to be held Saturday, September 27, at the Pennsylvania Convention Center in Philadelphia, also has sessions specific to young women, caregivers and others. Look for information on webstreaming, registration, travel grants and fee waivers at [lbbc.org/events/annual-fall-conference](http://lbbc.org/events/annual-fall-conference).

## LBBC Introduces New Board Chair and Members

LBBC has a new 2014 chair—**Barbara J. Yorke**. Ms. Yorke, a board member since 2011, has more than 20 years of experience helping businesses and nonprofits thrive.

Also new to the board: **Lyn Fitzgerald**, vice president, U.S. and global development, National Comprehensive Cancer Network; **Theresa Frangiosa**, principal and CEO, Frangiosa and Associates; **John McDonald, Esq.**, general counsel, Toll Brothers; and **Nivedita Singhal**, director of finance, pricing, Allied Barton. Welcome!

## Conference Recap

In April, our eighth **Annual Conference for Women Living With Metastatic Breast Cancer** drew nearly 300 attendees. Almost 200 joined our inaugural live Web stream of the plenary sessions. Watch the YouTube Web stream videos at [lbbc.org/metsconference](http://lbbc.org/metsconference).



## Young Women's Initiative

Our **Healthcare Provider Symposium: Understanding the Unique Needs of Young Women Affected by Breast Cancer**, a May 2014 pre-conference program to the Association of Oncology Social Work Annual Conference in Baltimore, Maryland, featured speakers from the medical and allied health fields who discussed strategies for providers to work more effectively with young women with breast cancer.

This summer, look for new installments in our **Let's Talk About It Video Series**. The new topics are body image, financial impact, and communicating with family and friends about metastatic breast cancer.

## New Series Coming Soon!

Our first **Breast Cancer in Focus** brochure is set to release this fall! For lesbians, gay men, bisexuals and transgender persons with breast cancer, it offers advice about ways to ensure you get the personalized care you deserve. Look for more new titles in the series later this year.

## Volunteer Awards and Training

This spring, **Lynn Folkman**, manager of volunteer programs, trained 31 new **Breast Cancer Helpline** volunteers to help give you emotional support, no matter where you live.

At our **Volunteer Appreciation Party**, held at honeygrow in Bala Cynwyd, Pennsylvania, we celebrated our local volunteers and honored five:

- The Ann Klein Volunteer Award—Caryn Kaplan and Tim Miller
- The Lee Plamondon Volunteer Award—Bev Parker
- The Paula A. Seidman Volunteer Award: Maureen Doron and Liz Barker

We thank all volunteers for helping support LBBC's mission!

## Changes on lbbc.org

[lbbc.org](http://lbbc.org) is now **mobile-friendly** for when you want breast cancer information on your smart phone or tablet.

Each page you visit now has a gold button reading "Terms Used on This Page," which takes you to our **Glossary**, adapted from the National Cancer Institute's Dictionary of Cancer Terms.

## Survey Update

Our **National Breast Cancer Survey** collected your responses so we could learn more about gaps in support needs.

- Among the differences we plan to explore:
- the needs of people diagnosed with triple-negative breast cancer versus other subtypes of breast cancer
  - those of people with metastatic versus early-stage breast cancer

We will also look at the results for a variety of other differences and will report them on [lbbc.org](http://lbbc.org).

Expect updates by early 2015.



# Beyond These Pages

BY JOSH FERNANDEZ

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



Download a print-friendly or full PDF, or order a print copy, of our *Guide to Understanding Fear of Recurrence*.

[lbbc.org/Understanding-Breast-Cancer/Guides-to-Understanding-Breast-Cancer](http://lbbc.org/Understanding-Breast-Cancer/Guides-to-Understanding-Breast-Cancer)



Listen to our Triple-Negative Breast Cancer webinar series **Part Two: Managing Fears of Recurrence** with Julie Larson, LCSW.

[lbbc.org/Events/2014-04-24-Triple-Negative-Breast-Cancer-Part-Two-Managing-Fears-of-Recurrence](http://lbbc.org/Events/2014-04-24-Triple-Negative-Breast-Cancer-Part-Two-Managing-Fears-of-Recurrence)



Download a PDF copy of our *Guide to Understanding Breast Cancer Treatment Research Studies*.

[lbbc.org/Understanding-Breast-Cancer/Guides-to-Understanding-Breast-Cancer](http://lbbc.org/Understanding-Breast-Cancer/Guides-to-Understanding-Breast-Cancer)



Read about open clinical trials.

[lbbc.org/Understanding-Breast-Cancer/Clinical-Trials-Research-Studies/Featured-Clinical-Trials](http://lbbc.org/Understanding-Breast-Cancer/Clinical-Trials-Research-Studies/Featured-Clinical-Trials)



Newly diagnosed with MBC? Learn more with our *Metastatic Breast Cancer Series*.

[lbbc.org/Understanding-Breast-Cancer/Metastatic-Breast-Cancer-Series-Guide-for-the-Newly-Diagnosed](http://lbbc.org/Understanding-Breast-Cancer/Metastatic-Breast-Cancer-Series-Guide-for-the-Newly-Diagnosed)



Get information just for you about metastatic breast cancer.

[lbbc.org/Audiences/Metastatic-Breast-Cancer](http://lbbc.org/Audiences/Metastatic-Breast-Cancer)



Register as a team captain or member for this summer's Yoga on the Steps: Kansas City or Yoga on the Steps: Denver.

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



Help support our programs by making a donation.

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

- **Phase II.** A slightly larger group of people, all with the same disease, get the study therapy to see how well it treats that disease. Researchers watch for side effects.
- **Phase III.** Because past findings show a therapy is likely safe and seems to be effective, a very large group of people is recruited so that the new treatment can be compared to standard treatments. The goal is to find out whether the new therapy is as good as, or better than, the one already in use.

Phase III clinical trials are usually *randomized*, which means a computer assigns participants to each treatment group. Having a computer select the groups gives everyone an equal chance of getting the trial therapy.

One common fear is that in a randomized study you won't get the approved treatment. Some people believe that if they aren't given the trial treatment, they won't receive treatment at all.

During phase III trials studying therapies for active treatment, researchers aren't allowed to give you no treatment, unless this is the standard of care for your disease. If you aren't receiving the trial medicine, you'll get the same treatment you would have had outside of the trial.

### BOARDS AND COMMITTEES FOR PROTECTION

One way participant safety during trials is monitored is through *Institutional Review Boards*, IRBs, teams of doctors, experts, researchers and sometimes community members, who decide whether a trial is safe. The IRB can stop a trial at any time if members feel participants are at risk.

*Data monitoring committees* serve the same purpose, but are made up mostly of scientists. A data monitoring committee can tell a sponsor to stop a trial for safety reasons or because members feel it won't lead to a useful result.

### Participant Safety

**Stacy Hansen**, 33, of Apopka, Florida, who has triple-negative breast cancer, is participating in a blind prevention trial of NeuVax, a vaccine developed to help prevent HER2-negative breast cancers from returning. In *blind* trials, neither the doctor nor the participant knows whether the participant is getting the trial medicine or the standard of care.

"It's a little annoying that it's blind, but I have a 50 percent chance of being in the group on NeuVax," Stacy explains. "Without joining the trial, my chance of having the vaccine was zero percent."

For people with triple-negative disease, clinical trials can offer a less sudden transition out of primary treatment. Unlike

hormone-positive cancers, triple-negative cancers do not have post-treatment maintenance therapy. Using a trial medicine may ease the common worry that there's nothing to protect you from a future recurrence.

"It can be scary as someone with TNBC because once you're finished with chemotherapy, you're done. You go from seeing doctors all the time to seeing them once a year. In the trial I see a doctor once a month," Stacy says.

### INFORMED CONSENT

Before you join a trial, you must first go through a process of giving *informed consent*, during which the research team or their coordinators talk with each participant about the details of the trial. You will learn about the benefits and risks of enrolling, financial costs, and how the study will be structured and monitored. In some cases, you may be asked to show the team you understand the information given. You should then be given time to think about whether to enroll.

**Barb Young**, 47, of Boyertown, Pennsylvania, took this approach before joining NSABP – B-49, a study comparing two different types of chemotherapy for HER2-negative, early-stage breast cancer. Barb has triple-negative breast cancer, which means it's negative for HER2 as well as estrogen and progesterone receptors.

"My oncologist recommended the trial to me but I didn't jump right in," says Barb. "I was worried at first, so I started asking questions. 'What's involved? What does joining mean for me and my health? Will I get the best care I can possibly get?'"

The research team and trial nurses took time to help Barb understand the trial before she made a decision.

"The trial nurse sat with me for a good half hour explaining all the details," she says. "Throughout the trial there was always someone there to guide me and make sure I knew what was happening next."

Many people report that during a clinical trial, doctors and staff are more involved in care coordination than they might be during regular treatment. In order for the data collected to be as useful as possible, each person's care must be handled almost exactly the same. Personal support staff, like trial nurses, are an important part of collecting the information needed so the study researchers can carefully analyze it.

Dr. Wickerham says the movement toward having strong staff support for participants is one way that clinical trials are becoming more sensitive to participants' needs.



Brooke Cole



Stacy Hansen



Barb Young

"Oncology has a very good reputation for supporting trials," says Wickerham. "The trial process is part of the residency and fellowship phases of oncology education."

### Accessing Clinical Trials

Clinical trials aren't just for people with metastatic cancers, though many people believe that's the case. The misconception comes from the belief that trials are a "last resort" meant for people who have tried many other treatments that haven't worked.

Today, many trials seek newly diagnosed people who have never had treatment in the past. These trials test medicines as *first-line therapies*, or the first treatment you receive after diagnosis. Many studies are available for those with metastatic breast cancer, too.

Your oncologist may suggest a clinical trial for you, as Barb Young's did. But if your doctor doesn't recommend one or know of any you might be eligible for, you can search for them yourself. Visit [clinicaltrials.gov](http://clinicaltrials.gov), a website run by the National Institutes of Health, to find studies open for enrollment. You can search for trials by breast cancer type, stage, or population needed. If your doctor isn't aware of open trials or seems unable to help you find one, try accessing listings on advocacy sites like [lbcc.org](http://lbcc.org).

If you are from a group underrepresented in trials, such as people under age 40 or over age 65, ethnic minorities or men with breast cancer, you can search for a trial seeking people like you. Living Beyond Breast Cancer also maintains a listing of clinical trials that can be searched by category.

**Brooke Cole**, 39, of Sanford, Maine, enrolled in a trial she found on [clinicaltrials.gov](http://clinicaltrials.gov) because she wanted to help future generations the way that past generations of trial participants helped her. As a woman with HER2-positive disease, she took trastuzumab (Herceptin), a medicine that wouldn't exist without successful clinical trials.

Brooke traveled from Maine to Baltimore, Maryland, once every 4 weeks for the first 7 months of a phase II vaccine trial (NCT00524277). She will now go every 6 months for the next 2–3 years. Though all medical costs were covered by trial sponsors, travel costs fell to Brooke.

Dr. Wickerham says this is one aspect of trials to be aware of. "It's important to know the costs of a trial, and that goes beyond the medical expenses to the time you spend and the costs of travel needed."

New legislation set forth by the Affordable Care Act requires that insurance companies cover the routine costs of participating in approved clinical trials. Many pharmaceutical companies also cover the medical costs if they are sponsoring the trial. The financial impact of joining a trial can be low if you can access one at a facility near your home.

For Brooke, the cost of travel was significant, but her commitment to research kept her going.

"We have to do this kind of research to get it done," Brooke says. "There have to be people, like me, willing to take part. If you can't travel and [a trial] is nearby, get involved and enroll. For me, it was an easy decision." 🌟

## Ask Your Peers

"What is one thing you wish you had known when first diagnosed with breast cancer?"



**Barbra Tugman, Boston, Massachusetts**  
"I wish I had known how important it is to have a caregiver. I was my own caregiver, which was so very hard. I don't recommend it to anyone, but I am so very proud of myself for staying strong and positive, fighting all day every day, and never, ever giving up."



**Candi Van Wagner, Doylestown, Pennsylvania**  
"I wish I had been told radiation therapy would limit or reduce the success of an implant and that chemotherapy could cause early menopause. I also wish I had been educated about testing for BRCA gene mutations."



**Julia, Hermosa Beach, California**  
"I wish I had known to bring someone besides a loved one to appointments to help me remember everything that they told me. You tend to only hear the word 'cancer,' and the rest is white noise."



**Angelique Collins, Stuttgart, Germany**  
"One mustn't fear exercise during or after treatment. In fact, some sort of physical movement can help relieve side effects of treatment and help accelerate recovery to our normal selves, help bolster self-esteem and remind us of all the wonderful things our bodies can still do. The greatest of these capabilities is to heal."



**Julie Ahrendt, Corvallis, Oregon**  
"I wish I had known there is time to make treatment decisions. I felt rushed to decide which treatment to do. Being a bit more educated first would have been helpful."

🌟 *What's the best way to tell others about your diagnosis? Let us know at [editor@lbcc.org](mailto:editor@lbcc.org).*

# PARTNER SPOTLIGHT Get Ready to DIY

BY KEVIN GIANOTTO



SSG's **Katherine Wright** played an instrumental role in putting together the 2013 event and has already begun planning for the 2nd Annual LBBC Charity Golf Tournament of 2014.

"The first time is the hardest, though 'hard' isn't exactly the right word," Ms. Wright says. "Maybe 'uncertain' is a better choice. But, working with an organization like LBBC, which is so well-respected and regarded, really helped engage people on a number of levels. Not only did we sell out of foursomes for the golfers—we still had tremendous turnout for the evening's cocktail hour and dinner, featuring our award ceremony, live auction and raffles!"

Regardless of size, events like these provide communities with information about the resources available to help people navigate life after a breast cancer diagnosis.

Being part of a DIY has benefits for LBBC—and for you. "The attention SSG received as host of the event was incredible. But, more importantly, the opportunity we had to spread the word about LBBC and the work they do to assist those in need was far more important," Ms. Wright says.

👉 *To learn more about how to host a DIY event in your home community, contact us at (855) 807-6386 to speak with LBBC's special events coordinator.*



Since Living Beyond Breast Cancer's founding, individual donors and grassroots fundraisers generously provided us with the financial stability to grow from a small, local organization into one of the country's most respected nonprofits serving people affected by breast cancer. LBBC's education and support services are now used by people in every state of the nation—people and their caregivers who depend on these resources as they navigate life after a breast cancer diagnosis.

As we've expanded the range and scope of our programs, we've often been asked by those who benefitted from them how they can help LBBC continue to provide services to those in need.

This summer, LBBC will introduce our new DIY, or "Do it Yourself," fundraising program. This program is for people interested in using their talents to raise awareness and funds for LBBC. It offers a "how-to" guide and online resources to aid in the organizing and hosting of community fundraising events regardless of size.

A perfect example of a DIY event occurred last fall, when LBBC volunteer and board member **Todd Sherman** enlisted the help of his friends and colleagues at the Sherman Sobin Group to host the inaugural LBBC Charity Golf Tournament.

"I became involved with Living Beyond Breast Cancer after being invited by friends to their annual gala," says Mr. Sherman, SSG's executive director and portfolio manager. "I was struck by the work this organization does, supporting women dealing with the disease. Last year, these same clients asked me if I would consider a position on the national board. At the time of the request, three of my friends were going through treatment. How could I say no?"

## DONOR PROFILE

# Kristin and John McDonald: Inspiring Involvement Through Giving



After **John McDonald** lost his mother, Ann, to breast cancer, he and his siblings knew that they needed to find a way to honor her and the extraordinary example that she set in her life.

"Mom's kindness, generosity, courage and grace were an inspiration to her family, friends, neighbors, co-workers and even the medical staff that treated her," says John.

In the first year after Ann's death, the McDonald family decided to combine their passion for sports with a charity fundraiser in her name. With the help of John's wife **Kristin** and her family, they created a basketball tournament to raise money for breast cancer causes.

"My family used our common passion for basketball to get together once a year with our friends and relatives and engage in a competitive, all-ages tournament that raised thousands of dollars."

The Ann N. McDonald Memorial Basketball Tournament became an annual tradition and, as John calls it, his "favorite day of the year." After raising money for other charities for a few years, John wanted a change. He and Kristin were raising a family in Philadelphia and wanted their event to be connected with a locally based organization with a personal, unique and caring approach to those affected by the disease. They learned about LBBC and admired LBBC's mission of connecting people with trusted breast cancer information and a community of support.

"In September 2012 I wrote a letter to [**Jean A. Sachs, LBBC's chief executive officer**] about Mom, her life and her valiant battle with breast cancer, and enclosed about 50 checks from that year's tournament," John said.

Jean sent a lovely personalized letter back. "That really had an impact on John," says Kristin, "At that point he was hooked on Jean and LBBC."

A month later, the couple went to the 2012 Butterfly Ball, our annual gala, and met Jean for the first time. The evening's events reinforced to John and Kristin that they chose the right place to give their time, commitment and support. Just after, they enthusiastically accepted Jean's request that they chair the 2013 gala alongside **Joe and Lynn Manko, Jeanne and Mike Egan and Donna and Barry Feinberg.**

Last October, Toll Brothers, a company based in Horsham, Pennsylvania, where John serves as general counsel, and its founders **Bob and Jane Toll** generously supported The Butterfly Ball.

The company continues to support LBBC by holding awareness activities to raise money for Breast Cancer Awareness Month. Kristin's family business, Pocono Profoods, has also offered support by donating food for Yoga on the Steps, LBBC's signature fundraising and awareness event.

John joined the board of directors in December, and 2014 will be the third year the McDonalds donate the proceeds of the tournament to LBBC. They continue to engage others with LBBC—one friend who came to The Butterfly Ball last year now serves on the planning committee with Kristin.

"We believe in LBBC's mission. Their comprehensive approach is so necessary to those affected by breast cancer, and they make every penny count by ensuring 86 cents of every dollar goes to the cause," Kristin says. "LBBC appreciated us getting involved and opened us up to more opportunities."

The McDonalds value the quality and commitment they've encountered with LBBC, and encourage others to give support in any way they can.

"When we hear stories of why others get involved, we realize the tremendous ways they are inspired by what LBBC is doing," Kristin says. "Once you're in, you're in—LBBC is like family." 🐛

“Once you're in, you're in—LBBC is like family.”

# SUMMER 2014 Calendar

## Educational Programs

### WEBINARS

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

JULY 25, 2014

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

AUGUST 11, 2014

**Hereditary Breast Cancer**

### COMMUNITY MEETINGS

Check [lbbc.org](http://lbbc.org) for events in the Denver, Kansas City and Philadelphia areas

## Conference

SEPTEMBER 27, 2014

**Annual Fall Conference**  
Philadelphia, Pennsylvania

## Special Events

JULY 20, 2014

**Yoga on the Steps:** Kansas City, Missouri

SEPTEMBER 13, 2014

**Yoga on the Steps:** Denver, Colorado

OCTOBER 18, 2014

**The Butterfly Ball**  
Philadelphia, Pennsylvania

Check [lbbc.org](http://lbbc.org) for the latest event information

# THANK YOU TO Our Donors

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# Insight

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SUMMER 2014



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LIVING BEYOND  BREAST CANCER



## ANNUAL FALL CONFERENCE

# Breast Cancer Today: Individual Treatment, Shared Experiences

**Saturday, September 27, 2014** Pennsylvania Convention Center

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