

Just for Me

Focusing on your unique experiences as a woman living with metastatic breast cancer



NEWS ON ADVANCED BREAST CANCER

Elizabeth Edwards Speaks at Advanced Breast Cancer Conference

By Michelle Zeigler

“We have the power of what defines us—cancer doesn’t define us,” said **Elizabeth Edwards** at the **3rd Annual Conference for Women Living with Advanced Breast Cancer**, held April 18-19 at the Philadelphia Marriott West in West Conshohocken, Pennsylvania. “I’m Elizabeth, I’m married to John, I have four children, I have blue eyes, I used to be a lawyer but am now opening a small furniture shop, I like tomato sandwiches and I have metastatic breast cancer.”

Mrs. Edwards identifies with your struggles to help others understand the meaning of your diagnosis while making sure cancer doesn’t define you. She opened her presentation by recalling her diagnosis five years ago at age 55. The cancer was found at an early stage, and she underwent chemotherapy and radiation. In 2007, the cancer returned and she was diagnosed with stage IV disease.

“I used to think living with breast cancer was about ignoring it,” she said. “It was never a matter of ignoring cancer. Cancer had a seat at the table, whether I liked it or not.”

Mrs. Edwards described her decision to go public with her diagnosis and treat-

ment. She felt an obligation to stand up and discuss her experiences. Her desire was to help people realize that women affected by breast cancer can lead fulfilling, empowering lives.



LAURIE BECK PHOTOGRAPHY

“Elizabeth with cancer is still Elizabeth, and I want to be that person,” she said. “I don’t want to be pitied. Pity diminishes me.”

She believes we have an obligation to keep breast cancer research moving forward by participating in clinical trials or research studies.

“We are sisters, and we are a part of a larger whole,” she said.

Living in the public eye while going through breast cancer treatment is difficult, Mrs. Edwards said, but she feels empowered by the large amount of support she receives.

While some people may think she’s doing something “bigger” than other women who share her diagnosis, Mrs. Edwards said she’s doing exactly what you do every day. She credits the breast cancer community for teaching her that

humor is a great weapon and that you become a “survivor” on the day you’re diagnosed.

“This is a group voyage and we are on it together,” she told conference participants. “Where do I find my strength? I find it here. I find it in you.”

She concluded by encouraging you to put yourself first and hold on to who you were before breast cancer.

Before Mrs. Edwards’ speech, LBBC debuted our video, **Living with Metastatic Breast Cancer: Stories of Perseverance, Triumph and Hope**. The video features 15 women sharing their stories about metastatic breast cancer diagnosis, treatment and life beyond cancer. The video inspired many women who attended the conference, and we were proud to debut it with Mrs. Edwards in the audience.

“This video provides awareness and gives women hope, courage and most of all, determination,” said **Lauren Hammons Groover**, 40, of Tupelo, Missouri.

Lynn Pevarnik, 45, of Bunker Hill, West Virginia, found strength and connection to women in the video. “I think all of these women truly reflected my reactions and emotions,” she said. “Their determination is a reinforcing power for all of us with metastatic breast cancer.”

Visit our YouTube page at youtube.com/user/LBBC1991 to view this video and other clips about our events and the amazing women we serve. **LBBC**



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Elizabeth Edwards signs copies of her book *Saving Graces: Finding Solace and Strength from Friends and Strangers*.

Talking with Children

In our last issue of *Just for Me* and on Facebook, we asked readers to respond to the question: How do you share your diagnosis with your children? One Facebook fan wrote about her second diagnosis:

I have been fighting breast cancer since 2005. In 2008, the cancer had metastasized to my liver. When I tried to explain the new diagnosis to my seven-year-old, she just kept saying, "But you are still going to get better, right?" Somehow I wrangled up the courage to say, "The cancer probably won't ever go away, but I am going to fight it a very long time." She got it right away and burst into tears.

That was a year ago, and she has been my little trooper through three more surgeries and many treatments. Every once in a while I hear an "I hate cancer" under her breath (usually when I'm too tired to do something she wants to do). She is interested in my treatments, and I try to answer all her questions clearly but only give the information she asks for. One day she made me promise that if it was time for her to worry about me dying I had to tell her.

The true blessing in this is that we are very close. I get lots of hugs.

Lynn Pevarnik

Bunker Hill, West Virginia

This issue's question:

How do you manage fatigue?

Send your answers to editor@lbcc.org.

To become a "fan" of our page, go to the Facebook pages application and type in "Living Beyond Breast Cancer."

Breast Cancer News

Researchers Identify New Therapeutic Target

By Mary Alice Hartsock; reviewed by Clifford A. Hudis, MD

Researchers identified a gene associated with increased risk of metastasis and resistance to chemotherapy, results of a recent study indicate.

This study, conducted by researchers from Princeton University and the Cancer Institute of New Jersey, may help build the foundation for major advances in breast cancer treatment. By developing a treatment targeted to limit the activity of this gene, future research may uncover treatments to reduce risk of metastasis and improve response to chemotherapy in up to 40 percent of breast cancers.

Study Design and Results

Scientists used a computer program to map results of large breast cancer databases and to find similarities between breast cancers that were likely to metastasize. They found a pattern in aggressive breast cancers: Many had multiple copies of a genetic "instruction" at a location called 8q22 on chromosome 8. They discovered that a gene called metadherin (MTDH) is present in 8q22. When "amplified" by the presence of multiple copies, MTDH makes cancer cells more powerful.

MTDH works by making it easier for tumors to stick to blood vessels in distant organs. It is "overexpressed" (there is too much of it) in 30 percent to 40 percent of breast cancers, and it is associated with poor outcomes.

The team validated its findings by analyzing tumor samples taken from people treated at the Cancer Institute of New Jersey. The researchers compared the genetic makeup of the human breast tumors to those in the computer analysis.

For further confirmation, the team recreated the MTDH genetic abnormality in mice to see whether the rodents developed metastases. They found that mice with overexpressed MTDH developed more metastases to the lungs, bones and other organs. Also, the MTDH-enhanced tumors proved more resistant to several standard chemotherapy medicines for breast cancer, including doxorubicin (brand name: Adriamycin) and paclitaxel (brand name: Taxol).

The researchers concluded that MTDH promotes the growth of metastatic breast cancers and can cause cancers to resist common chemotherapy treatments. To

Future studies may focus on improving response to chemotherapy, researchers say.



allow chemotherapies to be more effective, a medicine should be created to target MTDH and prevent its overexpression, thereby slowing metastasis growth and preventing resistance to chemotherapy, they said.

Why Is this Study Important?

The results of this study cannot be used immediately in clinical practice; however, according to **Clifford Hudis, MD**, chief of the Breast Cancer Medicine Service at Memorial Sloan-Kettering Cancer Center and a member of LBCC's Medical Advisory Board, "This kind of research paves the way for the development of medicines targeted to stop the action of specific and important genes, such as MTDH in this case. We hope that someday such medicines could enhance the effectiveness of chemotherapy and reduce the risk of metastatic breast and other cancers."

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Getting Good Care: My Story of Self-Advocacy

By Erin Pianko, for LBBC

On Tuesday, November 11, 2008, I heard the words, “You have breast cancer.” I was 31 years old, and I had always been very healthy. I had low cholesterol, had never smoked a cigarette and exercised five days a week. As I found out my diagnosis, I quickly learned that doctors are human and they make mistakes. It’s critical to keep your head high and keep asking questions.

When you are faced with a terrifying diagnosis, the last thing on your mind is how difficult it is to navigate the system of hospitals, doctors and treatment options. However, you are responsible for making sure you receive the best care. Finding a healthcare team that is focused on saving your life will help you make your way through the months and years ahead.

Unfortunately, I had many bad experiences with doctors throughout the year of my diagnosis. I was diagnosed with metastatic breast cancer because my gynecologist and my family doctor both dismissed my concerns about the lump in my breast.

After surgery for another condition, I still felt ill, so I went back to my gynecologist. As I left, she said, “Don’t worry, I still don’t think it is cancer.” To throw another iron on the fire, I had just gotten pregnant.

When I told the radiology center that I might be pregnant, they told me to wait for my mammogram, but I insisted on an ultrasound. Afterward, I was informed that I must get a mammogram. It was “suspicious,” and a biopsy was scheduled for the next day.

Two days later, I had an appointment with a surgeon to discuss my biopsy results. When the surgeon finally appeared, he was shocked that I had not already heard my results from my oncologist or gynecologist. At that point, I wanted the truth and a plan.

I ended up hearing my stage IV diagnosis from a high risk pregnancy doctor who had a copy of my test results. My oncologist

had not even viewed my test results. After I spoke with an insensitive counselor, I decided I had had enough. My healthcare team hadn’t tried to get to know me; I was being treated as a number, not an individual. I decided that I wanted to get my care in the area where my parents lived, so I got on a plane and went to a new hospital.

Unfortunately, my treatment options did not allow me to continue my pregnancy. Facing this news was more difficult than coping with my cancer diagnosis. The good news, though, was that my choice to change healthcare teams gave me many options I wouldn’t have had at home. Since preserving my fertility was a priority, I was able to have a new procedure to freeze my ovarian tissue. I also met fantastic, supportive hospital staff.

Wanting to get back to my normal home life, I did extensive research and found a very good facility an hour from home. I continue to advocate for myself to make sure I am receiving the best advice and proper treatment. It is essential to read and research as much as you can and attend breast cancer conferences. The checking and double checking never ends. It is, in fact, your life! [LBBC](#)

Would you like to share your story in our next issue? Write to us at editor@lbbc.org.



TIM SHARP PHOTOGRAPHIC SERVICES

Questions to Ask About Quality of Life

As you begin a new treatment, consider not only your medical needs but also your quality of life and what makes life meaningful for you. Ask yourself and your healthcare team these questions as you consider treatment:

- What does “quality of life” mean to me? How do I define having a good life while living with advanced breast cancer?
- Do the benefits of the treatment outweigh its impact on my day-to-day life?
- How will my treatments interfere with my goals and desires?
- How might I and my healthcare team work together to enhance my quality of life?
- What level of discomfort, pain or fatigue am I willing to tolerate? Will pain management impact my alertness or my quality of life? How can I find a good balance?
- What side effect worries me the most? Is it pain, hair loss, sexual side effects, nausea, weight gain or loss, fatigue or something else?
- Am I willing to take medicine or try a complementary therapy to offset side effects?
- How helpful is my support system?

Did you find this list helpful? Read more in **Understanding Treatment Options for Advanced Breast Cancer**, our publication from which this list is excerpted. To get your free copy, visit our “Marketplace” at lbbc.org or call us at (610) 645-4567.

When you are ready, we encourage you to call our Helpline at (888) 753-LBBC (5222) for guidance, information and peer support. Our trained volunteers are here to listen and help you.

Focus on Young Women

Our brochure on *Understanding Treatment Options for Advanced Breast Cancer* can help you learn the basics of metastatic disease and the treatments available to you. Below we share an excerpt that focuses on the unique treatment choices you may face as a young woman. Order your free copy of the full guide today at lbcc.org's "Marketplace" or by calling us at (610) 645-4567.

Your Treatment Options as a Young Woman

If you are a young woman living with metastatic disease, you may have different treatment options because of the way your body produces hormones.

If you have a hormone receptor-positive breast cancer, you may be able to take a SERM. [SERM stands for Selective Estrogen Receptor Modulator, a type of medicine that blocks the effects of estrogen on breast cancer cells so the estrogen cannot stimulate the cancer to grow.]

Your doctor may also recommend you shut down your ovaries (this is called ovarian ablation) either surgically or with medicine. Shutting down the ovaries significantly lowers your body's level of estrogen, which can cause the cancer to grow.

Medicines that shut down ovaries work by turning off signals from your brain that regulate ovarian function and keep your ovaries from producing and releasing estrogen. They are called luteinizing hormone-releasing hormone (LH-RH) or gonadotropin-releasing hormone (GnRH) agonists, and include goserelin acetate (brand name: Zoladex), leuprolide (brand name: Lupron) and triptorelin (brand name: Trelstar). These medicines are given by injection every one to three months.

Side effects may include hot flashes, sexual side effects and other postmenopausal symptoms. Ovarian ablation with medicine is gradual and happens over a period of weeks. The effects are not permanent, and ovarian function usually returns after treatment is stopped.

You may also consider having your ovaries removed surgically, an operation called oophorectomy. During an oophorectomy, the ovaries are removed through an incision (cut) in the lower belly, through the vagina or through a small incision at the top of the vagina using a laparoscope (a viewing tube through which structures within the belly and pelvis can be seen). Removing the ovaries takes away most of the estrogen in your body. Your adrenal glands (glands over the kidneys that help control important body functions) will still produce small amounts of estrogen.

While having your ovaries removed can significantly reduce your risk, it can be difficult because it causes you to go right into menopause instead of having the slow transition that natural menopause permits. Side effects include an increased risk of heart disease, increased risk of bone loss or fractures and decreased sexual desire.

Taking part in a clinical trial can offer you access to new treatments that are not available outside a trial and may prove to work better than standard treatments. Your participation in a clinical trial may also help researchers develop better treatments for other women who are

diagnosed with stage IV or early-stage breast cancer. (To find more information on clinical trials, see the sections on "Clinical Trials and You" and "Keeping Up to Date on New Treatments" when you order your free copy of the brochure at lbcc.org.)

Treatment decisions are highly personal, and you should talk to your health-care provider about your options. Many women like you find it helpful to connect with other young women who are going through advanced breast

cancer, so you can discuss your treatment options and get support. We encourage you to call our Helpline at (888) 753-LBBC (5222) for guidance, information and peer support. Our trained volunteers are here to listen and help you. [LBBC](http://lbcc.org)



Understanding Treatment Options for Advanced Breast Cancer