

# Insight

A quarterly educational  
newsletter from LBBC



## Knowledge Is Power: Tips and Tools for Managing Your Medical Records

BY ANNA SHAFFER

Throughout your life, your medical records get spread out among your providers, as each facility or doctor involved in your care keeps a separate record for you.

When you were diagnosed with breast cancer, you may have wished you had that information in one place—how do you keep track of everything when you're seeing multiple doctors and getting different kinds of therapy? Combining your separate records into a single, personal medical record creates a complete picture of your medical history while helping you take control of your care.

A personal medical record allows you to share accurate information with new healthcare providers, ensuring you continue to receive the best care possible. **Megan Worley**, 23, of Canton, Ohio, began collecting her own records after she was diagnosed with breast cancer three years ago. She had just moved from Georgia to North Carolina, and she couldn't start treatment without them.

"I had to go back to Georgia to get the records. After that, I had enough," Megan says. "I decided I needed to have a copy of everything."

**Pam Carter**, 58, of Minneapolis, began collecting her records a year after her diagnosis to establish eligibility for Social Security Disability Insurance. Pam had a number of other medical conditions, and keeping updated records helped her maintain a holistic view of her health.

"I would make notes as to what symptoms I had and questions I wanted to ask the doctor.

I was seeing a lot of doctors, so it kept me organized," she says. "My doctors take me more seriously because I have the information, and they know I write it down and pay attention to it."

A personal medical record can come in handy if a record is lost or destroyed.

"Women have been trained that no news is good news, but no news may mean results of a test have been lost or misfiled," says **Marie Savard, MD**, a women's health expert and author of *Save Your Own Life: The Savard System for Managing—and Controlling—Your Health Care*. "The patient is the only constant in our healthcare system. Doctors' offices often don't have great tracking systems, so you have to be your own safety net."

You also shouldn't assume that your doctors have all your information when they make a diagnosis, Dr. Savard says. "You may assume your doctor has looked at all your previous mammograms and test results, but they may not have found the files or known about them in the first place."

Keeping a full medical history enables you to create a treatment summary to share with your primary care doctor as you transition into life after treatment.

"At the end of the day, no one knows more, cares more or is in a position to have the information all in one place than you," Dr. Savard says. "Having the information in your own hands is one of the more powerful tools you have to fight the cancer; it can be life-saving at times."



MEGAN WORLEY



PAM CARTER

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## 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](mailto:mail@lbbc.org)  
Website: [lbbc.org](http://lbbc.org)

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## Dear Friends:

As LBBC celebrates 20 years of serving women and families affected by breast cancer, I am reaching the end of my first year of living without my mom. The culmination of these milestones makes me reflect on the lives LBBC has touched over the last two decades, as well as the impact one person can make during her lifetime.

LBBC was formed out of a need to answer the many questions asked by women diagnosed with breast cancer. LBBC initially responded to this unmet need by holding a conference to give women the chance to learn from experts and each other. Twenty years later, we continue to answer questions and provide support through an array of physical programs, publications and online communications so that no woman has to face a breast cancer diagnosis alone.

We ended 2011 with the wonderful news that LBBC was one of seven organizations selected to receive a grant from the Centers for Disease Control to enhance our programs for young women with breast cancer. This award—our first federal grant—reaffirmed the importance of the work we have been doing for young women since 1996. In the first year, federal funding for the program totals \$250,000.

I continue to hold on to my mother's practical wisdom about politics, people and life that guided and supported me for 48 years. Her impact on me was so great that she never feels far away. As the year comes to a close, I will make a donation to LBBC in her memory. I ask that you consider doing the same in honor or memory of someone who has inspired you.

From all of us at LBBC, I wish you a happy and healthy New Year.

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.*

# Vivian Chan: How Breast Cancer Changed a Young Woman's Direction

BY BARBARA LINK, FOR LBBC



**Vivian Chan** was standing in a gift shop at Hawaii Volcanoes National Park when she received a call from her breast surgeon.

The news was shocking—she had *mucinous carcinoma of the breast*, a rare form of invasive ductal carcinoma not usually found in young women. She had always had cystic breasts, and she was sure the lump she had felt would be benign. After all, she was only 25 years old.

"It was a bizarrely symbolic place to discover I had breast cancer," says Vivian, who was on vacation with her sister. "Half of the Big Island is covered in black sand from volcanic eruptions. As you travel along the perimeter, you see the change from luscious green to utter, desolate black, and then this lush, tropical forest again. I went into a corner of the shop and cried."

Vivian didn't tell her sister until they returned home to New York. In fact, she told very few members of her circle in the six months following her diagnosis.

"I had a really active social life, and I didn't want my relationships to change because I had cancer," says Vivian. "I didn't want people to treat me like I was fragile. I didn't want to lose my sense of 'normal.'"

The cancer was categorized as slow-growing. But after several lumpectomies, doctors continued finding cancer in healthy tissue, and Vivian learned that she would need chemotherapy.

"That's when I decided to 'come out' to my family and friends," Vivian says. She threw a "chemo party" featuring an impromptu auction and donated proceeds to help fund cancer research at New York University, where she would receive treatment.

"I was so excited about the donations and support that when I arrived to begin treatment the following day, the physician's assistant told me I was the most ecstatic person that ever came to see him," Vivian recalls.

Vivian's chemotherapy treatments—a combination of Adriamycin, Cytoxan and Taxotere (doxorubicin, cyclophosphamide and docetaxel) over four months—were followed by 25 sessions of radiation. She was surrounded by loved ones on every visit.

"I learned that friends and family are key," she says. "The support I received carried me through the whole experience."

Slowing down was Vivian's most significant challenge. At the time of her diagnosis, she was working as a government paralegal, volunteering at several community organizations and had just been accepted into a nonprofit fellowship at NYU.

"My life had to be stripped down to its bare bones—working nine to five, doctor's visits, chemo sessions and home to lie down on my couch and watch movies," Vivian says. "Not having enough energy to hang out with my friends was crushing. I obviously understood I had this paramount issue in my life, but letting go of socializing was momentous for me."

As far as her romantic life, Vivian says she didn't want to expend any energy in that department. "I didn't think it would be fair to start creating a relationship with someone else when a large part of me would be otherwise engaged," she says.

Despite her "firm decision," a few months after Vivian's diagnosis, she began dating someone who had been a friend for several years. They are still together today.

Among the most concrete changes in Vivian's life was a complete shift in her career path. "I thought I wanted to go to law school," she says. "But during treatment, I saw how healthcare professionals have this amazing job of helping people in a clearly obvious way. I had this 'eureka' moment." She applied and was accepted to the post baccalaureate pre-med program at Bryn Mawr College.

It was then that she discovered LBBC just down the road and biked over to volunteer. Today she serves as a Survivors' Helpline volunteer, offering peer support, information and hope to other women who need it.

"When I was diagnosed, talking with breast cancer survivors was instrumental," says Vivian. "It is so reassuring to talk to someone who has been through it, even if their diagnosis and their treatment choices differ from yours. I want to be that source of support for other women."

Now age 29, Vivian is back in New York working in hospital research, volunteering as an SAT tutor in Chinatown and applying to medical school. She is taking hormonal therapy with tamoxifen and goserelin (Zoladex), as well as zoledronic acid (Zometa) to keep her bones strong.

"You do a lot of growing up going through a cancer experience," says Vivian.

"I am much more settled now. My priorities are clearer. My perspective is better. It's a weird thing to say, but I think I'm funnier. Going through something that heavy makes everything else a whole lot lighter." 🍷

**"I learned that friends and family are key," Vivian says. "The support I received carried me through the whole experience."**

# Express Yourself: How Creative Therapies Promote Health and Healing

BY MICHAEL J. FORMICA, MS, MA, EdM

Holidays can be stressful because they may bring up emotions and reminders that are difficult to manage.

Creative therapies like art and music can provide an outlet for your feelings that supports and sustains you, both in your everyday life and if things become overwhelming.

In January 2010, 42-year-old **Sharon Marroquin**, of Austin, Tex., was at lunch when she received a phone call that would change her life forever. The news: she had early-stage breast cancer.

Since that day, Sharon says she has not felt like the same person and often doesn't recognize herself. "My body [feels like] a foreign puzzle with missing pieces," she says.

Like many women affected by breast cancer, Sharon used the healing power of art to help put those pieces back together. It not only transformed her experience of breast cancer, but it also made coping with its lasting psychological effects easier.

"The creative therapies are an extremely important component of integrative medicine—particularly integrative oncology," says **Barrie Cassileth, MS, PhD**, chief of integrative medicine and Laurance S. Rockefeller chair in integrative medicine at Memorial Sloan-Kettering Cancer Center in New York. "For many [women], being able to express themselves through art is very therapeutic," she says.

Researcher **Inger Öster, RNT, MSc**, of Umeå University in Sweden, recently reported that art and music therapy can help lessen anxiety and depression, increase self-esteem and improve health in women with breast cancer. After taking part in an art therapy program, participants showed a significant improvement in coping skills. Music therapy can also help manage pain through relaxation.

**Peg Salinger**, 72, of Phoenixville, Penn., was diagnosed 26 years ago and had a recurrence nine years later. In 2008, when she was diagnosed with bone metastasis, Peg had already been painting for about two years. She found art to be a "little island of



SHARON MARROQUIN

Photo: Todd V. Wolfson

certainty" at a time when she felt she had little control over what was happening.

"When I was diagnosed with metastatic disease, I had to learn about myself and about my cancer," Peg says. "[Painting] took on more meaning when I realized the uncertainty I was dealing with. This was something I could begin and I could finish. There it was. It was certain. I liked that."

## Art Therapy

Creating art can be healing, life-affirming and life-enhancing. Art therapy helps you organize your thoughts and feelings and express them through drawing, painting, working with clay, metalsmithing, sculpture and more.

"With a cancer diagnosis you can come to the end of your alphabet, and you need to create new letters. Art therapy expands your vocabulary," says **Edna Bacon, MA, MAAT, ATR-BC**, a board certified art therapist at Cancer Wellness at Piedmont Hospital in Atlanta. "It allows you to create these new letters and get a vocabulary to live this different life, or this new life, or this same life that has something you need new words for."

Expressing yourself through art can enhance mood, boost self-awareness and improve self-esteem. Research shows it also helps to reduce symptoms of mental distress and grief.

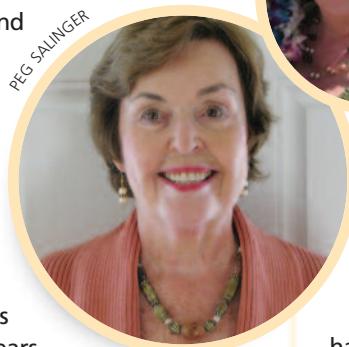
"[Art therapy] has taught me that everything I need is inside me. It's teaching me flexibility and ways to look at things differently. I have found a new joy in this crazy journey," says **Sharon Greer**, 44, of Escondido, Calif., who is living with metastatic breast cancer.



SHARON GREER

Art therapy sessions have little structure, focusing mostly on the creative process. At a meeting with an art therapist, you will discuss and interpret the meaning of what you create. This helps you increase your self-awareness and better cope with the emotional challenges of breast cancer. It also encourages you to exercise parts of your brain that might have been affected by chemotherapy or other treatments.

"Just doing the art itself can be cathartic," says Ms. Bacon. "Art is symbolic speech, giving you words where you may not have had words before."



PEG SALINGER

The emotional and physical benefits of art therapy that help improve your quality of life can also impact your overall experience of illness. Research suggests that emotional expression can positively affect your immune and heart systems.

"Making art is a life thread, an infusion of beauty and purpose and the path to a meaningful life," says **Susan Olds**, 58, of North Bend, Wash. "Art-making is my chief source of healing, next to my medical treatments. When I hear the term 'quality of life,' it means continuing to make art no matter what the future holds."

SUSAN OLDS



MARILYN SPEEDY

## Music Therapy

Recently, music therapy has become more readily available through treatment programs in hospitals, cancer centers and outpatient facilities.

Music therapy is not just listening to music, Dr. Cassileth says. Like psychotherapy, it's delivered by a professional, but music can sometimes be more effective than words in accessing and expressing difficult emotions.

**Marilyn Speedy**, 80, of Youngtown, Ariz. says, "Music [has been] my lifeline since I was diagnosed with metastatic breast cancer in 2005. It brings me so much joy, and...is the very best therapy."

A music therapist evaluates your strengths and needs. Your treatment plan may include creating, singing, playing, moving and listening to music. This exposure to music can help strengthen you physically, emotionally and socially, carrying over to areas of your life beyond treatment.

"There is no such thing as a 'typical' music therapy session. [It] will look vastly different depending on whom we work with and where we work," says **Kimberly Sena Moore, MM, MT-BC**, a board certified music therapist, neurologic music therapist and director of Neurosong Music Therapy Service in Warrensburg, Mo. "With individual sessions, we're working mostly on pain management and anxiety reduction. Group work is different...those sessions are geared more [toward] emotional, spiritual and social support—helping to process the journey."

Certified music therapists have a bachelor's degree in music therapy through a program approved by the American Music Therapy Association. To practice, they must be certified by the Certification Board of Music Therapists. Those who work in a cancer setting have typically done a practicum or internship in a hospital or cancer center that uses complementary therapies as part of cancer treatment.

"Music has a unique ability to touch us," Dr. Cassileth says. "It often reaches a primitive part of the brain and parts of the body and feelings and everything else that is beyond what words could ever accomplish."

"I have watched people change; watched people's lives change right in front of me—it's very transformative," says **Yvette Pecoraro** of Philadelphia, a yoga teacher who uses *kirtan*, the chanting of mantras, as a healing method with women affected by breast cancer. "I'm a real believer that [a woman's] own instrument—her voice—has deeply rooted healing potential," she says.

Along with providing an emotional outlet, music therapy lessens pain and anxiety in women diagnosed with breast cancer receiving chemotherapy or radiation treatments, a recent study shows. Music therapy also reduces anxiety for those undergoing procedures that can cause serious emotional distress—such as a biopsy or imaging to detect metastatic disease—and it has been used to reduce pain after surgery.

"The beauty and power of music therapy lies not only in the music itself," Ms. Sena Moore says. "It also lies in the relationship between the therapist and the client. Another component is our understanding of the science behind why it works, which helps make what we offer an accessible and powerful therapeutic approach."

**"Music has a unique ability to touch us," Dr. Cassileth says. "It often reaches a primitive part of the brain and parts of the body and feelings and everything else that is beyond what words could ever accomplish."**

## Where Can I Find It?

Art and music therapies are offered in hospitals and cancer centers that have an integrative medicine program. Check whether these practices are available to you by talking to a member of your healthcare team, a hospital social worker or a patient navigator. You can also contact the **American Music Therapy Association** at

[musictherapy.org](http://musictherapy.org) or the **American Art Therapy Association** at [arttherapy.org](http://arttherapy.org) to find a certified therapist in your area.

Many insurance companies cover the cost of complementary therapies when delivered by a certified professional. Contact your insurance provider to see if these services are covered by your policy.

You can find less formal programs in your community through support groups and classes. Dr. Cassileth says you can benefit from doing creative arts on your own.

"I would encourage [women] to seek creative therapies, even if they want to do it by turning on some music and just lying there," she says. "It really helps." 🧡

# LBBC Expands Programs for Young, Metastatic, African-Americans

BY JANINE E. GUGLIELMINO, MA

## Heading to the Big Easy

We're just months away from **C4YW**, the annual conference for young women affected by breast cancer, to be held Feb. 24–26, 2012, at the Hyatt Regency in New Orleans.

C4YW, a program of LBBC and **Young Survival Coalition**, provides insight and guidance on the medical, practical and emotional concerns of women diagnosed before age 45. With support from Lead Sponsor **Susan G. Komen for the Cure**, this conference offers a rare chance to meet with experts in research, support and care while connecting with hundreds of women your age.

This year's offerings include **Sharing Our Stories**, a plenary session featuring six perspectives on living young with breast cancer. Moderator **Generosa Grana, MD, FACP**, of Cooper Cancer Institute, will explore treatment decisions, long-term health, relationships, fertility and more. **Sabitha Pillai-Friedman, PhD, LCSW**, of Widener University, tackles **Reclaiming Your Sexual Mind and Body**, and a special appearance by TV nutrition coach **Dr. Ro** focuses on **Livin' Healthy** during and after treatment.

New this year: a body image/reconstruction open house on Friday evening. Check out reconstruction and breast form options, and try out hip and fashionable body wear. Throughout the weekend, attend classes in belly dancing, yoga and Zumba. You won't want to miss the Saturday night dance party, where we'll kick it N'awlins style.

Workshops explore varied topics, including genetics, breast cancer during pregnancy, side effects, complementary methods, social media, advocacy and the environment. You'll also find sessions for women with triple-negative and metastatic breast cancer, caregivers and lesbians.

Registration is open at [www.C4YW.org/register](http://www.C4YW.org/register). Travel grants and fee waivers are first-come, first-serve, so apply today. Follow us on Facebook and Twitter at @C4YW for program updates.

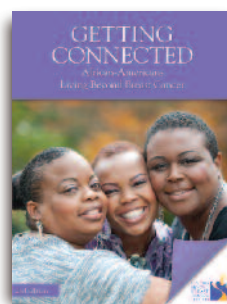


## Programs Grow

A federal agency has awarded LBBC a multiyear grant to develop programs and services for young women affected by breast cancer.

The **Centers for Disease Control and Prevention**, an agency of the U.S. Department of Health and Human Services, chose LBBC as one of seven winning groups from among 53 applicants. In the first year, federal funding for the program totals \$250,000.

The funding provides support to LBBC to assess the unique needs of women diagnosed before age 45. Findings will help us improve and expand services for premenopausal women. We will share our results widely to help improve the quality of life for all young women.



## Tell Your Providers

The women who lent their voices to **Getting Connected: African-Americans Living Beyond Breast Cancer** need your help to spread the word.

The 44 women participated in focus groups in Chicago, Little Rock and Philadelphia. Their words formed the basis of our second edition, which contains expanded sections on side effects, breast reconstruction, online medical information and follow-up care.

"This publication empowers women during a time of confusion and darkness," says **Stephanie Carter-Logan**, a Chicago participant. "It shows them that they have not been given a death sentence but an opportunity to rediscover themselves and what is really important to them."

Released in October, the second edition of **Getting Connected** contains powerful photos of the participants with their caregivers, children and doctors.

"I know several women right now who can benefit from seeing the many beautiful, strong faces of women from various backgrounds and ages," says **Sharon Rejistre**, of Little Rock. "Although we are all African-Americans, and we are all very different, we are 'overcomers' in the same way."



SHARON REJISTRE



STEPHANIE CARTER-LOGAN

The women started a Facebook group. To join the conversation, search for "Getting Connected: African-Americans Living Beyond Breast Cancer." We'll keep you updated on news, events and ideas.

*Getting Connected* is free to individuals and groups. Healthcare providers and support-group leaders who use *Getting Connected* may order the booklet in bulk. Visit [lbbc.org](http://lbbc.org) or call (610) 645-4567 for more information.

## Event Marks Milestone

LBBC kicked off a yearlong celebration of our twentieth anniversary at **News You Can Use: Breast Cancer Updates for Living Well**. Podcasts and transcripts from this conference, held Oct. 1 in Philadelphia, are available at [lbbc.org](http://lbbc.org).

Among the day's highlights were plenary sessions from **Wendy Demark-Wahnefried, PhD, RD**, and **Lu Ann Cahn**. A professor of nutrition sciences at UAB Cancer Center, Dr. Demark-Wahnefried offered tools and tips for improving diet during and after treatment. Ms. Cahn inspired with her story of living well for two decades after her 1991 breast cancer diagnosis.

The 300-plus participants gathered at lunchtime for a group photo honoring LBBC's anniversary. Afterward, they attended workshops on triple-negative and metastatic breast cancer, reconstruction, lymphedema, menopausal symptoms and healthcare reform. One popular workshop, **Still Strong and Still Speakin' Out**, focused on communication in African-American families. Download a recording of this and other workshops at our website.



## 'Hot' Off the Presses

LBBC's *Understanding Hormonal Therapies*, the latest title in our brochure series, is set to arrive this spring.

This guide explains the basics of hormonal treatment for women of all ages. Get tips to manage hot flashes, bone pain and other side effects. Explore the emotional side of hormonal therapy and ways to lessen risk for recurrence after treatment ends.

To preorder or request other brochures, please visit [lbbc.org](http://lbbc.org).

## You: Front and Center

LBBC was chosen to give one of two best abstract oral presentations at **ABC1: Advanced Breast Cancer First Consensus Conference**, in Lisbon, Portugal.



**Elyse Spatz Caplan, MA**, director of programs and partnerships, delivered findings from our survey of 600+ women. The goal of the event, held Nov. 3–5, was to develop standard, evidence-based guidelines for treating metastatic breast cancer.

The latest title in our metastatic breast cancer series, *Understanding Palliative Care*, is now available at [lbbc.org](http://lbbc.org). This guide explores the value of palliative care for ongoing treatment, the differences between hospice and palliative care and the importance of open communication. It contains information on managing pain and using complementary therapies.

For in-person support, consider joining us for the **Annual Conference for Women Living with Metastatic Breast Cancer** on April 28–29, 2012, in Philadelphia. Limited travel grants and fee waivers are available. Get the latest details at [lbbc.org/events/metastatic-breast-cancer-conference](http://lbbc.org/events/metastatic-breast-cancer-conference).

## Goodbye, Hello

LBBC's board of directors recently elevated **Byron Hewett** to chairperson for a two-year term, from 2012 through 2014. Mr. Hewett is executive chairman at BioBehavioral Diagnostics and the former president and CEO of Immunicon Corporation. Six new members also were elected:

- **Andrea Barsevick, PhD**, associate professor at Fox Chase Cancer Center
- **Beth L. Haas, Esq**, attorney and assistant teaching professor at Drexel University
- **Irene Kelso**, founder, CEO and president of Professional Recovery Services
- **Kathleen Kovach**, senior organizational development business partner at Independence Blue Cross
- **Kimberly Kubek, MD**, director of imaging at Diagnostic Breast Center in Newtown Square, Penn.
- **William C. Luff**, CEO of WAVCon Audio Visual Consultants

Our staff offers its deep gratitude to **Lisa Bayard**, our standing board chair, who steps down at the end of the year but will remain on the board. Many thanks also to those members leaving the board: **Denise Hyater**, **Cynthia Livingston, MSW**, and **Andrea Pedano, DO, FACOFP**. Thank you for your service!

## Request a Call

Did you know you can reach the **LBBC Helpline** day or night? Simply use our "Request a Call" feature from any page of [lbbc.org](http://lbbc.org). Click on the link and fill out a short form; a volunteer will call you back within 24 hours. ☺

Photos (middle): James Murphy of Creative Images

# October Promotions a Rousing Success

BY STACIA WEAVER, MS, AND KEVIN GIANOTTO

This October, over 700 **Fashion Bug** stores across the country conducted a fundraising initiative for LBBC to provide education and support services for the 230,000 women who are diagnosed with breast cancer annually.



A national outreach program included public service announcements featuring five women affected by breast cancer and information on LBBC's *Guide for the Newly Diagnosed*.

"Fashion Bug and LBBC's goal was to reach newly diagnosed women at a time when the organization's resources and programs can help them the most," says **Jean A. Sachs, MSS, MLSP**, chief executive officer of LBBC. "We are so appreciative of Fashion Bug's generosity and commitment to raise a minimum of \$400,000 to support our educational resources and support services."

Throughout Breast Cancer Awareness Month, "Fashion Bug stores donated 100 percent of proceeds from the sale

of an Inspirational Screen Tee and implemented a Round-Up-At-The-Register campaign," says **Kristin Mongello**, director of marketing for the women's clothing retailer.

Five women served as the campaign's official "face" and were featured in the PSAs. **Tyesha Love, Kathy DiGiorgio, Alice Budno Hope, Lisa Wetherhold Niedrowski** and **Lorie Lavinson** were professionally styled and photographed wearing the Inspirational Screen Tee, and their photograph is featured in each of the PSAs.

"This is one of the few times that we didn't use professional models for one of our fashion shoots," Ms. Mongello says. "Yet, you'd never have known they weren't accustomed to being in front of the camera. They were amazing. I was shocked when I learned that these five women had only met that day. The bond these women share because of their breast cancer experience made it seem like they had been special friends for a long time."

Photos: Laurie Beck Photography

Over 200 women, family members, friends and community leaders participated in the inaugural Yoga on the Steps: Washington, DC on Oct. 16. Participants gathered at Freedom Plaza, one of DC's greatest landmarks, to support women affected by breast cancer while experiencing the healing benefits of yoga. The event raised almost \$54,000 for LBBC's education and support programs. For more information about Yoga on the Steps, please contact Jeanne at [jeanne@lbcc.org](mailto:jeanne@lbcc.org).





Another new LBBC corporate partner, **Everything But Water**, designed an amazing necklace that spelled a secret message in Morse code—LOVE—as part of its support of LBBC’s programs and services.

“We are a company comprised largely of women, and we care deeply about helping women enjoy life, feel beautiful and act confidently,” says **Sheila Arnold**, president and chief executive officer of Everything But Water. “Because we often help women find new swim and resort wardrobes after breast cancer surgery, treatment and reconstruction, we were immediately drawn to LBBC and the work they do for women after they are diagnosed with this disease.”

The necklace offers Everything But Water customers “a way to support women and families affected by breast cancer and purchase something unique,” says Ms. Sachs. The piece sells for \$36 and sends a powerful secret message.

Also, while supplies last, be sure to purchase Dr.’s REMEDY Positive Pink enriched nail polish through your local Everything But Water or online. The vitamin-enhanced nail polish sells for \$17 and offers nourishment to brittle nails.

“LBBC’s goal to empower, inform and support women affected by breast cancer is close to our heart, and we feel it’s our corporate responsibility to contribute what we can,” Ms. Arnold says. 🍷

**Giv·ing—verb**

- ① To care about something to the value or extent of
- ② To make a gift or gifts; contribute
- ③ To impact
- ④ To be connected with
- ⑤ To cause; be responsible for
- ⑥ To present to an audience

Every two minutes, a woman is diagnosed with breast cancer.

By making a gift today, you can ensure that no one will make this journey alone.

Your support enables Living Beyond Breast Cancer to provide educational programs and services that directly impact the lives of all women affected by breast cancer, their families, caregivers and health-care professionals.

Make your gift online at [lbbc.org/Donate/Donate-Now](http://lbbc.org/Donate/Donate-Now).

**Thank you to our July 2011 – September 2011 contributors:**

**\$100,000+**  
Fashion Bug  
Susan G. Komen for the Cure

**\$50,000–\$99,999**  
boobies rule!!!

**\$25,000–\$49,999**  
Anonymous  
Celgene  
Cline Cellars  
Customers of Chico’s FAS  
Eisai Inc.  
Genomic Health Inc.  
GlaxoSmithKline Oncology

**\$10,000–\$24,999**  
Cancer Treatment Centers of America  
Comcast-Spectacor Foundation  
Marie and Joseph Field Greenberg Traurig, LLP  
Gail and Sandy Lipstein Myriad Genetic Laboratories, Inc.  
Pfizer Oncology  
Pfizer Pennsylvania Community Grants Program

**\$5,000–\$9,999**  
American Cancer Society Making Strides Against Breast Cancer Community Partnership Grant  
AstraZeneca  
Boehringer Ingelheim  
Iredale Mineral Cosmetics Ltd.  
John Harding Family Foundation  
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Continued from the cover

## The Basics: What to Collect

Keep detailed records of your diagnosis, treatment and follow-up care. Dr. Savard recommends you include copies of:

- Objective data such as *operative reports*, documents produced by your surgeon which include a detailed account of the results of surgical procedures such as biopsies
- Your final pathology report from after your surgery, which should include the cancer stage and characteristics of the tumor (ER, PR and HER2 status)
- Treatments and doses
- Problems with treatment and side effects
- Medicines you took to manage side effects
- Possible long-term side effects
- Imaging reports such as mammograms, MRIs and CT scans done before and after surgery
- All laboratory tests (especially blood tests)
- A schedule for future follow-up tests and appointments
- Recommended screening and surveillance tests for breast and other cancers and bone health

You should also collect basic information about your medical history and health, such as:

- Allergies, including medicines
- Details of past physical examinations including routine test results and immunizations
- Contact information for your general practitioner
- Details about your family medical history
- List and dates of other significant illnesses or health conditions
- Results of procedures such as colonoscopies, OB/GYN procedures, etc.
- Other medicines you are taking and doses
- Medical bills and insurance claims

If you are living with metastatic disease, keeping a personal medical record can be particularly helpful for tracking ongoing treatments and tests. Recording problems with treatment and side effects and sharing them with your doctor can ensure your quality of life is preserved.

Your records may be available in different formats, including paper results, scans and slides. The original tests that led to your diagnosis, such as mammograms and CT scans, should be available on a CD-ROM or slides, but you should at least ask for a typed report that you can put into a folder or scan into your computer, Dr. Savard says. You can get your bloodwork as a written report. Because of privacy concerns, new doctors may prefer you bring results to their offices, rather than put them in the mail.

If you need help figuring out which records you need, ask your doctor or an oncology nurse.

## Getting Started: Collecting Your Records

Figuring out where to get your records and trying to collect and understand them is a big job. To keep from feeling overwhelmed, “start with getting copies of your most recent records, especially the trigger for your breast cancer diagnosis such as your mammogram results. Then work back,” Dr. Savard says.

Every facility has a place that keeps medical records; ask the receptionist at your doctor’s office where to go. Some offices keep electronic records you can access yourself; otherwise, you will need to ask for copies.

Although the original documents are owned by your healthcare providers, hospitals and labs, the information in your medical records belongs to you. A federal law called the HIPAA Privacy Rule legally gives you the right to see, get copies of and correct your medical records. You will need to give your consent to each doctor to release your records, usually in writing. You may also need to provide identification. If you are sending away for your records, include a self-addressed stamped envelope with your request, Dr. Savard suggests.

The time it takes to access your records may vary. “They say it can take up to two weeks [to get the records you request], but I’ve also walked out of the hospital with them before,” Pam says. “If you need to request records later, find out the location of the clinic or hospital where the record is housed, then call ahead of time.”

State laws also entitle you to the information in your records. Although your doctors or facilities may legally charge for copies, they often won’t if you collect them as you go rather than wait and order them all later.

As you move forward, be proactive and ask for copies of records while you’re in the doctor’s office, including results of tests and procedures, medical bills and insurance claims.

If you already completed treatment, it’s not too late to put together a personal medical record. Start by contacting your oncologist and asking for a written summary of your diagnosis and treatment. You can also ask for copies at your doctor’s office and the medical records department of facilities where you were treated.

Medical records are usually kept between five and seven years, Dr. Savard says. Accessing archived information can be difficult. If the facility where you had the procedure no longer has the records, you will need to contact the doctor who helped you and ask for them.

Collecting your records is also a great job for relatives or friends. You may have to sign requests for personal information, but others can make phone calls and fill out forms for you.

## Organizing Your Records

Once you've collected your records, organize them in a format that works for you.

Pam keeps her records in a three-ring binder that she brings to doctor visits. The binder has dividers for each doctor. It includes a section for lab reports and blood test results so if she sees a doctor outside her healthcare system, she can give test results right away. Another section contains Pam's notes from before and during doctor visits. Imaging results such as CT scans are in the pocket of a separate notebook, as are copies of insurance referrals, statements and claims. All information is in chronological order, with the most current information on top.

Megan collects her information in a similar way. "I have three different binders—one for each doctor I have been to," she says. "Each binder has sections for test results, privacy forms, blood work results, and so on—each type of information has its own section," she says.

Megan also scans her records onto her computer and backs them up on an external drive. "It was easier to email copies of records from my previous doctor to my new one instead of having to get into the car and drive it over there," she says.

An online medical record service can help you organize everything in one place. Pam's records are available online through her facility, and she signed up to access them. "I get notice of new [test] results online; then I can print a report showing the results." She can also download a card with information on surgeries, personal medical history and family medical history.

The online program doesn't always have the information Pam wants. "When I get surgery I request the surgeon's notes, which is information not usually given to patients," she says. "With the HIPAA law, you have to fill out a form, but they have to give the information to you [if you ask for it]. If I ask strongly enough, I have it walking out the door." If Pam sees a specialist that is not in her healthcare system, she has to get physical copies of the records since the information is not available online.

If your facility doesn't have an online service, you can collect and keep track of your medical information through a virtual tool like Navigating Cancer ([navigatingcancer.com](http://navigatingcancer.com)). Individual accounts allow you to keep track of appointments with an online calendar, schedule reminders to take medicines, develop a treatment record by logging chemotherapy and radiation schedules or

scanning and uploading documents, and record symptoms and side effects in a daily health journal.

"We use the same encryption and security that banks use, and patients get to decide who they share their information with," says **Gena Cook**, CEO of Navigating Cancer.

Even if you have your medical records online, you should still keep your own copy on paper or on your computer hard drive and backup disk, Dr. Savard says. "It's arguably the most important thing you have. You can give it as a gift to your children as a record of your medical history."

## Taking Control and Managing Your Emotions

Reading the results of your tests and other medical information all at once can be traumatizing. "When I opened my notebook, I sat there looking at it thinking, 'This is really happening.' Reality set in," Megan says.

It can also be confusing. "I spent a lot of time on [dictionary.com](http://dictionary.com) and [WebMD](http://WebMD) trying to figure out the medical terminology and looking for explanations in common terms," Megan says. "Doing the extra research freaked me out more, but it also opened my eyes to treatment options I didn't know existed. It gave me some authority in my treatment, and I felt empowered knowing what my options were."

If you are struggling, Dr. Savard recommends you identify a loved one who can review the information with you. Megan went on [lbbc.org](http://lbbc.org) and found the Survivors' Helpline. "Two hours later, I got a phone call from a volunteer—that

really helped," she says.

Your doctors should also help you. "Sometimes you have to be the squeaky wheel to get your questions answered," Dr. Savard says.

Megan says having her medical record gave her some control. "I could see what the doctor was seeing, not just what the doctor wanted me to know."

Pat agrees. "I felt better having the notes from my surgeon and reading the narrative on my CT scan because the doctors don't always cover everything verbally. It's more emotionally draining to not know everything and let someone else have control over my information," she says.

"Knowledge is power. All of the preparation, research and record keeping helps me to plan my treatment and partner with my medical providers. I feel more confident and prepared, which provides certainty in an uncertain world." 🍷

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# Insight

A quarterly educational newsletter from LBBC



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... IN THIS ISSUE ...

- 1** MEDICAL INFORMATION  
**Knowledge Is Power:  
Tips and Tools  
for Managing Your  
Medical Records**
- 3** PROFILE  
**Vivian Chan: How  
Breast Cancer  
Changed a Young  
Woman's Direction**
- 4** QUALITY OF LIFE  
**Express Yourself:  
How Creative Therapies  
Promote Health and  
Healing**
- 6** NEWS AND  
EDUCATION UPDATE  
**LBBC Expands  
Programs for Young,  
Metastatic, African-  
Americans**
- 8** GIVING UPDATE  
**October Promotions a  
Rousing Success**

## Calendar

### Educational Programs

#### Teleconferences

JANUARY 11, 2012

✦ **News from the San Antonio Breast Cancer Symposium**

FEBRUARY 8, 2012

✦ **Understanding Hormonal Therapies**

#### Conferences

FEBRUARY 24–26, 2012

✦ **C4YW—Annual Conference for Young Women Affected by Breast Cancer**  
New Orleans, LA

APRIL 28–29, 2012

✦ **Annual Conference for Women Living with Metastatic Breast Cancer: Enhancing Your Health and Quality of Life**  
Philadelphia, PA

### Special Events

MAY 19, 2012

**Yoga on the Steps: Philadelphia**

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



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