

Insight

A quarterly educational
newsletter from LBBC



Medical Advances and Treatment Decisions: A 20-Year Retrospective

BY MARY ALICE HARTSOCK, FOR LBBC

When LBBC was founded 20 years ago in response to a woman's need for breast cancer-related information, connection and support after treatment ends, treatment choices were more limited than today.

Researchers were just beginning to understand that a one-size-fits-all approach could not effectively treat all breast cancers, and women struggled to incorporate individual options and preferences into decision making.

Today, research developments allow you to consider your lifestyle and career goals as you select treatments and strategies to manage side effects. "The advancements in our understanding of the biology of breast cancer have changed the face of treatment decision making," says **Larry Norton, MD**, deputy physician-in-chief for breast cancer programs at Memorial Sloan-Kettering Cancer Center in New York City. "These discoveries are helping us to understand what treatments could benefit each individual patient."

Biology and Decision Making

In the past two decades, researchers have learned that cancers have unique genetic profiles that predict how they will grow and what treatments will work best. Previously, mastectomy and chemotherapy were almost always standard treatment.

"When I was diagnosed in 1985, I had very little information on the cancer's characteristics," says **Claire Parker**, 62, of Denver. She needed more surgery after an excisional biopsy did not remove the entire tumor, but she didn't want a mastectomy, then the standard of care. After her insurance rejected a recommendation for a lumpectomy from a prominent doctor, Claire could not find a surgeon within her policy willing to perform it.



"The majority of our knowledge 20 years ago was based on what we could see under the microscope—tumor size, grade and number of involved lymph nodes," Dr. Norton says.

Today, medical tests performed on the breast tissue and lymph nodes provide information on the behavior of proteins that control our bodies' cells. If specific proteins are present, absent or malfunctioning, doctors can predict how a cancer will react to certain medicines and tailor your treatment accordingly.

Hormones

Your healthcare team may help you select treatments that target the misbehaving or absent genes in breast cancer cells to slow them down or stop their activity. Unlike chemotherapies, these treatments target cancer cells while avoiding healthy cells.

The first target identified for breast cancer treatment, the estrogen receptor, led to new treatments for hormone-sensitive breast cancers. *Hormone receptors* are proteins that receive messages from hormones in the bloodstream and tell cancer cells to grow.

Hormonal therapies stop or slow estrogen receptor-positive breast cancer growth by blocking estrogen's effects or reducing the body's estrogen levels. In 1977 the U.S. Food and Drug Administration approved tamoxifen, the first hormonal therapy, to treat ER+ metastatic disease. About 20 years ago, the FDA approved

Continued on page 10

LBBC STAFF

Jean A. Sachs, MSS, MLSP
Chief Executive Officer

Lisa D. Black
Catherine Creme Henry
Jeanne Marren Egan, MBA
Michael J. Formica, MS, MA, EdM
Kevin Gianotto
Amy B. Grillo
Janine E. Guglielmino, MA
Arin Ahlum Hanson, MPH, CHES
Geoffrey Harden
Jenna Jackson
Vicki Klopp
Sandra E. Martin
Anna Shaffer
Elyse Spatz Caplan, MA
Celeste C. Terrinoni, CPA
Christine Ware, MEd
Stacia Weaver, MS

Lisa Bayard
Chair, Board of Directors

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

LIVING BEYOND BREAST CANCER®

354 West Lancaster Avenue
Suite 224
Haverford, PA 19041
Survivors' Helpline
(888) 753-LBBC (5222)
Voice: (610) 645-4567
Fax: (610) 645-4573
Email: mail@lbbc.org
Website: lbbc.org

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

Newsletter design:
Masters Group Design

Main cover photo:
Laurie Beck Photography



Dear Friends:

It's been an exciting summer at Living Beyond Breast Cancer, and I am thrilled that you are among the first to learn about our plans to celebrate 20 years of serving women and families affected by breast cancer.

At our annual fall conference we will announce plans for a yearlong celebration in honor of LBBC's 20th anniversary. Working with our supporters—friends, donors, corporate sponsors, civic leaders and partners—we will use the next 12 months as a platform to reach more women affected by breast cancer than ever before. Ways we will accomplish this include:

- * Participating in the Combined Federal Campaign (see page 9 for details) for the first time, from September 1 through the end of 2011;
- * Partnering with corporations during October (see page 8) and continuing through 2012;
- * Introducing LBBC's signature fundraising event, Yoga on the Steps, in Washington, DC, on Sunday, October 16;
- * Promoting our anniversary with a special presentation in honor of former and current LBBC board chairs at The Butterfly Ball: Club 20 Gala on Saturday, November 12.

I welcome your thoughts on how we should mark our 20 years, and I thank you for being a part of our success.

Warmly,

Jean A. Sachs, MSS, MLSP



Susan Beard Photography



LIVING BEYOND BREAST CANCER

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

Worlds Apart: A Mother and Daughter Cope with Breast Cancer

BY ANNA SHAFFER

In July 1965, Catherine “Reita” Cruze, then age 41, kept itching a mosquito bite under her left armpit.

After discovering a lump in that area, she visited her doctor who told her to come back for a biopsy three days later.

He didn’t explain what the biopsy entailed or what the end result might be. Partway through the procedure, doctors spoke to Reita’s husband, Deane. They told him the lump was cancerous and had spread to the lymph nodes, so they needed to perform a *radical mastectomy*, removal of the breast, surrounding muscle and tissue—a procedure that was common then but is rarely performed today. They gave him a permission form, and he signed it.

Deane broke the news to Reita after she woke up. “It was a shock because I was still thinking it was a mosquito bite,” she says.

Doctors told Deane that Reita should “get her affairs in order.” They didn’t expect her to survive since her tumor was large and the cancer had spread to most of her lymph nodes. She stayed in the hospital for at least a week then returned home to heal before beginning radiation treatment.

But on September 9, 1965, Hurricane Betsy flooded the New Orleans neighborhood where Reita and her family lived.

“My husband called the hospital to find out how I could get there, and the Army took me to get my bandages removed,” she says. “I remember floating down the road.” Once the water receded, Deane took Reita to radiation treatment every day for six weeks.

Shortly after finishing treatment, Reita and her family moved to the Seattle area where she continued yearly exams and mammograms. “The doctors were surprised the cancer went into remission. Every year, I would fill out paperwork saying I was still going strong,” she says.

Reita doesn’t remember taking anything for side effects and still has lymphedema and limited motion in her left arm, but she has not had a recurrence.

At that time “cancer wasn’t talked about like it is now,” Reita says. Aside from her husband’s support, she went through the experience privately.

Reita’s daughter, Laurie Knott, was 8 when Reita was diagnosed. “I remember Dad bringing her home from treatments, and that she was weak and nauseous and wanted to go to bed,” Laurie says. “But it was years later before I realized how serious it was.”

Laurie didn’t learn about her family history of breast cancer until she was in her early 30s, when Reita insisted that her two daughters begin getting yearly mammograms.

In 2006, over 40 years after Reita’s diagnosis, 48-year-old Laurie was diagnosed stage I, triple-negative breast cancer.

“I just knew I would get it. It wasn’t a matter of if, it was a matter of when,” Laurie says. “The worst part about it was I knew nothing about the types. They told me it was aggressive, so I needed surgery right away. When they said ‘aggressive,’ I thought I was going to die.”

Research developments allowed Laurie access to tests, treatment choices and information about her diagnosis that Reita never had. Because one of Laurie’s friends emphasized the importance of being comfortable with her surgeon, she made appointments with several. The surgeon she chose recommended she see a genetic counselor before making treatment decisions. After discovering the high likelihood of the cancer coming back in her other breast, Laurie decided to have a double mastectomy. A genetic test came back positive for BRCA 1, a gene with inherited mutations linked to an increased risk of breast cancer.

“Back then people were just starting to learn about triple-negative breast cancer, so everything I was reading on the Internet was gloom and doom,” Laurie says. “But the oncologist said the fact that it hadn’t gone to the lymph nodes was good, and that having both breasts removed was a good option. He was very helpful and optimistic.”

Laurie underwent chemotherapy, the standard treatment for triple-negative breast cancer. She wrote letters to her family encouraging them to get genetic testing. Although most of them ignored it, three of her four siblings got tested.

Now five years later, Laurie gets regular screening for breast and other cancers. She volunteers for Y-ME National Breast Cancer Organization and Susan G. Komen for the Cure.

She says the love of family and friends—especially that of her mom—is what got her through her breast cancer experience.

“In the beginning, I thought I was going to die. But the more I learned about my mom and her cancer, I thought, ‘If she could do it, then I could do it,’” Laurie says.

“The fact that she did it with such dignity, that she went through it alone, was so inspiring to me. Even though we are BRCA1 positive with a strong family history, and there are no other survivors in our family other than Mom and now me, thanks to her I never gave up hope that even an aggressive cancer does not always mean death.”

“The fact that she did it with such dignity, that she went through it alone, was so inspiring to me.”



How the Trauma of Breast Cancer Impacts Well-Being

BY MICHAEL J. FORMICA, MS, MA, EdM

After she was diagnosed with breast cancer, 45-year-old **Randi Rentz**, of Philadelphia, did what she always does when she's feeling overwhelmed: she began making lists.



RANDI RENTZ

"Lists help me keep things orderly and allow me to just move through everything, one step at a time," Randi says. "They make me feel like I have some control over the situation."

"I was completely blindsided by my diagnosis, and having nursed my five children, was devastated at the thought of losing a breast," says **Pat Battaglia**, 55, of Rochester, NY. "I cherish the time I spent nursing and could not fathom that one of my breasts, which had been a source of nurturing, could become a threat to my life."

A breast cancer diagnosis can make you feel like you have no control over what's happening around you and what's happening to you. You may have felt—and may still feel—like your seemingly healthy body has somehow betrayed you or that your self-image has abruptly and radically changed.

"No one goes unaffected by a diagnosis of breast cancer," says **Beth E. Meyerowitz, PhD**, professor of psychology and preventive medicine at USC Dornsife College of Letters, Arts and Sciences in Los Angeles. "You can't make a blanket statement about what that might look like, because every woman's personal history is different, but some level of anxiety and sadness is a normal and reasonable reaction."

Some women, like Randi and Pat, have anxiety and depression that resolves over time, while others may experience an extreme level of distress that has a lasting impact on emotional well-being.

The sudden and often unexpected life changes that go along with breast cancer can be difficult to manage. Research shows that experiencing a radical change to your body because of breast cancer treatment can also cause changes in self-image, body image and interpersonal relationships.

Randi recalls, "At the time, I was in my early forties, not married, no children, no family and I kept thinking, 'How desirable am I going to be? How am I going to date?'"

Your feelings and reactions—whether these include the anxiety and depression you might expect or something more intense—are all valid, says **Hester Hill Schnipper**,

LICSW, BCD, OSW-C, chief of oncology social work at Beth Israel Deaconess Medical Center. Knowing there are reasons why you feel the way you do can be comforting, she says.

Anxiety, Stress and Traumatic Stress

The range of emotions you may have upon receiving a breast cancer diagnosis can be broad and complex. *Stress*, the body's response to an unexpected shock, may be one of your first and strongest reactions. *Anxiety* is a feeling that something dangerous has happened or is about to happen, according to **David M. Sachs, MD**, a psychiatrist in Philadelphia.

"This feeling and the meaning you give a stressful event is called *trauma*," says Dr. Sachs. "When the feeling returns after a trauma, it warns the person that the trauma may happen again. Often this is incorrect, and the anxiety only tells the person experiencing [traumatic or] post-traumatic stress that something reminded them of the trauma."

When the stress is very high and the feelings you connect with that stress are very intense, you can experience an extreme sort of anxiety called *traumatic stress*, a short-term condition that happens when you are unable to adapt to a particular source of stress.

Thinking about diagnosis and treatment in terms of traumatic stress, rather than anxiety and depression, may be more helpful, Ms. Hill Schnipper says. Anxiety happens in the moment and fades quickly when the stressor that caused it goes away. Even though it typically lasts less than six months, traumatic stress lingers because the emotions you associate with a stressful event like breast cancer diagnosis and treatment make that event something you hold onto in your thoughts. Difficulty coping with that event can negatively affect mental health.

Traumatic stress is more intense than anxiety and often interferes with day-to-day activities. It can get in the way of your ability to think clearly, disrupt your sleep and affect your mood, says **Amal Chakraborty, MD**, a psychiatrist at the Professional Psychiatry Corporation in Oklahoma City.

With traumatic stress, anxiety about breast cancer diagnosis and treatment can grow into intense, often unfounded anxiety about other parts of your life, sometimes related to breast cancer and sometimes not.



PAT BATTAGLIA

"If you're feeling suicidal, can't get out of bed, feel like you have nothing to live for, or your feelings and emotions are interfering with your life in general, you should consider talking with your medical team or a mental health professional," says Dr. Meyerowitz.

Post-Traumatic Stress and PTSD

In most cases, the negative thoughts and feelings associated with a trauma tend to diminish over time and may eventually disappear. When traumatic stress lingers longer than six months, it is called *post-traumatic stress*. Symptoms include *aversion*, working hard to avoid something that directly or indirectly reminds you of the initial trauma but has little or nothing to do with it, and *intrusions*, when thoughts related to the trauma pop into your head for no apparent reason. Other symptoms include sleeping problems and mood changes.

Aversion can make you dislike things you've always enjoyed. "I can't stand the color red," says **Debra Becker**, 51, of Calgary, Alberta. "I can't drink a cosmo martini, and I've thrown out every red piece of clothing in my wardrobe. Red reminds me of the A/C chemo."

If aversion, uncontrollable worries and sleep and mood problems become so strong that they interfere with your thinking, relationships and other day-to-day activities, you could have a more serious condition called *Post-Traumatic Stress Disorder (PTSD)*. In PTSD, symptoms are present for at least 30 days. Talk about your feelings with friends and relatives. If your symptoms do not improve soon or are making you very upset, contact your doctor. Seek help right away if you feel overwhelmed, are unable to control your behavior or are thinking of hurting yourself or anybody else.

The Trauma of Metastatic Disease

The ongoing nature of metastatic breast cancer treatment can create ongoing stress that presents little or no opportunity for resolution, making stress as constant a burden as the disease itself.

"I have experienced quiet desperation, blatant fear, intense discomfort, rage, confusion and profound sadness," says **Joani Gudeman**, 47, of Chicago. "Despite these intense feelings, or perhaps in tandem with them, I have also found hope, and experienced laughter and connectedness."

Identifying new ways to cope can help you manage. "I do my best to take a realistic approach to my illness," Joani

says. "I work to accept that metastatic breast cancer is likely to shorten my life; in doing so, I accept the reality of grief and loss. I think that compartmentalizing things works to channel pain, so that pain's intensity is controlled, diverted and made less destructive."

Taking Control and Finding Help

In some cases, the challenges of breast cancer can even prompt positive emotions, called *post-traumatic growth*.

"The moment cancer became an intimate part of my life is the moment that I realized my precious humanness," says **Jennifer Maroon**, 47, of Clifton, NJ. "For the first time in my life, I became centered, and my purpose and focus in life became apparent. My life energy intensified instantly, and my direction became to love my kids, deepen and sustain my friendships, keep my body healthy and do my best at work. I have been given this incredible life to be the best, most awesome me I could possibly be."

Finding positive emotions can be one way of coping with trauma, but if this is not your experience or you want to learn other ways to channel negative feelings, consider

getting professional help on your own or through a support group. 🧡

For more information on stress and anxiety, read LBBC's Guide to Understanding Your Emotions or Managing Stress and Anxiety in our Metastatic Breast Cancer Series.

"I have experienced quiet desperation, blatant fear, intense discomfort, rage, confusion and profound sadness," says Joani Gudeman. "I have also found hope, experienced laughter and connectedness."



JOANI GUDEMAN



JENNIFER MAROON

Fall Programs Offer Specialized Information, Support

BBY ANNA SHAFFER

Learn to Live Well

Kick off Breast Cancer Awareness Month at our fall conference, **News You Can Use: Breast Cancer Updates for Living Well**, on Saturday, October 1, at the Loews Philadelphia Hotel. Mark your calendar for a day filled with information and practical resources to help you navigate your breast cancer experience.

Wendy Demark-Wahnefried, PhD, RD, of University of Alabama at Birmingham Comprehensive Cancer Center, will start the day by discussing how fitness and nutrition impact treatment, recovery and life beyond breast cancer. Following the opening session, we'll take a group photo of conference attendees in honor of LBBC's 20th anniversary. Our closing plenary speaker, **Lu Ann Cahn**, an Emmy award-winning journalist, will speak about her own 20-year journey through breast cancer.

Get tools for making choices that positively impact your physical and emotional health at workshops covering treatments for early-stage and metastatic breast cancer; communicating with family and friends; fitness and exercise; caregiving; reconstruction; fear of recurrence; managing side effects; triple-negative breast cancer; health insurance and more. Your caregivers, friends and family will also find this conference valuable as they support you in your journey.

The \$50 per person registration fee includes all educational programs, a continental breakfast, lunch and networking reception. Register at lbbc.org or by calling our office.

Triple-Negative News

This fall, we will launch a new section of lbbc.org especially for women diagnosed with triple-negative breast cancer.

This website community will offer easy access to resources such as LBBC's **Guide to Understanding Triple-Negative Breast Cancer**. You'll also be able to find podcasts of our two-part teleconference series in partnership with **Triple Negative Breast Cancer Foundation**, questions and answers from our online ask-the-expert series, breast cancer news, information on clinical trials, profiles of women diagnosed with triple-negative disease and more.

Visit lbbc.org and email webmaster@lbbc.org to let us know what you think!



More Metastatic Programs

Get the latest information on treatments and quality-of-life issues for metastatic breast cancer during our October teleconference series. On October 12, **George Sledge, MD**, of Indiana University School of Medicine, will give tips on how you can get involved with cutting-edge research, how

to maintain your quality of life while undergoing

treatment and how to discuss side effects with your doctor. On October 24, explore

what's meaningful to you with **Jamie**

H. Von Roenn, MD, of Northwestern

University Feinberg School of

Medicine, who will cover how a

palliative care plan supports

ongoing treatment and quality

of life.

We also will release a new

guide to help you gain an under-

standing of what **Palliative Care** is

and how it differs from hospice care.

Get strategies for coping with your

emotions as well as those of family

members and others connected to you.

Understand how to integrate palliative care

into your treatment plan and get resources to

enhance your life. Preorder your free copies at lbbc.org's

Library, or call our office.

Save the date! Our **Annual Conference for Women**

Living with Metastatic Breast Cancer will take place April

28–29, 2012, at the Loews Philadelphia Hotel. Mark your

calendars to get updates on a variety of medical and

quality-of-life issues important to you. Visit lbbc.org for

information on travel grants, registration, workshop

topics and speakers.

Improve Your Quality of Life

Our fall teleconferences will help you stay up to date on quality-of-life issues specific to your needs.

During our November 1 teleconference on **Cancer**

Caregiving: Support from a Distance in partnership with

Cancer Support Community, speaker **Nora Jean Levin** of

Caring from a Distance will discuss how to manage common

concerns you may face as a long-distance caregiver to a

woman affected by breast cancer.

Explore the impact of breast cancer on your self-

esteem during **Creating a More Positive Body Image** on

November 17. Sexuality counselor and clinical nurse

specialist **Anne Katz, RN, PhD**, of CancerCare Manitoba,

will provide strategies for gaining greater self-acceptance. She will help you enhance physical and emotional well-being and speak openly about body image and intimacy with your partner and healthcare providers. And during our December 1 teleconference on **Lymphedema**, certified lymphedema therapist **Loraine Lovejoy-Evans, MPT, DPT, CLT-Földi**, of Independence Through Physical Therapy, will help you understand the causes of lymphedema, early prevention strategies, treatments and how to maintain your quality of life.

These free teleconferences are held from 12:00 p.m. to 1:15 p.m. Eastern Time (ET). Register today at lbbc.org.

Don't miss a program! Get practical tips for managing your concerns and follow-up care by listening to a podcast of our September teleconference on **Monitoring for Recurrence and Managing Fears**. **Carey K. Anders, MD**, shared tips to help you cope with the feelings you may have when treatment ends and discussed how your doctor will monitor for recurrence over time. Special thanks to the **Avon Foundation for Women** for its support of this teleconference.

Visit the LBBC Library or Event Archives at lbbc.org to access transcripts and podcasts of our programs.



With Avon's help, we will have distributed 20,000 copies by early September!

Order your free copies of brochures in our **Understanding** series at lbbc.org's Library or call our office.

Getting Connected

A new edition of our culturally relevant booklet **Getting Connected: African-Americans Living Beyond Breast Cancer** is now available.

The booklet—which features a new design and images of women who were recently diagnosed with breast cancer—will help you find strength in connecting with yourself, friends, family, God and your healthcare team as you go through your breast cancer journey. You can also get updated information on treatment decisions, side effects and strategies for finding reliable medical information. Order copies at lbbc.org's Library or call our office.

Help us get this resource to those who need it! If you have ideas for where we should distribute **Getting Connected**, contact us at publications@lbbc.org.

Congratulations, Helpline Volunteers!

Special thanks and congratulations to over 25 new Helpline volunteers who recently joined our team!

Helpline volunteers are trained to offer support, information and hope in a confidential setting. Our personalized matching service can connect you with someone with a similar diagnosis, who is your age or shares your ethnic background, if that's important to you.

To speak one-on-one with someone who has "been there," call our Helpline at (888) 753-LBBC (5222). Or if you prefer to request a call using our online form, visit lbbc.org to submit your request and a Helpline volunteer will contact you by phone within 24 hours.

Save the Date: C4YW 2012

LBBC and **Young Survival Coalition** are excited to announce the **Annual Conference for Young Women Affected by Breast Cancer (C4YW)** will be held February 24-26, 2012, at the Hyatt Regency in New Orleans. This is the only three-day educational program for women who are diagnosed with the disease before age 45.

Be sure to mark your calendars and spread the word—it's going to be another amazing event. We'll see you in the Big Easy! 🍷



Understanding Early-Stage Breast Cancer

If you are newly diagnosed with early-stage breast cancer, be sure to pick up the new edition of our **Guide to Understanding Treatment Decisions**, available in October. Get up-to-date information on how diagnostic and pathology tests help your doctor build a tailored plan for your breast cancer treatment, and find out what questions to explore so you can make informed decisions about surgery, chemotherapy, radiation, hormonal therapy and targeted therapy. The guide includes images from a photo shoot of women affected by breast cancer we recently held in Philadelphia and Washington, DC.

A revised edition of our **Guide to Understanding Your Emotions** will also be available in late winter. This brochure covers common emotions, signs of anxiety and depression, consulting a healthcare professional, responding to emotions, understanding your feelings after initial treatment ends and practical strategies for moving forward.

Special thanks to **Avon Foundation for Women** for helping us get our **Guide to Understanding Fear of Recurrence** into the hands of more women who need it.

Shop to Support Partnerships Grow Stronger

BY STACIA WEAVER, MS, AND KEVIN GIANOTTO

*LBBC has the honor and pleasure of working with amazing companies from across the country that provide financial resources via our **Shop to Support** program. This year, STS was redesigned as a partnership program allowing retailers to align themselves with LBBC. The growth of the program has provided much-needed financial assistance for LBBC to continue our mission.*

Give Hope: White House | Black Market

White House | Black Market has been an active supporter of LBBC since 2004, allowing us to reach people across the country.

"Our company and our customers have demonstrated a sincere commitment to making a difference for women affected by breast cancer," says White House | Black Market brand president **Donna Noce**. "This October, we will unveil new items developed for our Give Hope Collection with 100 percent of net proceeds benefitting LBBC."

Shop to support LBBC at White House | Black Market locations across the United States by purchasing these exclusive items: The Give Hope T-Shirt (\$38); the Give Hope Reversible Tote (\$68); the Hope Necklace (\$68); and the Butterfly Keychain (\$15). For a store near you, visit whitehouseblackmarket.com.



Chico's 'Love Charms' Bracelet

For the past three years, **Chico's** has designed a special piece for LBBC "with great anticipation," says Chico's brand president **Cinny Murray**. "The collector's item represents both the boutiques' unique fashion and attention to personal service, as well as our passion for the cause."

This year's design is a double-strand rose quartz bracelet that can be stacked or worn separately. Historically, rose quartz has served as a symbol of the power of love and serenity. Beginning October 1, Chico's will donate \$10 from each \$24 bracelet sold to LBBC.

Visit chicos.com to find a store near you or to purchase online.



Cline Cellars Cashmere

Cline Cellars, producers of award-winning Rhône-style wines and zinfandels, approached LBBC shortly after the New Year to discuss partnership opportunities. The winery, headquartered in Sonoma, CA, wanted to explore the positive impact its support would have on women facing breast cancer.

"We reached out to LBBC because of the scope and breadth of services it provides to women and families affected by breast cancer," says Cline Cellars owner **Nancy Cline**. "We were taken by the care and attention to detail that LBBC brings to every program."

In addition to a donation of \$25,000, Cline Cellars will promote our new partnership on packaging, point-of-purchase displays and advertising for the specialty wine Cashmere starting in October.

Cashmere can be found at better wine shops across the United States.



Rise Above with Love®

jane iredale will celebrate the launch of its second annual Rise Above with Love campaign by continuing its long-term partnership with LBBC. For Jane Iredale, president and chief executive officer of Iredale Mineral Cosmetics, the partnership is a perfect fit.

"No woman should be defined by a diagnosis," says Ms. Iredale. "The first two words of LBBC say it all: 'Living Beyond.' We're proud to partner with an organization that supports women and families as they deal with a disease that touches all areas of life."



Each year, *jane iredale* designs a limited edition product for its RAWL campaign. This year, the company will donate 100 percent of proceeds from the sale of *Roses & Lollipops*, a lip duo featuring two new and universally flattering shades in a portable keychain locket. The locket features two best selling products, *PureMoist LipColour* and *PureGloss for Lips*. *Roses & Lollipops* (\$30) is available through fine spas and salons, resorts, apothecaries, medical offices and online at shop.janeiredale.com.

Be a Fashion Bug

LBBC is excited to announce that **Fashion Bug** has named us a new charity partner for 2011!

"Not only will Fashion Bug stores across the country support LBBC's mission through the donation of 100 percent of proceeds from the sale of a one-of-a-kind t-shirt, we will also conduct a 'Round-Up-At-The-Register' campaign," says **Kristin Mongello**, Fashion Bug's director of marketing. "During the month of October, our sales associates will ask each of our patrons to 'round up' their Fashion Bug purchase total to the next dollar, using the difference as a donation to LBBC. You can imagine the potential of a campaign like this when you factor in the thousands of women who shop our 700 stores every day."

Visit your local Fashion Bug to purchase your commemorative t-shirt and to round up your purchase for LBBC. For a store near you, visit fashionbug.com. ♡

For a listing of all LBBC's Shop to Support partners and products, visit lbbc.org/Donate/Shop-to-Support.



Support LBBC through the Combined Federal Campaign



This September, federal workers can support LBBC via the Combined Federal Campaign, the world's largest and most successful annual workplace payroll deduction giving program.

The CFC promotes and supports philanthropy through a program that provides federal employees the opportunity to improve quality of life for those in need. With more than 200 CFC campaigns throughout the country and internationally, millions of dollars are raised each year through pledges made during the campaign season (traditionally, September 1 through December 15).

All CFC participating charities are screened to ensure that they are registered as 501(c)(3) charities to which donor contributions are tax deductible. All CFC charities are reviewed annually for evidence that they provide services on a local, state, national or international level, and have public and financial accountability.

For the first time, LBBC will participate in the CFC and has been assigned **giving designation code #78012**. For additional information, contact Geoffrey, manager of individual giving, at geoffrey@lbbc.org.

Thank you to our February 2011–June 2011 contributors:

\$50,000–\$99,999

Amgen
Customers of Chico's FAS
Eisai Inc.
Susan G. Komen for the Cure

\$25,000–\$49,999

Bristol-Myers Squibb
Celgene
Iredale Mineral Cosmetics Ltd.
Novartis Oncology
Unite for HER

\$10,000–\$24,999

Centocor Ortho Biotech Inc.
Eli Lilly and Company
Irene Kelso/Professional Recovery Services, Inc.
Jack McCusker
Merck
Saatchi & Saatchi Health Communications
Under Armour
White House | Black Market

\$5,000–\$9,999

14th Annual Celebrate Life Event/Joy & Steven Rubeo
Aberdeen
Andrea & Abraham Morris Foundation
Genentech
Genomic Health Inc.
HealthAmerica
Pennsylvania, Inc.
Independence Blue Cross
JadeYoga
Jean Karotkin
LIVESTRONG
SmartWool
Veridex, LLC
Margaret and Andy Zuccotti

\$2,500–4,999

Jackie Allen/BJNB Foundation
Anjali Power Yoga
Aria Health
Cancer Treatment Centers of America at Eastern Regional Medical Center
CaringBridge
Digges Charitable Trust
Dolfinger-McMahon Foundation
Emily Schmidt's Breast Cancer Benefit/ Katie Mulloy, Emily Schmidt and Family
Insider Guides, Inc.
Johnson & Johnson
Matching Gifts Program

LympheDIVAs, LLC
Mercedes-Benz of Fort Washington
Omega Hospital, LLC
Premier Meeting Solutions
Frances Seidman
Teva Women's Health, Inc.
THOR•LO, Inc. and Subsidiaries
Valley Green Bank

Continued from cover

tamoxifen to help prevent recurrence in early-stage breast cancers. In 1998, it was approved to reduce risk in healthy women.

Ruth Pogarsky, 72, of Lakewood, NJ, was diagnosed with breast cancer in 1984 and 1994. At her first diagnosis, she had surgery to remove a stage I cancer confined to her breast, but she didn't know her hormone receptor status. After a second lumpectomy in 1994, her doctor learned she had ER+ breast cancer and prescribed tamoxifen.

Beginning with hormone-sensitive cancers, "the 1990s saw the dawn of the understanding that a tumor's biochemical characteristics were more important than its anatomic characteristics," Dr. Norton says.

In 1995 the FDA approved the first aromatase inhibitor, anastrozole (Arimidex), for postmenopausal women with ER+ metastatic breast cancer whose disease progressed after tamoxifen. Over the next ten years, additional AIs were approved as long-term treatment for postmenopausal women with early-stage disease and first-line treatment for metastatic breast cancer. Recent studies suggest switching from tamoxifen to an AI after several years may lower recurrence risk in postmenopausal women. Tamoxifen and AIs have also begun to be used for early management of hormone receptor-positive metastatic disease.

"Women with hormone-sensitive metastatic breast cancer didn't have many treatment options 20 years ago," says **Lillie D. Shockney, RN, BS, MAS**, university distinguished service associate professor of breast cancer at John Hopkins University School of Medicine. "Hormone therapy may allow these women to live a longer, healthier life."

When Helpline volunteer **Nancy Clark**, of Hendersonville, NC, was diagnosed with ER+ metastatic breast cancer at age 49, the cancer remained stable with tamoxifen and leuprolide (Lupron), a medicine that suppresses the ovaries' ability to produce estrogen.

Five months later, Nancy decided to switch to anastrozole, an aromatase inhibitor. She wasn't satisfied with the cancer being stable, and she had read that anastrozole might offer more benefits. Seven years later, tests continue to show no evidence of cancer.

HER2 and Other Targets

The development of medicines in 1998 that target the *HER2 (human epidermal growth factor receptor-2) protein*, which in about a quarter of breast cancers is involved in the signals that tell the cancer to divide and grow or not, allows doctors to provide options to many women who do not have hormone-sensitive breast cancers and even some who do, says Dr. Norton.

Medicines that attack HER2 provided choices for Claire when she was diagnosed with HER2 positive breast cancer in 2010.



RUTH POGARSKY

"Unlike my first diagnosis, I engaged in frank discussion with my treatment team and was given resources for information on targeted treatments and chemotherapy," Claire says.

When she learned the HER2 signals in the tumor could cause the cancer to grow and recur, she decided to take trastuzumab (Herceptin), a targeted therapy that binds to the HER2 receptor on the cell surface and blocks its function. She also had chemotherapy to enhance the medicine's effectiveness.

The FDA approved trastuzumab for HER2+ metastatic breast cancer in 1998, and in 2006 it was approved in combination with chemotherapy for early-stage, HER2 positive disease.

Because targeted therapies attack specific pathways and features of cancer cells, they may not cause many of the most feared side effects of chemotherapy, such as nausea, vomiting and hair loss. If you're taking one, your doctor will need to monitor you for possible heart damage.

Targeted therapies that cross the blood-brain barrier have lengthened life for women with metastatic breast cancer, explains Ms. Shockney. Lapatinib (Tykerb), which blocks the effect of HER2 and a related protein, HER1, by interfering with a pathway inside the cell, is taken as a pill and has limited heart effects. FDA approved lapatinib in 2007, and it is available in combination with the chemotherapy pill capecitabine (Xeloda) for metastatic breast cancers that stop responding to trastuzumab.

"Targeted therapies offer a refreshing improvement in seeing how cancer can be treated and managed," Ms. Shockney says. With additional research, "we will continue to see more medicines created."

Triple-Negative Breast Cancer

Although doctors did not use the term "triple-negative breast cancer" for hormone receptor-, HER2 negative disease 20 years ago, research revealing the many different types of breast cancer has led to identification of this subtype.

Chemotherapy often provides successful treatment, but researchers hope to find features common among these cancers that will lead to better treatments with fewer side effects.

Many believe triple-negative cancers are related to proteins and enzymes that cause breast cancer growth. Some triple-negative breast cancers contain Vascular Endothelial Growth Factor Receptor 2, a protein that inhibits *angiogenesis*, a process by which tumors create new blood vessels to get oxygen and nutrients they need to grow. A protein called Epidermal Growth Factor Receptor (EGFR), which causes tumors to grow when they produce too much of it, also may fuel these cancers. Researchers are studying an enzyme called polyadenosine-disphosphate-ribose polymerase (PARP), which fixes DNA breaks common in triple-negative breast cancers. Clinical trials of medicines that block or target these proteins and enzymes are ongoing.

Predictive Testing

Doctors are also working to reduce risk of overtreatment, says Ms. Shockney. *Genomic assays*, tests that examine whether groups of genes in cancer cells are present, absent or too active, can help determine if hormone-positive cancers need chemotherapy. These assays predict how likely the cancer is to respond to chemotherapy treatment as well as the likelihood of the cancer coming back in the future.

At the 2005 San Antonio Breast Cancer Symposium researchers reported that a genomic assay called *Oncotype DX* successfully predicted the need for chemotherapy in ER+ disease based on a Recurrence Risk score. *Oncotype DX* uses a tumor tissue sample to examine activity patterns in 21 genes and predict the likelihood of recurrence within ten years.

In 2007 the FDA cleared another test, *MammaPrint*, to assess recurrence risk in early-stage, lymph node-negative breast cancer. This test, performed on a tumor tissue sample during surgery, looks at the activity of 70 genes to predict whether cancer could recur within five and ten years.

Eileen Frazzetta, of New York City, had a bilateral mastectomy after her diagnosis with early-stage, ER+ breast cancer in 2009 at age 51. Because of the tumor's size and stage, her oncologist recommended chemotherapy.

The fifth of five sisters to be diagnosed, Eileen was extremely concerned about having problems with thinking and memory because of chemotherapy. "I am a professional person, and I was worried about prolonging the process of getting back to work," she says.

She suggested *Oncotype DX* to her doctor, which she "had read about online, and we talked about the benefits and open issues," Eileen says.

Eileen's results were not definitive, but they did not suggest a strong need for chemotherapy. She decided to pursue hormonal therapy. She feels confident she made an informed decision based on her test results and goals.



EILEEN FRAZZETTA

Antiemetics "enable you to work, get a paycheck and keep your health insurance, which will reduce anxiety," says Ms. Shockney. "Chemotherapy is getting added into your schedule, whereas 20 years ago it took over your life."

Medicines that build up white blood cell count, like *pegfilgrastim* (*Neulasta*), have helped women avoid fever and hospitalization, Ms. Shockney says.

More research needs to be done, she says, to prevent neuropathies (nerve damage), heart problems, issues with thinking and memory and complications from surgery and radiation. Researchers also must find ways to reduce menopause-like side effects during long-term treatment.

Looking Forward

These advances have provided many new options, but decision making is more complex because all choices have strengths and weaknesses, says Ms. Shockney. Seek information and ask questions until you find a plan that fits your goals and lifestyle.

If you're a long-term survivor, you might wonder what these changes mean for you. Ruth, a Helpline volunteer, has stayed up to date on the "dazzling array of choices" available to newly diagnosed women.

"Every day in the newspaper, there's something new. I'm always wondering, 'Did I miss out? Did I do the right thing?' It can be mind boggling to know all of this!" She is diligent with follow-up testing and asks her medical team how new developments could impact her care.

As researchers learn more about the many types of breast cancer and methods to incorporate individual options and preferences into treatment decision making, medical breakthroughs will continue to expand treatment options. This will impact decision making for all women with breast cancer. If you want to help, consider joining a clinical trial. Visit lbbc.org for more information. 🍷

Managing Side Effects

Researchers are developing new ways to reduce chemotherapy side effects and improve everyday life, Ms. Shockney says.

When **Etsuko Kagawa**, 49, of San Francisco, entered a clinical trial for triple-negative breast cancer that included chemotherapy, she took the medicines *aprepitant* (*Emend*) and *ondansetron* (*Zofran*) to prevent nausea and vomiting.

"I didn't feel sick at all, and I could continue eating and working," Etsuko says. "Though I was weak from treatment, support from colleagues was an invisible drug."



ETSUKO KAGAWA

FALL 2011

Insight

A quarterly educational newsletter from LBBC

Non-profit Org.
US Postage
PAID
Philadelphia, PA
PERMIT NO. 138



354 West Lancaster Avenue, Suite 224
Haverford, PA 19041

LIVING
BEYOND
BREAST
CANCER
LBBC.ORG

NEWS • INFORMATION • EDUCATIONAL RESOURCES • LEARN MORE ONLINE AT LBBC.ORG

... IN THIS ISSUE ...

- 1** MEDICAL INFORMATION
Medical Advances and Treatment Decisions: A 20-Year Retrospective
- 3** PROFILE
Worlds Apart: A Mother and Daughter Cope with Breast Cancer
- 4** QUALITY OF LIFE
How the Trauma of Breast Cancer Impacts Well-Being
- 6** NEWS AND EDUCATION UPDATE
Fall Programs Offer Specialized Information, Support
- 8** GIVING UPDATE
Shop to Support Partnerships Grow Stronger

Calendar

Educational Programs Teleconferences

- OCTOBER 12, 2011
✦ **Metastatic Breast Cancer: Understanding Your Treatment Options**
- OCTOBER 24, 2011
✦ **Understanding the Role of Palliative Care: Exploring What's Meaningful for You**
- NOVEMBER 1, 2011
✦ **Cancer Caregiving: Support from a Distance**
In partnership with Cancer Support Community
- NOVEMBER 17, 2011
✦ **Creating a More Positive Body Image**

Conferences

- OCTOBER 1, 2011
✦ **Annual Fall Conference**
Philadelphia, PA
- FEBRUARY 24–26, 2012
✦ **Annual Conference for Young Women Affected by Breast Cancer (C4YW)**
New Orleans, LA

Special Events

- OCTOBER 16, 2011
Yoga on the Steps: Washington, DC
- NOVEMBER 12, 2011
The Butterfly Ball: Celebrating 20 years of empowering women
Philadelphia, PA

Check lbbc.org for the latest program information



Photos: Coleman Yunger, Laurie Beck Photography

LBBC