

# Insight

An educational newsletter  
from LBBC



... MEDICAL INFORMATION ...

## Tamoxifen: New Findings Stir Questions on Treatment Length

BY ROBIN WARSHAW, FOR LBBC

**L**auren Magliaro, of Rockaway, N.J., plans to have a party in November 2014 when her five-year treatment with the hormonal therapy tamoxifen ends.

Five years has been the standard time length for taking tamoxifen. The daily pill is given to women diagnosed with estrogen receptor-positive breast cancer to keep the cancer from returning and to improve survival.

Lauren takes tamoxifen as *adjuvant* (after surgery and chemotherapy) treatment for stage II, ER positive, lymph node-positive breast cancer. Diagnosed when she was 32, Lauren has suffered difficult side effects, including hot flashes.

"I've been counting down the days," she says. "I'm so looking forward to seeing how I feel when I go off of it."

She also has been thinking about having another child—something she can't do safely while taking tamoxifen because it could harm her fetus.

Then, in December, she heard news reports about a large international study, called ATLAS (Adjuvant Tamoxifen, Longer Against Shorter), presented at the San Antonio Breast Cancer Symposium. Researchers found that taking tamoxifen for 10 years increased the proven benefits over the standard five years of treatment. The findings could lead to extending the length of tamoxifen therapy.

"I was horrified," Lauren recalls. "I said, 'This is the worst news ever!' I realize the value of the study, but it's not a decision I want to have to make."

**Tina Grisham**, of Carthage, Tenn., will also reach the end of her five years on tamoxifen

in 2014. After treatment for a large ER positive tumor with no node involvement, Tina started tamoxifen and experienced night sweats, joint pain and vaginal bleeding.

"It took my body a little while to adjust to it," she says, but then the side effects eased. Now 48, she made lifestyle changes that helped, including losing weight, starting to run and taking a less pressured job.

How would Tina feel if her doctor advised she stay on tamoxifen for another five years? "I'd be perfectly fine with it," she says. "I consider it my security blanket."



LAUREN MAGLIARO

### Thinking About Tamoxifen

Women taking tamoxifen often have a love it/hate it/endure it relationship with the medicine as they balance demonstrated benefits against potential side effects, impact on family planning and the long treatment time required.

Some women experience no side effects. For others, problems range from annoying to uncomfortable to intolerable. A very small number of women have the rare, but most severe, side effects of blood clots or endometrial cancer.

Tamoxifen works by blocking estrogen receptors on breast cancer cells. This keeps estrogen from fueling cancer growth. It also decreases the risk of a first breast cancer in women at high risk of developing the disease because of genetics or family history. For early-stage breast cancer, it is given primarily to premenopausal and perimenopausal women. Postmenopausal women now typically receive medicines called *aromatase inhibitors*, or AIs.

As word spreads about the ATLAS research on taking tamoxifen for 10 years instead of five, many women are



TINA GRISHAM

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#### LIVING BEYOND BREAST CANCER®

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## Dear Friends,



As spring is a time of growth and change, I am happy to announce the launch of a new educational program at LBBC as well as the expansion of a long-standing one.

In January we launched our new monthly webinar, Second Tuesdays. This free educational program offers women newly diagnosed with early-stage breast cancer the opportunity to "drop in" to hear breast cancer basics from a trusted medical expert. Women of all ages can also get answers to questions they may have during this often overwhelming phase of diagnosis. Webinars are held the second Tuesday of every month from noon to 1 p.m. ET.

We have also expanded our free, confidential peer support resource: Women and families who have questions and concerns now have live access to LBBC's Survivors' Helpline eight hours a day, five days a week, with all other calls answered within 24 hours. This adds 35 additional hours for women affected by breast cancer to speak directly with volunteers who have been through or are living with similar diagnoses. A greater need for peer support along with volunteers dedicated to helping others through diagnosis, treatment and beyond made the new hours possible.

For more details, I invite you to read the News and Education Update on page 6 and visit [lbbc.org](http://lbbc.org). I thank you for your continued support and send best wishes from all of us at LBBC.

Warmly,

Jean A. Sachs, MSS, MLSP



Laurie Beck Photography

## LIVING BEYOND BREAST CANCER

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

# Supporting Loved Ones, Living Life: Vernell Kelly's Story

BY JOSH FERNANDEZ

As a mom, wife, friend, hospital scheduling assistant, churchgoer and leader of a local Girl Scout troop, **Vernell Kelly**, 51, tended to put others ahead of herself.

Even when she learned she had stage I breast cancer in spring 2010, Vernell's first concern was disclosing her diagnosis to her family. After she told her husband, **Carey**, Vernell told her daughter, **Carissa**, who had just finished her midterms at the University of Arkansas. Although Carissa didn't handle the news well at first, on the morning of her lumpectomy Vernell got a photo of Carissa standing in a Wal-Mart holding a bouquet of flowers.

"She said she couldn't afford to buy them for me, so she thought the photo would give me a laugh," Vernell says. "And it did."

After discovering the lump in her breast, Vernell began to seek and accept more support for herself. She turned to her colleagues at the MRI center of the Baptist Health Medical Center—Little Rock, telling one of the radiologists what she felt. He advised her to get a mammogram and an ultrasound. Later that week, Vernell learned she had breast cancer.

Having worked with Vernell for 15 years, her doctor colleagues took the news of her diagnosis hard. They offered professional input as much as they could on treatment, follow-up tests and other aspects of care.

"To this day, they still check on me to make sure I'm still getting scans and even offer to look at them for me," Vernell says.

Vernell also reached out to her close friend and hair stylist, **Vera Jefferson**. Vera was diagnosed with breast cancer almost a year before Vernell, so Vernell instantly felt comfortable relying on Vera for emotional support. They talked about everything from loved ones' reactions to diagnosis to concerns about treatment.

"She was the first person I reached out to, because although I had all the information, she was able to talk to me and relate to me," Vernell recalls.

Vernell's 90-year-old grandmother was also a pillar of support. Because she had never seen a doctor nor taken prescription medicine, she was troubled when she learned that Vernell had to undergo surgery, chemotherapy and radiation. But when she saw that

Vernell was confident in the treatment plan, her apprehension subsided, and she showed nothing but support.

"She was just the most comforting overall," Vernell says. "She asked me, 'Have you prayed about it?' And I said, 'Yes ma'am.' Then she said, 'OK, I have, too.' And we moved on to a different conversation topic."

Vernell's concern for others prompted her to be more active in making African-American women aware of their breast cancer risk. She was shocked to learn that about 27,000 African-American women were diagnosed with breast cancer in 2012, and that African-American women have a lower five-year survival rate for the disease—77.5 percent, versus 88.8 percent for white women.

Because of where she works, Vernell thought she was "pretty much aware of everything about breast cancer. Never did I know how high the numbers were for

African-American women," she says.

In addition to participating in a 2010 focus group and photo shoot for Living Beyond Breast Cancer's free booklet, *Getting Connected: African-Americans Living Beyond Breast Cancer*, Vernell has encouraged her family and friends to take screenings seriously, not to hesitate if they experience health issues and to seek treatment and guidance if they are diagnosed with breast cancer. She creates a team each year for the Susan G. Komen 3-Day, and she listens to and supports African-American women newly diagnosed with breast cancer.

When she's not working, going to church or spending time with her husband and daughter, Vernell travels. She recently flew to Atlanta to visit with family and chaperoned a trip to Washington, D.C., for her Girl Scout troop. She will return to D.C. this summer to celebrate the 100th birthday of her college sorority, Delta Sigma Theta.

"Breast cancer put things in perspective," Vernell says. "I learned to do things that I want to do, things like this weeklong celebration. My family, God and work are still high priorities, but so is my overall health. If that's good, [then] I can deal with anything else that comes along." 🌸

**Vernell's concern for others prompted her to be more active in making African-American women aware of their breast cancer risk.**





# Long-Term Survivorship: What It Means to Me

BY JOSH FERNANDEZ

After finishing radiation therapy for breast cancer in 1989, the then 37-year-old **Barbara Musser** transformed her life.



BARBARA MUSSER

An MBA graduate once on the fast track in the corporate world, over the next 24 years Barbara quit her job, got divorced, became a parent, wrote a book, remarried, divorced, and found a new romantic partner before starting *Sexy After Cancer*, an online resource named after her book, which focuses on rekindling intimacy and sexuality after cancer.

"I was interested in making a lot of money, and then my priorities really changed. All of a sudden it was more about living the life I wanted to live," says the now 60-year-old sex educator from San Francisco, Calif.

Barbara is among the many women who have experienced significant changes as they go through the process of living long-term with, through and beyond cancer. But how each woman deals with these transitions and how she views long-term survivorship may vary.

## Defining Long-Term Survivorship

For Barbara, long-term survivorship means living the life she wants and finding personal and professional balance. Emotional and mental healing were integral to her transition into life beyond cancer, because she did not want to live her life "feeling like a victim," she says.

"Just the language we use around cancer disagrees with me, calling [those diagnosed with] it 'victims' and 'survivors,'" Barbara says. "That's not to diminish that it really is a battle for many, many people and [that] not everybody wins that battle, but ... that also can become a self-fulfilling prophecy."

It's been seven years since **Amy J. Koreen**, 48, of Long Island, N.Y., was diagnosed with stage III breast cancer. Because Amy still receives the aromatase inhibitor letrozole (Femara), she still feels the safety net of therapy.

"I hate to sound cliché, but you just live each day at a time and make the most of it," Amy says.

To **Deena Weinstein**, 65, of Portland, Maine, long-term survivorship means "appreciating life fully, but also feeling trepidation whenever confronting any illness or awaiting

results of annual tests." She adds that it also means being available to help others and shifting priorities more readily.

"Even if I hadn't had cancer, by this point in my life I'd probably be thinking, 'Wow, I don't have that much time to get in all that I want to do.' Cancer moved that feeling ahead by a decade or more," says Deena, who was diagnosed nine years ago.

**Betsy Stout**, 59, also of Portland, was diagnosed with breast cancer in 1997. To her, long-term survivorship is about reflection, looking at the positives in life and accepting her limits.

"I learn to live with not knowing and not being in control of everything, because you're not," she says.



BETSY STOUT

## The Impact of Long-Term Survivorship

**Rebecca Crane-Okada, PhD, RN, CNS, AOCN**, a clinical nurse specialist and nurse navigator at Long Beach Memorial Medical Center in Long Beach, Calif., says it's important to develop a follow-up care plan with a healthcare provider before the end of active treatment.

A *survivorship care plan* is a written report including schedules for routine check-ups and exams, discussions on reducing risk of recurrence and other health conditions, cognitive and emotional concerns and long-term side effects.

The end of treatment can be a difficult time, Dr. Crane-Okada says. Instead of experiencing joy, many women feel anxious about being left on their own.

Betsy dealt with a number of medical issues after she finished treatment. In 2004, she had a tissue flap surgery for breast reconstruction where tissue was taken from her belly. Following the procedure, she noticed a bulge on her side. After reaching out to her healthcare providers, an ultrasound revealed she had a tumor on her kidney, which triggered fear associated with an uncle who died from metastatic breast cancer.

"I thought, 'Wow, I'm just like Uncle Julian—I just had breast cancer and now I'm going to have a bunch of tumors, and then I'm going to die,'" she recalls.

After tests revealed the tumor was benign, Betsy was relieved. Because she has a family history of breast cancer, she is undergoing genetic counseling and testing for the BRCA1 and BRCA2 genes.



AMY KOREEN

Amy, who works for an insurance company, is concerned about job security. Her employer was accommodating, allowing her to work on-and-off while she underwent chemotherapy, but even now she finds it difficult to do every task required of her. Regular doctor's appointments, daily hot flashes from hormonal therapy and other long-term side effects make work hard to manage.

"I am still working the same job and have the same health insurance, but maintaining both is a concern for me. What would I do without my health insurance? My health insurance pays for everything," Amy adds.

The hardest reality Amy faced was learning that her treatment might have affected her fertility. "Whenever I saw women walking around with babies, I always felt like I didn't know if that was going to happen for me," Amy says. She still hopes to have a child one day and is considering adoption.

Though she too had fertility concerns, Barbara was able to have a baby with her second husband. Her daughter will be 20 this year.

Tell your oncologist if you are concerned about fertility. You can also meet with a reproductive endocrinologist to discuss your family planning options.

Dr. Crane-Okada says changes in sexual intimacy can be difficult for women during and after treatment.

"Patients taking aromatase inhibitors or an estrogen-blocking agent often experience problems like hot flashes and vaginal dryness. It is important that women voice such concerns so that possible solutions can be offered."

After her active treatment was complete, Barbara attended a workshop on intimacy and sexuality that involved showing attendees her scars. She didn't have reconstructive surgery because it wasn't covered by insurance at the time.

"I stood there shaking like a leaf, saying I felt like 'damaged goods,' and I knew I wasn't beautiful. People standing 10 feet away literally couldn't see the scar and said, 'What scar are you talking about?' A lot of people came up to me and said it looked beautiful," she said.

Others attending the workshop who had been diagnosed with breast cancer shared similar concerns.

"They told me what I had done was very healing for them. To be as open as I was also was healing for me," Barbara recalls.

Deena is passionately and primarily concerned with the cognitive effects of chemotherapy.

"The memory problems I am experiencing and difficulty making decisions shouldn't be this bad at my age—my mind was always sharp [before treatment]," she says.

Deena is participating in a nationwide clinical trial looking at *chemobrain*, or problems with thinking and memory after treatment. She plans on getting further tests, joining or creating support groups and using techniques like meditation to help her to live in the moment, control anxiety and deal with confusion.

As an active participant in Portland's poetry, writing and political communities, Deena has spoken openly about her cognitive impairment, hoping for patience and

compassion so she can remain involved and effective in these communities. But recently she's wondered whether self-disclosure might cause a loss of respect for her and doubts about her capacity to fully participate.

**The end of treatment can be a difficult time, Dr. Crane-Okada says. Instead of experiencing joy, many women feel anxious about being left on their own.**

## Managing Fear of Recurrence

Carey Anders, MD, a medical oncologist and researcher at the University of North Carolina Lineberger Comprehensive Cancer Center, says although most women handle fear of recurrence very well, emotions can be heightened around the time of surveillance tests.

"It's important for patients to recognize that those feelings of recurrence probably are there, and they are just not tapped into. That's why it's important to find strategies and methods to help deal with the feelings of recurrence as opposed to just suppressing them," Dr. Anders says.

When Amy has these feelings, talking in a support group helps.

"You can't spend your whole day worrying, so I don't," Amy says.

Betsy agrees. "If the cancer comes back or it appears in the other breast, I'll deal with it then," she says.

Meditation and embracing positivity helped Deena keep thoughts of recurrence at bay.

"Dying is a part of living," Deena says. "That was a big piece for me to keep in mind while facing the fears and possibilities of recurrence head on."

Barbara says her fear surfaced any time she felt ill during the first two years after treatment. By the third year, she began to live her life without letting fear dominate her.

"Every time I had a symptom like a sore throat I thought, 'Oh, God, the cancer is back.' I've had a few scares, but I have been healthy," she says. "Life is not a dress rehearsal, so I do my best to live my life fully. And if something ever does happen, I'll deal." 🧡



DEENA WEINSTEIN

# Resources Reach Further as Programs Grow

BY NICOLE KATZE, MA

## Enhancing Health and Quality of Life

There's still time to register for our **Annual Conference for Women Living with Metastatic Breast Cancer**, to be held April 13 – 14 at the Loews Philadelphia Hotel. Get information and practical resources to help you live well with stage IV breast cancer during three plenary sessions and more than 15 workshops. Walk-ins are welcome!

Opening plenary speaker **Andrew Seidman, MD**, of Memorial Sloan-Kettering Cancer Center, will discuss advances in metastatic breast cancer care. **Wendy G. Lichtenthal, PhD**, also of Memorial Sloan-Kettering Cancer Center, will cover how to move forward with a stage IV diagnosis. **Linda and Bob Carey**, founders of The Tutu Project, will talk about Linda's experience living with metastatic disease, how they cope and the fundraiser they created to support others with breast cancer.

Visit [lbcc.org/Events/Metastatic-Breast-Cancer-Conference](http://lbcc.org/Events/Metastatic-Breast-Cancer-Conference) for more information and registration. If you can't attend, podcasts will be available after the event on [lbcc.org](http://lbcc.org).



online form and a volunteer will respond within 24 hours. The service is free and confidential; Spanish-language speakers are available. Call (888) 753-LBCC (5222).



## Triple-Negative Research

In February, LBBC began an in-depth assessment of what women diagnosed with triple-negative breast cancer (TNBC) want, what is already available and what should be created to give more access to information and resources.

In early 2014, we will share results and recommendations with support organizations, healthcare providers and women with TNBC. During phase I, LBBC interviewed providers and women with TNBC. During phase II, five focus groups will be held in different U.S. cities to learn about the physical and psychosocial concerns of diagnosis, ending treatment and living with metastatic TNBC. Two groups will be held at our **Annual Conference for Women Living with Metastatic Breast Cancer** April 13 – 14 in Philadelphia.

An executive committee of healthcare providers, women with TNBC and members of the **Triple Negative Breast Cancer Foundation** will advise LBBC throughout the project.

Interested in participating in a focus group? Email [publications@lbcc.org](mailto:publications@lbcc.org).

## Annual Conference Expands

This year's annual fall conference, **News You Can Use: Breast Cancer Updates for Living Well**, will expand to two days. Get updates from expert speakers while connecting with other women and caregivers Oct. 26 – 27 at the DoubleTree by Hilton Hotel Philadelphia Center City.

**Siddhartha Mukherjee, MD, PhD**, will be a keynote speaker at the conference. Dr. Mukherjee is a leading cancer physician and researcher, assistant professor of medicine at Columbia University, a cancer physician at the CU/NYU Presbyterian Hospital and author of the book *The Emperor Of All Maladies: A Biography Of Cancer*.

Visit [lbcc.org/Events/Annual-Fall-Conference](http://lbcc.org/Events/Annual-Fall-Conference) soon for more information.



## Extended Helpline Hours

Have questions, need to talk or just want someone to listen? Call our Survivors' Helpline to speak with someone who has been there.

A trained volunteer affected by breast cancer answers calls Monday through Friday, 9 a.m. to 5 p.m. ET. At any other time, leave a message or submit a request using our



## New Publications

We are proud to announce additions to our educational brochure series.

In **Guide to Understanding Intimacy and Sexuality**, get an in-depth look at how breast cancer diagnosis and treatment can impact your sexual life. Our **Guide to Understanding Hormonal Therapy** discusses how anti-estrogen therapies work to decrease your risk for recurrence, as well as how to manage side effects.

**Metastatic Breast Cancer Series: Guide for the Newly Diagnosed**, created with the **Metastatic Breast Cancer Network**, offers an introduction to what you need to know in the first few months following a diagnosis.

Download PDFs or order print copies at [lbcc.org](http://lbcc.org).

## Programs for the Newly Diagnosed

"Drop in" on **Second Tuesdays: Monthly Webinar for the Newly Diagnosed** to learn breast cancer basics from a trusted

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medical expert, and interact with speakers by voicing or submitting your questions. Webinars are held

every second Tuesday of the month from noon to 1 p.m. ET and are accessible by phone or computer.

The free programs feature a 30-minute, interview-style conversation between an LBBC moderator and expert guest speaker on topics related to a breast cancer diagnosis, followed by a question-and-answer session.

Visit [lbbc.org/Events/Newly-Diagnosed-Webinar](http://lbbc.org/Events/Newly-Diagnosed-Webinar) for more information.

## Tell Us What You Think!

We want your feedback on *Insight!* Take our online survey at [surveymonkey.com/s/2013LBBC](http://surveymonkey.com/s/2013LBBC) to help us improve our programs and services. Enter to win a \$25 gift card for your participation (U.S. residents only).



## C4YW in Seattle

In February LBBC and **Young Survival Coalition** welcomed nearly 600 women, caregivers and medical professionals to the Hyatt Regency Bellevue on Seattle's Eastside for **C4YW**, the Annual Conference for Young Women Affected by Breast Cancer.

In the opening plenary, **Julie R. Gralow, MD**, of the University of Washington School of Medicine, discussed how research impacts breast cancer care; the closing featured **Nancy Buermeyer** and **Connie Engel, PhD**, of Breast Cancer Fund, on protecting your family from toxins and chemicals. **Susan Matsuko Shinagawa**, of Asian and Pacific Islander National Cancer Survivors Network, covered how to turn experience and passion into effective advocacy.

Workshops included clinical trials, employment, sex and intimacy, and family and genetic risk, among others.

Visit [lbbc.org](http://lbbc.org) and [c4yw.org](http://c4yw.org) for podcasts and transcripts of keynote presentations and workshops, and plan to join us

next year! C4YW will be held Feb. 21–23, 2014, in Orlando, Fla. Check [c4yw.org](http://c4yw.org) this winter for more information.

## LBBC Presents

LBBC staff recently attended the **American Psychosocial Oncology Society** annual conference Feb. 14–16. **Katie Creme Henry**, our outreach coordinator, gave a poster presentation on our culturally sensitive publication *Getting Connected: African-Americans Living Beyond Breast Cancer*. **Arin Ahlum Hanson, MPH, CHES**, manager of our Young Women's Initiative, presented findings of our YWI needs assessment (see below for results).

LBBC will also give a presentation on *Getting Connected* at the **Association of Oncology Social Work** conference in June.

## New to the Board

LBBC is pleased to welcome seven new members to our national board of directors:

- **Annemarie Armstrong**, managing director at Saatchi & Saatchi Science
- **Lauren Bolen**, pharmaceutical strategic marketing consultant and partner and practice leader, employer and coalition service at Health Industries Research
- **Philip M. Browne**, managing director of finance and administration at Franklin Square Capital Partners
- **Moirra Rooney**, director of strategic investment at Mission First Housing Development Corporation
- **Todd L. Sherman, CIMA**, portfolio management and family wealth director at Sherman Sobin Group at Morgan Stanley
- **Ramona Swaby, MD**, director of oncology clinical research and development at GlaxoSmithKline
- **Margaret Zuccotti, MEd**

Many thanks to our outgoing board members: **Jennifer L.A. Armstrong, MD**, **Lisa Bayard**, **Robin Bender Stevens**, **Danielle Halstrom**, **Colleen Kryka**, **Sandy Lipstein** and **Barbara Lopez**. 💖

Photos: Bryan Mead, Laurie Beck Photography, Epaul Julien Photography



## YWI SURVEY RESULTS

Our Young Women's Initiative survey asked women diagnosed with breast cancer under age 45 how and where they access support and information, how they want to receive it and what topics interest them. Here's a glance at what they said:

- 70 percent say it's important to have breast cancer information specific to their needs as young women. Only

21 percent found it easy or very easy to find it.

- Although 60 percent said it was very important to have age-specific emotional support, 40 percent had a hard time finding services that met their needs.
- Younger women want different information and want to access that information in different ways than their older peers. Women diagnosed before age 30 were more interested

in learning about sex and intimacy concerns than older age groups and were more likely to want information or emotional support online.

- Limited resources exist for young women on long-term side effects of breast cancer and other survivorship concerns. Even fewer programs exist for select groups of young women, including women of color, women living with metastatic breast cancer and LGBTQ women.

# Shop to Support: An Interview with Everything But Water

BY KEVIN GIANOTTO

In October 2011, LBBC began a partnership with retailer **Everything But Water**. The company's 70 stores coast to coast and online at [everythingbutwater.com](http://everythingbutwater.com) feature an extensive collection of designer swimwear, resort wear and accessories.

In our first year working together, Everything But Water donated a portion of proceeds from the sale of a necklace that offered a secret message, "LOVE," to spell support for women affected by breast cancer.

To celebrate its second year of partnering with LBBC and to raise funds and awareness for our education and support resources, Everything But Water donated 25 percent of proceeds from its Deux Lux for Everything But Water smartphone wristlet. The wristlet was designed to carry a woman's essentials, with compartments to accommodate a smartphone, credit cards, bills, coins and keys.

We recently caught up with **Sheila Arnold**, chief executive officer and president of Everything But Water, to talk about the partnership.



gala, The Butterfly Ball. The past two years we've developed a product specifically for the purpose of donating proceeds to LBBC. We place the product in all 70 of our stores and feature it at the cash register. Last year, we also featured it in our windows. The sales associates are all well-informed about the effort and LBBC as an organization. They have a lot of fun and are committed to spreading the message to customers and selling the product.

**Can you give us the "scoop" on what may be in store for your 2013 October Breast Cancer Awareness Month promotion?**

**Ms. Arnold:** We are working on it—it's too soon to tell, but we have a lot of fun developing products to support the effort. We are looking forward to figuring out what's next!

*For more information on Everything But Water and other corporate partners in our Shop to Support program, visit [lbbc.org/Donate/Shop-to-Support](http://lbbc.org/Donate/Shop-to-Support). To purchase the wristlet, visit [everythingbutwater.com](http://everythingbutwater.com) or a store location near you. ☺*

**How did you learn about Living Beyond Breast Cancer?**

**Ms. Arnold:** When we decided to contribute to breast cancer efforts, we did an extensive search which included asking for referrals from others involved, looking at ratings, etc. We found out about LBBC through someone else involved with the organization, and then after reading about it and talking to [LBBC's CEO] Jean Sachs, we were sold on LBBC's mission and passion for the cause.

**What about LBBC led you to partner with us?**

**Ms. Arnold:** We are a business comprised primarily of female employees, selling to only female customers. Day in and day out, our sales associates strive to make women feel beautiful and confident. Unlike many other organizations that are focused (importantly) on research, we like that LBBC is focused on information and support—things that are so desperately needed. This mission also feels more closely aligned with our own business.

**How would you describe your partnership with LBBC, and how does it meet your company's philanthropic goals?**

**Ms. Arnold:** Our goal is to both raise money as well as awareness for LBBC and its work. We have also helped by donating a gift certificate and goodie bag stuffers to LBBC's annual

## PLANNED GIVING AND YOUR LEGACY

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

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

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

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

For more information, contact Becky Mills at [mbmills@lbbc.org](mailto:mbmills@lbbc.org) or (484) 708-1806.





- 1** (from left) Jackie Roth, Debra Somers Copit, MD, Tyesha Love and Stephanie Lawrence were honored at our annual gala, The Butterfly Ball, on Nov. 10, 2012. Jackie, Tyesha and Stephanie were recipients of LBBC's Going Beyond Award. Dr. Copit received LBBC's highest honor when she was presented with The Founders Award.
- 2** (from left) The 2012 Butterfly Ball Founders Award recipient Debra Somers Copit, MD, and Donna Noce, brand president of the event's presenting sponsor, White House | Black Market.

## Save the Date!

Help raise funds and awareness at **Yoga on the Steps**, LBBC's signature education and fundraising event. The heart of the event is a one-hour yoga class designed for all skill levels and body types led by **Jennifer Schelter, MFA**. After the class, participants and supporters can enjoy refreshments and browse a Healthy Living Expo featuring health and nutrition experts, event sponsors, yoga and fitness studios, vendors, and information about local area nonprofits and service organizations.

The purpose of Yoga on the Steps is to educate communities about healthy living and quality-of-life issues while creating awareness and raising funds for LBBC's education and support resources.

- MAY 19, 2013** ..... Yoga on the Steps: Philadelphia  
**JUNE 13, 2013** ..... Yoga on the Steps: Washington, D.C.  
**JULY 28, 2013** ..... Yoga on the Steps: Kansas City, Mo.  
**SEPT. 15, 2013** ..... Yoga on the Steps: Denver

Register for an event near you and watch videos of past events at the new [yogaonthesteps.org](http://yogaonthesteps.org).



Photo: Laurie Beck Photography

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**Continued from cover**

wondering: Should I extend the treatment I am on? If I finished taking tamoxifen, should I start again? If I am now postmenopausal, should I take an AI for an additional five years instead?

Finding the right answer for you or for someone you care about depends upon understanding tamoxifen, assessing your experiences on it, thinking about a possible future pregnancy and talking with your oncologist about your individual situation.

Because early results of the ATLAS trial were first presented in 2007, **Julie R. Gralow, MD**, director of breast medical oncology at Seattle Cancer Care Alliance, has been having such discussions for several years with women who are “at highest risk of recurrence” after finishing five years of tamoxifen. That group includes those who had large tumors or several positive lymph nodes at diagnosis. She asks about any side effects experienced on tamoxifen and how each woman feels about stopping.

Based on that information, Dr. Gralow has recommended that some premenopausal women continue tamoxifen longer.

“Am I doing it with everyone? No,” she says, noting there are considerations other than lowering recurrence risk beyond that achieved by five years of treatment. “Is this someone who barely got to five years, or is this someone who tolerated tamoxifen well? The impact on quality of life is a big question.”

Professional organizations such as the American Society of Clinical Oncology (ASCO) and National Comprehensive Cancer Network (NCCN) have not yet changed recommendations for the length of tamoxifen therapy but are expected to address the issue. “I don’t think anybody is going to say that it should be 10 years for everyone,” says Dr. Gralow.

## ATLAS Study Results

More than 30 years of clinical trials have shown that tamoxifen helps prevent the return of breast cancer. The medicine also has a carryover effect that extends protection for years after treatment ends.

Since the early 1990s, research has looked at how long women should stay on tamoxifen. Two years were shown to be better than one and five years better than two. Researchers began examining whether 10 years would be of even more help.

With extended treatment time, rare but serious side effects emerged, including an increased risk of endometrial cancer and blood clots.

Studies in the early 1990s found no benefit for longer treatment. In 1995, the National Cancer Institute (NCI) recommended limiting tamoxifen to five years. Later research produced conflicting findings, so the five-year standard held.

The recent ATLAS study looked at 6,846 women diag-

nosed with ER positive breast cancer who had completed five years of tamoxifen with no recurrence. Half of the women were assigned to take it for five more years; the other half stopped treatment. Unlike earlier studies which only looked at node-negative women, about half of ATLAS participants had positive lymph nodes.

Recurrence, mortality and serious side effects were recorded for years five to 14 after each woman’s diagnosis (years one to five were the original tamoxifen therapy timeframe). No difference in recurrence or mortality was found in years five through nine between the women who continued tamoxifen and those who stopped.

Improvements came in years 10 to 14. Women continuing tamoxifen had a 25 percent lower recurrence rate and 29 percent lower breast cancer mortality rate. That produced an absolute reduction in mortality of 2.8 percent—a modest number, but representing more survival.

“Earlier studies showed that women who completed five years of tamoxifen and then discontinued therapy gained benefit compared to women who had never taken tamoxifen,” says **Douglas Yee, MD**, director

of the Masonic Cancer Center at the University of Minnesota. “ATLAS extends these results showing that treatment with tamoxifen for 10 years is better than stopping at five years.”

ATLAS also found that among women ages 50+ who continued tamoxifen past five years, the risk of endometrial cancer and *pulmonary embolism*, or blood clots, rose. Premenopausal women in the 10-year ATLAS group showed no increase in the most serious side effects.

For women who become postmenopausal during their first five years of tamoxifen, “the clinical trial data argue more strongly that you switch to an AI,” Dr. Yee says.

**Elizabeth M. Taylor**, of Buffalo, N.Y., was diagnosed at 51 with stage II, node-negative, ER positive breast cancer. Elizabeth was on tamoxifen for three years when she changed to an AI. Because she had severe stiffness and joint problems on the AI, she was put back on tamoxifen for two more years, then given a different AI. Tamoxifen gave her hot flashes, but she found the pain on AIs much worse. She remains on AIs, as her doctors want her to have 10 years of adjuvant treatment. (Current standard AI treatment lasts for five years.)

**More than 30 years of clinical trials have shown that tamoxifen helps prevent the return of breast cancer.**

ELIZABETH M. TAYLOR



CARLA ZAMBELLI



## Tamoxifen Effects

About 20 percent of ATLAS participants chosen for longer treatment stopped taking tamoxifen before they completed 10 years. Even on the standard five-year regimen, women stop



early or never begin for two common reasons: side effects and wanting to become pregnant.

While side effects are Lauren's main concern, both reasons are influencing her to not want another five years. She hopes her side effects will end when she stops the medicine. "If I stay on another five years, I'll be 43, and with chemo and my advanced age it'll be almost impossible to get pregnant," she says.

**Carla Zambelli**, 48, of West Chester, Pa., has had hot flashes, mood swings, dry skin, weight gain and insomnia since starting tamoxifen for stage II, node-negative, ER positive breast cancer.

"I might have a hard time taking it for 10 years, but if they told me I had to, I probably would," she says. "What's the alternative? I don't want a recurrence."

**Cheryl Garner** heard women talk about side effects in her support group. "I was a little scared to start it, hearing some of the stories," she says.

Diagnosed with stage IIA, node-negative, ER positive breast cancer, Cheryl has now been on tamoxifen for four years—including while serving in Afghanistan as a lieutenant colonel in the U.S. Air Force. She developed a benign ovarian cyst but no other side effects. "Taking tamoxifen wasn't as bad as I thought it would be," she says.

But extending treatment could affect her professionally. "In the military, as long as you're seeing an oncologist, it limits opportunities overseas," she explains.

Cheryl describes herself, at 40, as at "a point where I want to be done with it" to enjoy activities with her two young children and have no military duty limitations.

She plans on talking with her oncologist and possibly getting a second opinion about whether to continue beyond five years.

At age 28, **Meg Beazley** is on tamoxifen and wants a family in the future. Recently diagnosed with stage I, node-negative, ER positive disease, her doctor told her she should probably continue tamoxifen for more than five years due to her age. The doctor

said Meg could take a break after five years, have a baby, then resume tamoxifen. "I'm grateful to have something that's pretty tried-and-true," she says.

Women on AIs also wonder whether ATLAS results mean they should stay on treatment longer. **Margie Williams**, 64, of Redding, Calif., has joint and hip pain and "fuzzy thinking" on AIs for stage I, node-negative, ER positive breast cancer. For now, she is following her doctor's urging that she continue but, due to ongoing side effects, Margie is not certain that she will complete an additional five years.

"Oncologists have a hard time talking about side effects," she says. "They don't want to discourage you from taking a drug that could be life-saving."

## To Start Again Or Not?

Taking a pill every day for years can be tough. It may be a reminder of breast cancer or prolong unwelcome effects. Meg, on tamoxifen only a few months, has trouble remembering to take it daily.

**Jenee Bobbora**, of Houston, took it diligently for five years. Diagnosed in 2003 with stage IIIC inflammatory breast cancer with positive lymph nodes, she was 32, tested positive for the BRCA2 gene mutation and had a family breast cancer history. When her tamoxifen therapy was ending, Jenee read about ATLAS, then in progress. She convinced her doctor to let her continue. That lasted 2 1/2 years.

About 18 months after she stopped, the ATLAS findings were announced. Jenee asked to start again.

"I have been cancer-free since completing treatment, and I give a lot of that credit to tamoxifen," she says.

Her doctor thought it would provide only "a tiny bit of improvement," but agreed. Jenee is back on tamoxifen. According to Dr. Gralow, starting tamoxifen again after a time gap should not create a problem. She sees it as appropriate mostly for women with higher risk of recurrence.

**Michele Rumfola**, of San Francisco, completed five years of tamoxifen after being diagnosed with stage I, grade 3, ER positive breast cancer. She has been off tamoxifen for three years. At 38, she would like to have a baby in the near future.

"I didn't hate tamoxifen, but being off it, I like my body being healthy," she says. "I'm also the type of patient to do anything to not have [breast cancer] happen again."

Hearing about ATLAS "throws you back into that wondering. Every decision you make weighs on you," says Michele. "Ultimately, what is the decision that is going to make me feel comfortable and not feel worried or regretful?"

A lot depends upon how much value each woman places on a treatment, Dr. Yee says. "Attitudes vary."

Dr. Yee is inclined not to extend treatment for women with smaller tumors or at less risk of recurrence, or for those who don't have cancer in their lymph nodes.

"Some of those women are uncomfortable with that," he says. "ATLAS allows us to have that discussion."

Talk with your doctor about side effects, family planning and other concerns you may have. Reviewing the statistics with your doctor can help you understand the value of continuing treatment and make an informed decision based on your comfort level.

For more details on the study, visit [lbbc.org/Understanding-Breast-Cancer/Breast-Cancer-News/Taking-Tamoxifen-for-10-Years-Lowers-Recurrence-and-Mortality](http://lbbc.org/Understanding-Breast-Cancer/Breast-Cancer-News/Taking-Tamoxifen-for-10-Years-Lowers-Recurrence-and-Mortality). 🍷



JENEЕ BOBBORA



CHERYL GARNER



MEG BEAZLEY



MICHELE RUMFOLA



SPRING 2013

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**Long-Term Survivorship: What It Means to Me**

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**Resources Reach Further as Programs Grow**

**8** GIVING UPDATE  
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## Calendar

### Educational Programs

#### Webinars

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

MAY 14, 2013

✦ **Second Tuesdays:**  
**Living Beyond Breast Cancer's  
Monthly Webinar for the  
Newly Diagnosed**

MAY 15, 2013

✦ **Anxiety and Depression  
After Breast Cancer**

JUNE 20, 2013

✦ **Annual ASCO Meeting Update**

#### Conferences

OCTOBER 26–27, 2013

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

FEBRUARY 21–23, 2014

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

### Special Events

MAY 19, 2013

**Yoga on the Steps: Philadelphia**

June 13, 2013

**Yoga on the Steps:**  
**Washington, D.C.**

July 28, 2013

**Yoga on the Steps:**  
**Kansas City, Mo.**

September 15, 2013

**Yoga on the Steps: Denver**

October 12, 2013

**The Butterfly Ball**  
Philadelphia, Pa.

Check [lbcc.org](http://lbcc.org) for the latest  
program information



Photo: Bryan Mead

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