



## CLINICAL TRIALS:

# What They Are, Who Participates and Why It Matters

BY ERIC FITZSIMMONS



Kathy Conway

Changes to standard treatment in the last 50 years have dramatically changed breast cancer care.

“When I started medical school in the early 1970s, the treatment of breast cancer was simple: Everybody had a radical mastectomy,” says **Lawrence Wickerham, MD**, the deputy chair of NRG Oncology, a nonprofit research organization. Radical mastectomy, a surgery that was common for nearly 100 years, cut away the entire breast, the chest muscles underneath and all the nearby lymph nodes.

“Today, our [medical] residents have never seen a radical mastectomy,” Dr. Wickerham says. “They’re just not done.”

Surgeries that remove less tissue and tailored medicines for particular types of breast cancer have replaced radical mastectomies. And like all treatments, they were first proved safe and effective in clinical trials.

Clinical trials are studies carried out in people to learn more about diseases, like breast cancer, and their treatments. Clinical trials for breast cancer often explore

- new treatments
- new combinations of existing treatments
- the order treatments are given
- the dose and timing of treatment
- how a treatment is given (by mouth or by vein, for example)
- quality of life

## About Clinical Trials

Many people worry about getting untested treatments. But trials come in different types and phases designed to identify safety issues and protect participants as much as possible.

For treatment trials, researchers must first find strong evidence, through lab experiments, that the treatment might work. Then they can run a phase I clinical trial in people. Phase I trials recruit up to 30 people and look for unexpected side effects. In phase II, researchers measure how well the treatment works in a larger group, usually fewer than 100 people, while still tracking side effects. Phase III treatment trials recruit hundreds or thousands of participants. They compare the study treatment to a standard treatment, and are often the last step before approval from the U.S. Food and Drug Administration.

Trials can be randomized, meaning a computer assigns people to a group getting standard therapy, called the control arm, or one getting the study treatment. Randomization increases accuracy by spreading other factors that could affect a person’s health evenly among the groups.

*Continued on page 7*

## INSIGHT STAFF

Erin Rowley, *Editor*  
Susan FitzGerald, *Contributing Writer*  
Eric Fitzsimmons, *Staff Writer, Programs*  
Kirstie Kimball, *Staff Writer, Advancement*

## LBBC STAFF

Jean A. Sachs, MSS, MLSP  
*Chief Executive Officer*

Jessica Albano  
Kathy Arocho  
Lynn Folkman Auspitz  
Emily Bamforth  
Jessica Betts  
Joanne Bursich  
Jamie Cohen  
Catherine Cutuli  
Bernadette Foy  
Amy B. Grillo  
Janine E. Guglielmino, MA  
Melissa Hamilton  
Arin Ahlum Hanson, MPH, CHES  
Nicole Katze, MA  
Vicki Klopp  
Kendra Lawton-Ajuba  
Kristen Leinheiser  
Kira Mabry  
Ingrid Mapanao  
Sandra E. Martin  
Becky Mastin  
Mary Beth Mills, MS  
Catherine Ormerod, MSS, MLSP  
Sharon Sood  
Celeste C. Terrinoni, CPA  
Christine Ware, MEd

Laura Kowal, MPT, JD  
*Chair, Board of Directors*

Barbara J. Yorke  
*Immediate Past Chair, Board of Directors*

Living Beyond Breast Cancer's *Insight* newsletter is designed for education and information purposes only. The information provided is general in nature. For answers to specific healthcare questions, consult your healthcare provider, as treatment for different people varies with individual circumstances. The content is not intended in any way to substitute for professional counseling or medical advice.

## LIVING BEYOND BREAST CANCER®

40 Monument Road, Suite 104  
Bala Cynwyd, PA 19004

**Breast Cancer Helpline**

**(888) 753-5222**

**Tel: (855) 807-6386**

**Fax: (610) 645-4573**

**Email: [mail@lbbc.org](mailto:mail@lbbc.org)**

**Website: [LBBC.ORG](http://LBBC.ORG)**

**Blog: [lbbc.org/blog](http://lbbc.org/blog)**

 [facebook.com/  
livingbeyondbreastcancer](https://www.facebook.com/livingbeyondbreastcancer)

 [@LivingBeyondBC](https://twitter.com/LivingBeyondBC)

 [Instagram.com/livingbeyondbc](https://www.instagram.com/livingbeyondbc)

 [youtube.com/LBBC1991](https://www.youtube.com/LBBC1991)

 [pinterest.com/livingbeyondbc](https://www.pinterest.com/livingbeyondbc)

Design: Masters Group Design

## Dear Friends,

In this issue of *Insight*, contributing writer Susan FitzGerald writes in *Breast Cancer Anniversaries: Finding What Works* about a woman who “observes her cancer anniversary in the same spirit as some people do New Year’s Day. It is a time to look backward and forward, to reflect ... and to set goals for the months ahead.”

At LBBC we’re also looking backward and forward. Being deeply responsive to your needs is a core value for us. And in the past few years we’ve carefully used technology to deliver more programs to more people, while staying true to that deep responsiveness captured in our in-person programming. Two examples from 2017 come to mind. Our Breast Cancer 360s take place in front of a live audience, but we also use live web streaming to reach more people with our brand of trusted information. They feature a panel discussion that deeply examines one issue from the perspectives of healthcare experts and people impacted by breast cancer — the other kind of expert. Importantly, this program takes questions from people in the live audience and from those watching live on the web. Another program that comes to mind is our Breast Cancer Helpline. Earlier this year, we relaunched it as a matching service, allowing you to request a match at [lbbc.org/helpline](http://lbbc.org/helpline) so you can speak with a trained volunteer who has a similar experience to you, whether that be diagnosis type, stage, age or concern. These innovations — in newer programs, and mature ones — are allowing us to reach thousands more people every year.

As the new year unfolds, I invite you to take part in our in-person and online programs. Make sure you let us know how you feel we are meeting your needs for education and support! We look forward to continuing to serve you.

Wishing you a happy and healthy 2018,



Jean A. Sachs, MSS, MLSP  
CEO



## In This Issue

- 1 Clinical Trials: What They Are, Who Participates and Why It Matters**
- 3 My Story: ‘As Long as my Family Is With Me, I Will Always Have Support’**
- 4 Breast Cancer Anniversaries: Finding What Works for You**
- 6 News & Education**
- 10 ‘Farm-to-Table’ Butterfly Ball Raises a Healthy Amount of Support**

# ‘As Long as my Family Is With Me, I Will Always Have Support’



Sophia K-Franklin

BY SOPHIA K-FRANKLIN

*Sophia K-Franklin, 51, from St. Albans, New York, is an LBBC Community Connector. This program provides the tools and training to help volunteers use their personal breast cancer experience to make a difference in their communities.*

In October 1998, while I was 7 months pregnant, I felt a lump in my right breast. When I arrived at work the next day, I shared my discovery with my dear friend Bette, who later became my daughter’s godmother. We went in the ladies’ room and I disrobed. She felt it and said, “It’s hard but don’t worry. When you go for your prenatal care appointment, let the doctor know so he can check it out.”

I shared my discovery with my doctor. She too said, “Not to worry, it’s probably your milk ducts getting ready to produce milk so you can breastfeed.” Still, she scheduled an appointment for me with a surgeon.

I went back to work eager to tell Bette what had happened. She was waiting for me with a prayer and my favorite hot chocolate to drink. She said we would get through this together.

My appointment with the surgeon was in November. He stuck a long needle into my lump and extracted fluid. He told me to go have my baby and that he would see me after the baby was born, in about 4 weeks.

My beautiful baby girl, Lena Monay Franklin, was born December 22, 1998. We came home on Christmas Eve. I wrapped her in a pink blanket and put her under the Christmas tree. She was the best Christmas present my family had ever received, especially for my husband Tommy (now deceased) who had his little princess.

Lena was here but I still had the lump in my breast. The surgeon had scheduled me to have a mammogram. I had never had one before, since I was just 33. Everything I read stated I didn’t need one until I was 40.

I was on maternity leave, thinking I would enjoy it with Lena, but that changed. I hired a neighbor to babysit Lena while Tommy took me to my mammogram appointment.

I didn’t share any information with my family and friends until I had something to tell them, and boy, did I. On January 8, 1999, while sitting in my doctor’s office with Lena in my arms and Tommy by my side, I heard, “You have carcinoma of the right breast.” I said, “What is that? I just had a baby. I want to live.”

Once we got home and I put Lena in her bassinet, Tommy began to cry. He blamed himself, saying that because he smoked cigarettes around me I got cancer. It didn’t help that his mother had cervical cancer and his sister had breast cancer. I told him, “No, it was just my time.”

Next I called my family and shared the information with them. I have five sisters and three brothers. It wasn’t easy telling my sisters. My younger sister Sabrina understood the most. She didn’t ask me a lot of questions. She just said, “What do you need me to do?” She took off a week from her job and came and stayed with me to help with Lena. Bette came to visit me and took Lena to her house on the weekends so I could get some rest once I started chemotherapy.

I returned to work for a month and then took time off in February 1999 to have a biopsy and lumpectomy. In April 1999, to have more surgery, I left work as part of the Family and Medical Leave Act (FMLA), which gives certain employees the right to take up to 12 weeks of unpaid job-protected leave. But because I had saved my paid time off, I was able to keep getting paid while I was out. I had my mastectomy on a Wednesday and was home by Friday. It was Good Friday to be exact. I returned to work in May and kept working while getting chemotherapy.

I walked in all the breast cancer walks in Manhattan. Bette was the CEO of my walk team, which she named “Sophia’s Our Choice.” My colleagues, friends and family joined the team, too. Lena took her first steps at a breast cancer walk. Some of my family and friends told me I helped them understand what breast cancer was really about and how chemotherapy affects your body. I told them that they helped me get through it.

Eighteen years later I am still thriving and “living beyond breast cancer.” As long as my family is with me, I will always have support. 🍌



Sophia’s daughter, Lena, at 3 days old



## BEYOND THESE PAGES

Learn more about LBBC’s Community Connectors at [lbbc.org/communityconnector](http://lbbc.org/communityconnector)

## BREAST CANCER ANNIVERSARIES:

# Finding What Works for You

BY SUSAN FITZGERALD



Yvonne McLean Florence



Diane Cooney

**D**iane Cooney, 53, an accountant from Horsham, Pennsylvania, goes to Aruba every year on the anniversary of her last day of radiation: January 23, 2015. Diane can tick off other dates, like July 8, when she received a diagnosis of hormone receptor-positive stage III breast cancer, and November 14, when she had a bilateral mastectomy. But the day when active treatment was behind her means the most.

“I count myself as a survivor from that point on,” says Diane, who also bought a motorcycle to celebrate the end of treatment. “I am not the same person I was before I had cancer.”

Many people who have dealt with cancer mark milestones or “cancerversaries.” They might take note of their date of diagnosis, the day they completed chemotherapy, or the day their doctor told them scans showed “no evidence of disease.” Some people take time for personal reflection or a ritual such as lighting a candle, while others prefer doing something festive.

“I think some people are drawn to a certain date and it is very important to them,” says **Jennifer Bires, LICSW, OSW-C**. Ms. Bires is a social worker and the executive director of the Smith Center for Healing and the Arts, in Washington, DC. “For some people the date is hard. They are so glad to be back to normal, and it is something they don’t want to pay attention to. Some people hold it close to them and don’t tell anyone that it’s an important day. I don’t think there is a right or a wrong way of doing it.”

## Conflicting Emotions

**Yvonne McLean Florence**, 55, of Yeadon, Pennsylvania, was ready for a celebration when she was 1 year out from treatment. So she hosted a “pink party” at her house for family, friends and others who had also faced breast cancer. The guests wore pink, the decorations were pink and the food, including watermelon and a cake, matched the theme.

“I was very thankful that I had no evidence of cancer,” says Yvonne, who was diagnosed in 2012 with HER2-positive stage III breast cancer.

In the years since her party she has lost some friends to breast cancer, so she now observes her anniversary quietly, taking time to think of others who are in treatment and who have also shared her experience.

Social workers and counselors who work with people with breast cancer say there can be value in marking certain dates. But anniversaries can also cause distress. **Lindsay Chisholm, LCSW**, an oncology social worker at Rocky Mountain Cancer Centers, in Denver, Colorado, often sees people who feel conflicted about their anniversaries.

“I see more patients feeling hesitant because the reality is that their life has changed, their view of what the world looks like has changed,” she says.

## Metastatic and Trying ‘to Live as Normal a Life as Possible’

Anniversaries may feel different for people living with metastatic cancer because the disease is never behind them.

**Dikla Benzeevi**, 47, of Los Angeles, has had stage IV breast cancer for a decade-and-a-half. She volunteers as a peer mentor and patient advocate within the metastatic breast cancer community. To recognize the 15-year anniversary of her diagnosis, she celebrated over a low-key dinner with family and a few friends. She also reveled in hearing from loved ones who, at her request, shared photos from the previous 15 years and made her feel “a lot of joy and support.”

Despite the physical and financial toll of her disease, Dikla says she tries “to look on the bright side” at her diagnosis anniversary because “I am grateful to be alive.” She hopes that in acknowledging how long it’s been she sends a positive message to others that it’s possible to achieve “thrivership.”



Dikla Benzeevi

She also hopes to bring attention to the need for more research for metastatic breast cancer, focused on long-term survivorship with good quality of life.

“There are more people living with metastatic breast cancer for a longer period of time now,” she says. “We don’t always speak about it because we want to live as normal a life as possible.”

## Talking to Loved Ones About Cancerservaries

Every year when the anniversary of her diagnosis with stage III triple-negative breast cancer comes around, **Sally Teltow** slips away for a couple of days alone. She observes her cancer anniversary in the same spirit as some people do New Year’s Day. It is a time to look backward and forward, to reflect on what she’s accomplished and to set goals for the months ahead.

“It’s a mental health weekend,” explains Sally, 50, an IT engineer and blogger from Austin, Texas. “I take time away from my household, my husband and children to think. ‘I had another year, another year of experiences. Have I used the time wisely? Have I made those meaningful memories?’ And then I think of what I want to do next.”

Sally, who is 6 years past diagnosis, uses the getaways to feel grateful for people who have helped her deal with breast cancer. At her 5-year cancerservary she threw a “thank you” party for her loved ones. A happy, upbeat person by nature, Sally also makes a point during her annual time alone to acknowledge the cancer-related fear, anger and sadness that occasionally nags at her.

“When you’re surrounded with family and loved ones it is difficult to show all the negative emotions because it’s hard on them to see it,” says Sally, who has two sons, ages 10 and 16.

Not everyone in your social circles may be on the same page when it comes to cancerservaries, and that can be upsetting, Ms. Chisholm says. If an anniversary is important to you and loved ones forget it or don’t want to talk about it, that can be hurtful. But it can also be hurtful if you want to ignore the day or privately recognize that time has passed while loved ones want to talk about it. Ms. Chisholm encourages people with a history of breast cancer to advocate for what they need.

“Finding someone you trust and you can share your feelings with, in an authentic way, can be very healing and assist a person in moving through some of the emotions that come with anniversaries,” she says.

## Finding What Works

Ms. Chisholm says it’s common for people, like Sally, to mark the end of treatment or a cancer anniversary by saying “thank you” to those who took care of them or supported them. For others, expressing themselves through journaling or artwork may be the ideal way to recognize the occasion.

Connecting or reconnecting with a breast cancer support group or individual counselor may be helpful. Mindfulness, the practice of focusing on the present moment and accepting your thoughts or feelings without judgment, is another good strategy.

“It helps to create a space where you can unmask your humanness and say, ‘I am excited and grateful, but I am also nervous and scared,’” Ms. Chisholm says. “You can have joy, you can have distress. You can have it all together at once.”

At one point, Yvonne created a poster to chronicle her experience with breast cancer, and she found it therapeutic. For a while she kept the poster, which is filled with photos of her during treatment, within easy sight in her home. But she recently moved it to her basement office because she was concerned it might make some visitors feel uncomfortable. Yvonne says the poster continues to be a personal reminder of how far she’s come since diagnosis.

As more cancerservaries go by, you may experience less fear of recurrence. But that isn’t true for everyone, and it doesn’t mean thinking about the impact of cancer on your past or future is over.

Yvonne still has anxiety when she goes to the doctor for test results. She says getting further away from frequent checkups is reassuring, but “the thought of not having those extra eyes to monitor me does not put me in a celebratory mood.”

Yvonne says she’s come to realize that cancer anniversaries are important to acknowledge, though it’s up to an individual to choose how to honor them.

“My advice to other survivors is to celebrate life every day because the milestones and anniversaries may come and go,” she says. 🍌



Sally Teltow

# News & Education

BY ERIN ROWLEY



## Meet Your Match

Our **Breast Cancer Helpline** provides you with emotional support, guidance and hope from a trained volunteer who has been diagnosed with breast cancer. Whether you are recently diagnosed, in treatment, years beyond treatment, living with metastatic breast cancer, or a caregiver of someone impacted by breast cancer, you are not alone. We're here to help.

After you fill out a form online, we will match you with a trained volunteer who has a similar experience to you, whether that be diagnosis type, stage, age or concern. When you're ready to talk, we're ready to listen.

Visit [lbbc.org/helpline](http://lbbc.org/helpline) for more information and to fill out an online match form or call us at (888) 753-5222.

## Save the Date and Make Your Voice Heard

Our annual Conference on Metastatic Breast Cancer brings hundreds of people together every year to connect, learn and make their voices heard. We hope you'll join us for the 2018 conference, April 20 to 22, in Philadelphia.

To learn more about **Thriving Together: 2018 Conference on Metastatic Breast Cancer**, visit [lbbc.org/2018MBCconf](http://lbbc.org/2018MBCconf).

As in the past, we will train a class of **Hear My Voice** volunteers at this conference. Our Hear My Voice volunteers are dedicated advocates whose outreach activities educate their communities about stage IV breast cancer.

To learn more about this program, and how to apply, visit [lbbc.org/hearmyvoice](http://lbbc.org/hearmyvoice).



## Preventing Recurrence and Dealing With Fear of the Cancer Coming Back

We know many people want more information about preventing recurrence and about methods to cope with the fear of cancer coming back.

Our **Breast Cancer 360** program, **Keeping Cancer at Bay: What Researchers Are Learning About Recurrence**, took place in November. Our panelists explored what we know about why breast cancer recurs, which tests doctors use to monitor you for recurrence and what you can do if you are at a high risk for recurrence, including exploring clinical trials and making changes to your everyday life to support good health.

Our December webinar, **Coping With Fear of Recurrence**, explored the powerful effect this fear can have on the quality of your life and provided coping strategies for dealing with it.

For resources from these programs, visit [lbbc.org/recurrence](http://lbbc.org/recurrence) and [lbbc.org/recurwebinar](http://lbbc.org/recurwebinar).

## Connect With Our Young Women's Initiative and Get Support

Living Beyond Breast Cancer's **Young Women's Initiative (YWI)** has grown a lot this year. Enrollment in our **YWiConnect** program grew 40 percent in 2017! YWiConnect provides people diagnosed with breast cancer before age 45 with text message updates on new resources and upcoming programs. The service is provided for free (message and data rates may apply in some cases) and sends out 2 to 4 texts per month. A subscriber recently told us, "It's the greatest program I've found — even better information than I get from my oncologist."

Our **YWI Facebook group** has also grown by 40 percent, and has more than 1,100 members. The group is a place where you can connect with other young women across the country, share resources and get support. Leadership volunteers take turns as monthly hosts, encouraging conversation and providing peer support to the group's members. This is a great way to find out about our unique resources and upcoming programs for young women in a closed Facebook group setting.

Visit [lbbc.org/youngwoman](http://lbbc.org/youngwoman) to learn more about our Young Women's Initiative or to sign up for either of these programs. 🍌

## Clinical Trials: What They Are, Who Participates and Why It Matters (continued from page 1)

Trials also may be blinded, meaning you and your doctor may not know whether you are getting the study or the standard treatment. In a double-blind study neither you nor the healthcare team knows. In a single-blind study, the doctor knows but you do not. In an open-label study, both you and your care team know what you are taking.

Not all research assigns and compare treatments. Observational studies collect data about people and their health by sending them surveys or looking at medical records. Other clinical trials study medical tests, fitness programs, diets, complementary therapies, and more.

**Kathy Conway**, 60, of Wilmette, Illinois, was diagnosed in 2009 with stage III hormone receptor-positive breast cancer. Her doctor recommended a clinical trial. She agreed to a phase III double-blind, randomized trial testing how a newer medicine worked in breast cancers with a high risk of metastasizing.

For her trial, Kathy got standard chemotherapy by vein. Then she was given another medicine: She did not know at the time if it was the study medicine or a placebo, something that looks like the treatment but has no active medicine. She felt disappointed when she learned she received the placebo, but she still sees the trial as a positive experience. She got the treatment she needed and helped researchers better understand the study medicine. She went on to participate in other studies, too.

In all trials, researchers closely watch the health of participants. If you start experiencing treatment side effects, the study doctors may adjust your dose, or if the effects are too much, suggest you discontinue the study treatment. Researchers will still be able to use data from your participation even if you and your doctors decide you should stop taking the medicine, but you have the right at any time to remove yourself and your data from the study if you wish.

## On Getting (and not Getting) Participants

A big challenge for researchers is finding enough people to participate in clinical trials. Only 3 percent of adults with a cancer diagnosis participate in clinical trials. But getting meaningful results requires a large number of participants. Trials also need people with diverse backgrounds, since factors like ethnicity, weight and income can affect results.

Far fewer people with lower incomes enroll than those with higher incomes. Racial and ethnic minority women are also less likely to participate. There are many possible reasons, Dr. Wickerham says, from bad past experiences to practical challenges such as paying for childcare or transportation to get to appointments.

Many trials are run by large research hospitals in major cities. This puts trials out of reach to some in rural areas and smaller towns or cities.

“The problem still exists but we improved upon things,” Dr. Wickerham says. “They’re still done in those places but ... now patients can enter [some] clinical trials in their communities.”

As a patient, finding the right trial can be a challenge. Clinical trials can have requirements related to your age, menopausal status, diagnosis, genetic mutations, past treatments and other health conditions.

Other challenges include access and costs. You may be able to keep your current healthcare team, or you may have to see doctors at a different location. Trials may require extra time or visits. Some costs may be covered by the trial. The research team can tell you what’s needed.

---

***Only 3 percent of adults with a cancer diagnosis participate in clinical trials. But getting meaningful results requires a large number of participants. Trials also need people with diverse backgrounds, since factors like ethnicity, weight and income can affect results.***

---

Most people who enroll in clinical trials learn about them from their doctor, but **Elly Cohen, PhD**, program director of BreastCancerTrials.org, says you can take action if you are interested. Start by telling your doctor, so he or she can see if any are available for you. Look at resources like BreastCancerTrials.org, which allows you to find trials that match your situation, or ClinicalTrials.gov, a database of most open trials.

## Easing Concerns

Another obstacle: earning people’s trust in the process. This is especially true for African-Americans and other minority groups who were taken advantage of in past clinical trials.

In the Tuskegee Syphilis Study, hundreds of African-American men were lied to over 40 years, from the 1930s to the 1970s. Of the 600 men enrolled, 399 had syphilis. The men were told they were being treated for “bad blood” but were denied proper treatment. By the time the trial was brought to people’s attention in 1972, seven men had died of syphilis, and many more suffered and died of issues linked to the disease.

**Sonnetta Jones**, 41, of New Brunswick, New Jersey, was diagnosed with stage II triple-negative breast cancer in May 2013. Her doctor suggested a clinical trial for a medicine showing promise for early-stage breast cancers like Sonnetta’s. But Sonnetta was reluctant.

“I remember reading about [Tuskegee]. I was so angry. I was like ‘How can we test [on] these people and not have them be aware of the dangers?’” Sonnetta says. She worried she would receive a placebo instead of active treatment.

Concern about getting a placebo is common, according to Dr. Cohen, and springs from people not knowing today’s trial process. People in the control arm, the group that does not get the treatment under study, may be given a placebo. But it is always in addition to a standard treatment. Your treatment with the placebo must be as good as the treatment you can expect outside the trial.

To put her mind at ease, Sonnetta’s doctors brought in the study researchers to explain it and answer her questions. They went over the safety measures and her rights as a participant. The discussion eased Sonnetta’s concerns, but it wasn’t until she later read an article they provided that she decided to enter the trial.

In the article, “they were speaking about African-Americans and [how] they need more of us to be involved in clinical trials because they need to figure out why cancer is so aggressive in our bodies,” Sonnetta says.

Studies show breast cancer is more likely to be diagnosed at a later stage and more likely to be triple-negative in African-American women, Dr. Cohen says.

For Sonnetta the article was a sign that she should join the trial, a decision she is happy with after treatment with the trial medicine shrank the tumor before she had a lumpectomy.

---

***Clinical trials are now designed and reviewed by experts before they enroll participants. They must be approved by institutional review boards, made up of doctors and people outside medicine, often administrators, religious leaders, ethicists or lawyers.***

---

“Everybody wants the best possible care for themselves, or their friends or family, and I often tell them clinical trials fall into that category,” Dr. Wickerham says.

Dr. Wickerham points to today’s institutional standards and oversight. Clinical trials are now designed and reviewed by experts before they enroll participants. They must be approved by institutional review boards, made up of doctors and people outside medicine, often administrators, religious leaders, ethicists or lawyers. Their role is to oversee the study in the interest of its participants.

And before enrolling, you must give informed consent. This means researchers must talk to you about the details of the trial, including its benefits and risks, any financial costs, and how it will be structured and monitored. Once enrolled in the study, you can choose to leave it at any time.



Sonnetta Jones

## Targeted Therapies and New Formats for Trials

A recent trend in clinical trials is to focus on characteristics of the person or the cancer, according to Dr. Wickerham. A study may focus on postmenopausal women, HER2-positive breast cancers, or gene mutations.

“The benefits of the targeted therapies [is that] they have the promise of being far more effective [in certain people],” Dr. Wickerham says. But recruiting enough people with a specific feature can be difficult.

Researchers have responded by using new formats. Umbrella trials focus on breast cancers with unique features, such as certain genetic mutations. These trials have multiple arms, each testing a different treatment. It allows researchers to test more than one treatment at a time.

In basket trials, people with any type of cancer that shares a certain feature or behavior are enrolled in one trial, no matter where the cancer started. People with breast cancer may be enrolled in the same trial as people with lung or colorectal cancer, all testing the same treatment. This type of trial resulted in pembrolizumab (Keytruda) becoming the first medicine approved based on the way it treats a genetic feature of cancer, not on where the cancer is located.

## Benefits of Clinical Trials

The benefits of clinical trials to you and to cancer research can be significant. **Pat Hazebrouck**, 59, from Millville, Massachusetts, was diagnosed with metastatic breast cancer in 2015. She was first treated with chemotherapy pills, but by summer 2016 the cancer had grown. Hoping to delay the move to chemotherapy by vein, her doctor suggested a phase I clinical trial exploring another type of chemotherapy and a medicine called a cyclin-dependent kinase inhibitor, both taken as pills.

As with any cancer treatment, these new medicines had side effects. Doctors lowered the dose for one medicine because it affected Pat's kidneys. After that, she had few other side effects. She continued to work part-time as a nurse throughout the trial, which she stayed in for just over a year before the cancer grew again.

Not all medicines in clinical trials succeed. The trial may find the new medicine does no better than current medicines. Even if the medicine meets goals set out by the researcher, it may not work for you. Your healthcare team will watch and change your treatment if the cancer does not respond. If the treatment does not work in many people or causes severe side effects, the review board will stop the trial.

Pat was happy to put off IV chemotherapy for another year. She now receives chemotherapy by vein, but plans to enroll in other clinical trials when she finds the right one.

What most excites Pat is helping researchers learn more about breast cancer and possible new treatments. 🐾



Pat Hazebrouck



### BEYOND THESE PAGES

In early December, LBBC copy editor and content coordinator Eric Fitzsimmons attended the San Antonio Breast Cancer Symposium and reported on medical research that was presented there. Find his coverage on [LBBC.ORG](http://LBBC.ORG).

## Ask Your Peers

*What do you do to ease lymphedema symptoms?*



**Karla Dautenhahn, 59**  
**Overland Park, Kansas**

"I do lymphedema therapy weekly, use a compression pump daily, and wear a compression sleeve and glove when I am not wrapping. I wrap at night or wear a special night sleeve. I did pretty well for a couple years but had foot surgery in May and have been having trouble again with swelling. I am back to wrapping daily and trying my best to get it under control again. It is a lifelong disease and needs to be treated constantly."



**Jennifer Wilburn, 67**  
**Pittsburgh, Pennsylvania**

"My doctor told me the swelling would go down as I lost weight, and it has. I go to a seminar every year about lymphedema and it keeps me informed on options to treat the condition."



**Janet Kifarkis, 39**  
**Glenview, Illinois**

"I always wear my sleeve when I clean the house, I don't lift anything heavy, I wear my purse on my other shoulder, and I do daily stretches. I do my own manicures and apply Neosporin if I have a cut on that arm. When I travel, I wear my gauntlet, too."

🐾 How do you remember to take your medicine? Let us know at [editor@lbbc.org](mailto:editor@lbbc.org).

# ‘Farm-to-Table’ Butterfly Ball Raises a Healthy Amount of Support

BY ERIN ROWLEY

More than 620 supporters came together at the annual Butterfly Ball, Living Beyond Breast Cancer’s biggest night of the year, on November 11, 2017, in Philadelphia. The evening honored five individuals who have demonstrated a commitment to serving those living with breast cancer, as well as LBBC. Overall, the Butterfly Ball raised more than \$950,000, which will help LBBC continue to fulfill its mission that no one impacted by breast cancer feel uninformed or alone.

This year’s gala helped attendees feel good while doing good. LBBC and gala co-chairs **Linda and Jonathan Brassington**, **Katy and Jason Friedland**, **Jennifer and Samuel Goldfarb**, and **Susie and Steve Krupnick** designed a “green” evening at the Loews Philadelphia Hotel that emphasized how healthy options can taste good. The event featured cocktails with antioxidant-rich mixers, centerpieces including native greenery and edible plants, and a menu of locally sourced products.

This year, the Going Beyond Award was presented to **Megan Do Nascimento**, **Marisa Gefen, MD**, **Felicia Johnson** and **Teresa Kohl**, four women who have used their personal experience with breast cancer to help and inspire others.

The Founders Award, LBBC’s highest honor, was presented to **Pallav K. Mehta, MD**. Dr. Mehta is a medical oncologist whose compassion for people with breast cancer and knowledge of the disease are obvious in his integrative approach to care.

In a video shown at the event, Dr. Mehta said he’s excited about the future of breast cancer care.

“There’s so much on the horizon for my patients that it really does allow us to give them some real hope,” he said.

Of the total raised, \$91,000 of it was donated by guests to LBBC’s Cis B. Golder Quality of Life Grant, which provides small grants to families in the greater Philadelphia region who need immediate help with living expenses because of a breast cancer diagnosis.

We are very thankful to our presenting sponsor, **White House Black Market**, for their extraordinary support. 🍌



## BEYOND THESE PAGES

Visit Living Beyond Breast Cancer’s YouTube page to find our Butterfly Ball 2017 playlist, featuring the video about Dr. Mehta mentioned above and a video about our Going Beyond Award recipients.



A. From left, Founders Award recipient **Pallav Mehta, MD**, with Going Beyond honorees **Teresa Kohl**, **Marisa Gefen**, **Felicia Johnson** and **Megan Do Nascimento**, and LBBC CEO **Jean. A Sachs, MSS, MLSP**.  
 B. Soma President **Mary von Praag**, left, with White House Black Market President **Donna Noce Colaco**.  
 C. Butterfly Ball co-chairs **Jennifer and Samuel Goldfarb**.  
 D. Butterfly Ball co-chairs **Jonathan and Linda Brassington**.  
 E. LBBC board chair **Laura Kowal** with her husband, **Walter Kowal**.  
 F. Butterfly Ball co-chairs **Steve and Susie Krupnick**, left, with co-chairs **Katy and Jason Friedland**.

## DONOR PROFILE:

# Thank You, *jane iredale*, for 10 Years of Support!

BY KIRSTIE KIMBALL

**A** lot of important things happened in 2007. The original iPhone was released. The last Harry Potter book came out. And Living Beyond Breast Cancer and mineral makeup company *jane iredale* began an exciting partnership that continues to this day.

This year, we celebrate 10 years of that partnership. Since 2007, *jane iredale* has donated over \$475,000 to LBBC. The company has also joined with us to spread the word about our educational programming, and it has participated in multiple LBBC events.

“Working with *jane iredale* over the last decade has been such an honor,” says **Jean A. Sachs, MSS, MLSP**, CEO of Living Beyond Breast Cancer. “Their products are such high quality and the partnership is truly appreciated by the women LBBC serves.”

“It has meant so much to our employees all over the world that we have partnered for the past 10 years with LBBC, an organization that is so meaningfully aligned with our company mission of enhancing women’s lives and inspiring them to feel confident in their own skin,” says **Sarah Steven**, *jane iredale*’s vice president of marketing.

The company’s first product benefitting LBBC was a lipstick. Since then, *jane iredale* has donated the profits from an eyeshadow compact, Bright Future; a two-sided lip stain, Cherish; and a facial spritz, Smell the Roses; among other products. Each of these products was chosen because of their gentleness, so women with breast cancer could feel comfortable using them.

“Our strategy was to select products that would be flattering to most skin tones and shades, thereby driving the highest sales and the largest possible donation to LBBC,” says Ms. Steven.

In 2016, *jane iredale* makeup artists came out for **Shimmer and Shine**, a night of beauty and relaxation held as part of the **2016 Living Beyond Breast Cancer Conference: Individual Treatments, Shared Experiences**. Makeup artists taught attendees how to draw natural looking eyebrows, selected products that would pair best with their skin concerns and worked with each woman to make sure she left the chair feeling beautiful.

“The participation of *jane iredale* really elevated the event and made the women impacted by breast cancer feel special,” says Ms. Sachs.

Through the end of this year, *jane iredale* is donating to LBBC 100 percent of net profits from the Magic Mitt, a cloth that removes makeup with no chemicals and keeps harmful bacteria at bay.

“It is one of our top sellers and it’s also great for sensitive skin,” says Ms. Steven. “You don’t need anything but water, which is how we came up with the tagline, ‘Pure Care, Just Add Water.’”

To learn more, and to support LBBC by buying the Magic Mitt, visit [janeiredale.com](http://janeiredale.com). 🍌



Magic Mitt makeup  
remover cloth



URBN Field Day

## DIY SPOTLIGHT:

# Having a Field Day

**WHO:** Greg Young, leadership and development director for URBN, the parent company of Urban Outfitters, Anthropologie, Free People, BHLDN, Terrain and Vetri

**WHAT:** A field day for URBN staff. Each attendee paid \$5 for a lunch voucher and proceeds were donated to LBBC

**WHEN:** Friday, August 4, 2017

**WHERE:** URBN’s corporate headquarters in the Philadelphia Navy Yard

**AMOUNT RAISED FOR LBBC:** \$1,800

**TOTAL ATTENDEES:** 360

LBBC board member and Reach & Raise team captain Ayanna Z. Kalasunas worked for Urban Outfitters for many years before her metastatic breast cancer diagnosis. When she passed away from the disease in May 2017, her co-workers and friends vowed to continue Ayanna’s commitment to support LBBC.

Greg says, “We chose LBBC because of the work they do here in the Philadelphia community, and their commitment to empowering people with breast cancer. Our home office and store teams are mostly women and we felt that supporting LBBC made sense to the Anthropologie and Urban Outfitters community because of both who we are and who we serve.”

—Compiled by LBBC  
advancement staff

**Interested in hosting a Do-It-Yourself event in support of LBBC?** To find out more, contact Jamie Cohen at [jcohen@lbbc.org](mailto:jcohen@lbbc.org)



**LIVING BEYOND  
BREAST CANCER®**

With you, for you.

40 Monument Road, Suite 104  
Bala Cynwyd, PA 19004

# Insight

If you received more than one copy of this newsletter or would like to be removed from our mailing list, email [information@lbbc.org](mailto:information@lbbc.org).

**Connecting you**  
to trusted breast cancer information  
and a community of support

Every two  
minutes

A WOMAN IS DIAGNOSED WITH BREAST CANCER

IN THE UNITED STATES

Every minute

ONE PERSON TURNS TO LIVING BEYOND BREAST CANCER TO

- Learn about treatment options
- Talk to someone who understands
- Connect with a supportive community
- Learn ways to manage side effects
- Improve their everyday life

A few minutes is all it takes to make an online donation and provide over 500,000 people per year with a supportive community.

Make a secure year-end donation by visiting [lbbc.org/gift](https://lbbc.org/gift)



**WINTER 2017/2018**

# Calendar

## Educational Programs

### WEBINARS

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

**JANUARY 16**

**Breakthroughs in Breast Cancer Treatment**

**BREAST CANCER 360s**

*Online and in person!*

**FEBRUARY 21**

**Doctor-Patient Communication**

*Philadelphia, Pennsylvania*

## Conferences and Special Events

**APRIL 20-22**

**Thriving Together**

**2018 Conference on Metastatic Breast Cancer**

*Philadelphia, Pennsylvania*

**MAY 20**

**Living Beyond Breast Cancer's Reach & Raise: Philadelphia**

*Philadelphia, Pennsylvania*

**SEPTEMBER 28-30**

**2018 Living Beyond Breast Cancer Conference**

*Philadelphia, Pennsylvania*

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

# THANK YOU TO Our Donors

## \$200,000 and above



## \$100,000 to \$199,999

Centers for Disease Control and  
Prevention

## \$50,000 to \$99,999

Chico's FAS  
Triple Negative Breast Cancer  
Foundation  
White House Black Market

## \$20,000 to \$49,999

21st Annual Paddle Rally  
Liane & Philip Browne  
Cis B. Golder Quality of Life Grant  
Luncheon at Neiman Marcus  
Eisai  
Merck  
Soma

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

17th Annual Ann N. McDonald  
Memorial Basketball  
Tournament  
Allergan  
Amgen  
Donna & Frank Colaco  
Genentech  
Susie & Steven Krupnick  
MacroGenics  
Karen & David Mandelbaum  
Andrea & Robert Orsher  
Pfizer Oncology  
Puma Biotechnology, Inc.  
Toll Brothers, Inc.

## \$5,000 to \$9,999

AirXpanders, Inc.  
Andy Sealy Fundraising Event  
Linda & Jonathan Brassington  
California Exotic Novelties, LLC  
Depeche Mode Clothing Co., Inc.  
Ellen & Peter Evans  
Donna & Barry Feinberg  
Keystone Property Group  
KRD Imports Ltd.  
Robert and Jane Toll Foundation  
Susan G. Komen  
Susan Leonard Charitable Trust  
Syndax Pharmaceuticals, Inc.  
The Tutu Project of the Carey  
Foundation

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

AmerisourceBergen Corporation  
Amoena  
Joan & Joe Aronson  
Kelly & Joe Bilko  
Janet & Barry Burkholder  
CliftonLarsonAllen  
Amy & Michael Cohen  
Debra & Steven Copit  
Everything But Water  
Jennifer & David Fiss  
Fox Chase Temple Cancer Center  
Sandy L. Grimes  
Randie & Robert Harmelin  
Spencer Hoffman  
Holy Redeemer Hospital and  
Medical Center  
Patricia & Robert Isen  
Karr Barth Associates/AXA  
Advisors, LLC  
Kathy & Jeffrey Friedland  
Foundation  
Laura & Walter Kowal  
Christine & Brian Lobleby  
LymphedIVAs  
Meridian Bank  
Meyer Capital Group  
Michael Pizzitola  
Ellyn Golder Saft & Stephen Saft  
Toby & Mark Soble  
William E. Connor & Associates Ltd.

*August 1-October 31, 2017*