

Touch of Courage

. . . Connection

January 2017



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BREAST CANCER INDEX: New Tool to Help Guide Cancer Therapy

By Kim Maxfield RN, CCRC - Clinical Research Nurse

Having the diagnosis of breast cancer is scary and the treatment benefit for long term endocrine therapy after 5 years is still uncertain.

Patients with ER+ breast cancer usually have a good prognosis; however, the risk of the cancer recurring before and after 5 years is similar. How long does a patient need to be on anti-estrogen therapy? Initially, it was thought that 5 years was adequate. Recent studies have shown that for some women, an additional 5 years of anti-estrogen therapy is beneficial. For women who were recurrence free at 5 years, only about 3-5% benefited from an additional 5 years of treatment. It is also important to weigh the benefits of continuing treatment to the potential risks and side effects. Some reported side effects of anti-estrogen therapy are:

Long term safety concerns: Endometrial cancer, osteoporosis, cataracts, bone fractures, blood clots and heart disease.

Day to day tolerability issues: Vaginal dryness, itchiness and discharge, hot flashes or night sweats, joint stiffness or pain, muscle pain and sexual dysfunction.

The Breast Cancer Index test, made by BioTheragnostics can help to answer

some of these questions. The Breast Cancer

Index uses tissue from the original Breast Cancer surgery and analyzes seven genes that can influence how likely the cancer is to come back 5 to 10 years after diagnosis, as well as how likely a woman is to benefit from an additional 5 years of treatment.

The Breast Cancer Index result has two scores.

The first score predicts the risk of the cancer coming back beyond 5 years (years 5-10). Scores range from 0-10. Cancers with scores of 0-5 are classified as having low risk of late recurrence. Cancers with scores of 5.1-10 are classified as having a high risk of late recurrence.

The second score predicts the likelihood of benefit from an additional 5 years of anti-estrogen therapy. The results are reported as low likelihood of benefit or high likelihood of benefit.

Who is eligible for the breast cancer index?

- Patients that were diagnosed with early stage (stage I-III) breast cancer
- The cancer was hormone-receptor positive and HER2-negative

Continued on page 2, Breast Cancer Index

Index, continued from page 1

- There was no cancer in the lymph nodes (lymph node-negative disease)
- Patients that have been taking hormonal therapy for 4-5 years and want to know if taking hormonal therapy for more time will be beneficial

The BCI offers a validated predictive tool that women along with their physician can use to decide treatment strategies that is right for them. The test is currently not approved by the US Food and Drug Administration.

Medicare covers the BCI at a predetermined rate with no fees charged to the patient as long as the eligibility criteria are met. Many commercial insurance companies also reimburse for the BCI but be sure that you or your physician's office checks for coverage before ordering the test. BioTheranostics (the company that makes the test) does have a patient advocate team to help with verifying insurance coverage and obtaining reimbursement. They also have a patient assistance program that helps to pay for testing.

To contact the patient advocate team you can call 877-886-6739 or patientadvocates@biotheranostics.com.

There are new treatments and tools being studied all the time for breast cancer patients. The Breast Cancer Index is one of the new tools being used to help with long term treatment decisions and is being reimbursed by more insurance companies daily. For patients that are interested in more information or would like to have the test done, please talk to your oncologist to see if you qualify and if your insurance will cover the test.



Where Are They Now? Beginning in 2017, we would like to share with our readers, especially survivors, how others are doing years after their diagnosis. Our first survivor to share is Mary Seitz, who is an eight year survivor.

Breast Cancer Diagnosis – Now a Distant Memory

By Mary Seitz, an 8 year survivor

Eight years ago I never thought my diagnosis of breast cancer would be a distant memory. I felt as though my life had just been sucked up into the vortex of a tornado. But here I am 8 years later and doing great.

I was diagnosed with breast cancer in December of 2008. At that time I was working in the Mammography Suite. I wasn't so much shocked with the diagnosis, as I have a strong family history of breast cancer, but it was more of a fear. Fear of the unknown. At the time I had a 13 year old son who I worried what his life would be like without his mom and 2 adult children who were still finding their way. I worried about the treatments, work, family, friends, no hair, medical costs and the list went on with my fears. I have a strong faith in God, so I prayed along with all my friends, family and co-workers. My concerns were relieved by all the wonderful people who came into my life to walk the journey with me, including doctors, nurses, social workers, family, friends and even complete strangers.

I elected to have a bilateral mastectomy and reconstructive surgery done January 2009. I was very comfortable with my decision and still am today.

I don't recall feeling like "why me" when I found out I had cancer, but I questioned my purpose moving forward. That answer came quickly, as I was able to relate and talk with other women coming in for breast biopsies. I had firsthand information on what it was like to have a biopsy, what it was like waiting for those results. I joined the Beyond Pink TEAM. I enjoyed being around people who shared the same stories and discussing their journeys. I learned more of what I could do to advocate for a better tomorrow.

Somewhere along the line time slipped away. The demands of everyday life slipped back in. The appointments were getting scheduled further and further apart, my hair came back and had to be cut more often. Kids grew, grandchildren came along. Now it's just an annual trip to the Cancer Treatment Center and my primary care physician. My life has resumed to what I call an everyday normal. I have since left the Mammography Department and now work with a general surgeon. Today the diagnosis of breast cancer is now only a distant memory. It is no longer mine to carry. Someday I pray all cancers will be a distant memory of a disease we were able to eradicate.

Be There! Listen!

It is often difficult to know what to say or do when someone you care about has cancer. The best thing to do is just listen and not talk. Listen with your ears and your heart. One key way to help with communicating is not only to ask "How are you feeling?" but also "What are you feeling?" But be prepared to hear anything and remember you don't have to reply.

American Cancer Society has several helpful booklets on this subject.

See a list of other resources on page 6 of this newsletter.

Beyond Pink TEAM's Annual Celebration of 2016 Accomplishments

An Open House format was held on Thursday, October 20th showcasing the various elements of the Beyond Pink TEAM through informational display boards. These included:

Taking Action – detailed BPT support groups, *Splash of Color*, *Young Cancer Survivors*, and *Touch of Courage* explaining each group, who it supports and activities of these groups.

Educate – *Community Outreach* sharing BPT's involvement with health fairs, speaking engagements, quarterly newsletters and social media.

Advocate – *Breast Cancer Deadline 2020* informed of progress to ending this disease. *Ignite the Cancer Conversation* an event held in the spring of 2016 told of purpose of event and plans for 2017.

Making a Difference – *Where Your Donations Go* detailed how BPT funds stay in our community to support breast cancer survivors within our community and the Cedar Valley. *Mission Circle Leaders* were recognized and thanked for their donations to the Beyond Pink TEAM to continue the mission.



For information about the Beyond Pink TEAM Fund, go to: www.beyondpinkteam.org
Click on **Beyond Pink Fund** under **CARE** or call Gabbi at 319.292.2225.

BPT 2016 Beyond Pink TEAM Volunteer of the Year went to two individuals new to Beyond Pink TEAM but headed up the "Ignite the Conversation" event held in April 2016. Their creativity, marketing, logo and bookmark design, event planning, online registration, logistics planning and contract interpretations skills were top notch and made this event a huge success. Congratulations to Tiffany Bohlen and Whitney Johnson for all they did in 2016 for "Ignite the Cancer



Many individuals "Go Beyond Pink" to support the Beyond Pink TEAM. This year we were honored to recognize Mo Hardy, a professional hairdresser, for giving her time to be a "cheerleader" for all cancer survivors. She not only has taken lead roles in various fundraisers for the BPT, but gives her time and talents to volunteer for the American Cancer Society's "Look Good...Feel Better" program. In addition she provides complimentary haircuts to survivors who are losing their hair, and also to those wanting to donate their hair to Beautiful Pantene, an organization who makes wigs for ALL cancer patients. Pictured left is Mo donating her own hair this year at the Relay For Life of Black Hawk County. Congratulations to Mo for being a "cheerleader" for cancer survivors!

The 2016 Sue Witwer Scholarship recipient was recognized. This year Jill Hansen received the scholarship and was able to attend the National Breast Cancer Coalition Summit in May 2016. This event allowed Jill to learn how she can advocate for others in ending breast cancer. In photo to the right, Jill, along with other BPT members, Lori Seawell, Kristin Teig-Torres and Christine Carpenter visited with Senator Joni Ernst.



Support Group Meeting Dates

January 3, 1:30 p.m.

Care & Share Cancer Support Group

Covenant Cancer Treatment Center
200 E Ridgeway Ave., Waterloo
Jeanne 319-272-2816

January 9, 1:30 p.m.

Touch of Courage

Breast Cancer Support Group

2101 Kimball Ave., Waterloo
Pat – 319-232-8691

January 17, 4:30-7:00 p.m.

Young Cancer Survivors – Meet, Mingle and Learn

Cedar Valley Unitarian Universalist
3912 Cedar Heights Dr., Cedar Falls
Gabbi – 319-292-2225

February 6, 1:30 p.m.

Touch of Courage

Breast Cancer Support Group

2101 Kimball Ave., Waterloo
Pat – 319-232-8691

February 7, 1:30 p.m.

Care & Share Cancer Support Group

Covenant Cancer Treatment Center
200 E Ridgeway Ave., Waterloo
Jeanne – 319-272-2816

February 13, 1:30-3:30 p.m.

Look Good ...Feel Better

Hair – Make-up – Nails – Skin

Covenant Cancer Treatment Center
200 E Ridgeway Ave., Waterloo
RSVP at 1-800-227-2345

February 16, 5:00-7:00 p.m.

Splash of Color – Women of Color

Breast Cancer Support Group

Bowling at Maple Lanes, Waterloo
Cathy – 319-493-8857 for details

March 6, 1:30 p.m.

Touch of Courage

Breast Cancer Support Group

2101 Kimball Ave., Waterloo
Pat – 319-232-8691

March 7, 1:30 p.m.

Care & Share Cancer Support Group

Covenant Cancer Treatment Center
200 E Ridgeway Ave., Waterloo
Jeanne – 319-272-2816

April 3, 1:30 p.m.

Touch of Courage

Breast Cancer Support Group

2101 Kimball Ave., Waterloo
Pat – 319-232-8691

April 4, 1:30 p.m.

Care & Share Cancer Support Group

Covenant Cancer Treatment Center
200 E Ridgeway Ave., Waterloo
Jeanne 319-272-2816

April 11, 1:30-3:30 p.m.

Look Good ...Feel Better

Hair – Make-up – Nails – Skin

Covenant Cancer Treatment Center
200 E Ridgeway Ave., Waterloo
RSVP at 1-800-227-2345

April 18, 4:30-7:00 p.m.

Young Cancer Survivors

Meet, Mingle and Learn

Cedar Valley Unitarian Universalists
3912 Cedar Heights Dr., Cedar Falls
Gabbi – 319-292-2225

Living Green !!!

By Cindy Harris, a Survivor



Winter is Here!!!

This is the editor's favorite and useful tip from Cindy. I have used it and it works great!

With this cold weather we will have frost on the car windows. Since I don't like to scrape, I keep a spray bottle of alcohol/water mix in my car. The mixture needs to be stronger than 50% alcohol or at least 70/30 mix. I use 90% alcohol/10% water. Spray it on, let it soak in, and

drive off! Don't put the alcohol mixture in the washer container of your car as it will dry out the hose and container and ruin both.

Another tip, if you spray vinegar on the window at night, frost usually won't even form.



The second annual Ignite the Cancer Conversation will be held on Thursday, April 20, 2017 at the Waterloo Center for the Arts. After our inaugural Ignite event drew over 200 people to the Cedar Valley, it was determined we need to continue the conversation!

The Ignite vision is to bring diverse communities together and activate the conversation that will initiate and develop concrete steps to conquer cancer. Our mission is to ignite the cancer conversation by going beyond discussions limited to awareness, early detection, and treatment.

This year, the event will focus on the environment and three experts will be presenting current information that directly impacts Iowa residents. Dr. Kamyar Enshayan will present on Iowa Pesticides, Dr. Catherine Zeman will discuss Iowa water quality and Gail Orcutt will present on the danger of Radon. The event will be interactive, and allow participants to create their own personal action plan. For more information, please check the Beyond Pink TEAM website www.beyondpinkteam.org and Ignite the Cancer conversation Facebook pages.

MISSION LEADERS

The Beyond Pink TEAM would not be able to provide the services and support to the breast cancer survivors in the Cedar Valley without the generosity of the many individuals, groups, organizations and businesses who donate. Below is the list of our Mission Leaders for the fiscal year of September 1, 2015 through August 31, 2016 whose accumulative gifts were of \$100 or more. Thank you to all who donated any amount, their time and talents or fundraising. Because of these donations, the Beyond Pink TEAM was able to provide assistance to:

- Persons who are within a year of breast cancer diagnosis or persons more than a year from diagnosis but still receiving active treatment such as chemo, radiation, or surgery.
- Persons living with breast cancer and is still following up with a physician, on oral medications, needing lymphedema assistance and more.
- Persons who have had a breast problem (lump, nipple changes, etc.) that are being followed by the Care For Yourself program or does not qualify for the Care For Yourself program.

Circle of Action (\$10,000 +)

Kathy Bunger Memorial Ride

Circle of Commitment (\$5,000-\$9,999)

University of Iowa Community Credit Union
Oakridge Realtors
Community Auto Plaza

Circle of Advocacy (\$1,000-\$4,999)

Cedar Falls Girls Night Out
NE Iowa Saddle Club-Pretty In Pink Horse Show
Kids Driving Out Cancer Golf Outing
Donna O'Brien Arbonne Products
Blush Ledet Salon Spa
Veridian Credit Union
Carol's Crew Cares
Genetech
Agendia
Fredsville Lutheran Church
Scheels All Sports
Thomas & Stephanie Bardal
Covenant Medical Center-Wheaton Franciscan Healthcare
Terry L. Butz
John Deery Motors
VGM Group Inc.
Clark & Associates Prosthetics & Orthotics
Allen Hospital/Unity Point Health
Kimball & Beecher Family Denistry

Circle of Support (\$500-\$999)

Visions Hair Studio
Wally Markham
Beecher Law Firm
L & N Transportation Services Inc.
Peoples Insurance Agency
Flowerama

Cedar Valley Medical Specialists
Nucara Pharmacy
Park Place Event Centre/Barmuda Cares
Alan Steffen
CHF LLC
Nagle Signs Inc.
Jennifer's on Main
PDCM Insurance
Trio SalonSpa

Circle of Hope (\$100-\$499)

Pat Buls
Waterloo Homecoming 2009
Martin & Dee Hughes
Scharron Clayton
Sherrie Jones
Diana Brookman
Valley Park Family Dental PC
Madear LLC
Social Action Inc.
Ruthie Stigler
Constance McGovern
Ester Stokes
Allen Student Nurses Association
Cedar Valley Medical Specialists
Saviour Missionary Baptist Church
Cheryl Thayer
Dorsey Thompson
Marcene Seavey
Rita Wilson
Kate Conlon Salon and Spa
Denver Savings Bank
Bill Coldwell Ford
NewAldaya Lifescapes
Peek-A-Boo Baby
Curves of Cedar Falls
Peoples Community Health Clinic
Paradigm Benefits LLC
Financial Designs
Caribou Coffee Shop
Banklowa

C David & Glenda Christensen
Alex & Kristi Syhlman
. Singh
Rabo AgriFinance
Shawn Smeins
Janesville Fire Rescue
Cedar Valley Unitarian Universalists
Panera Bread
Darren Witwer
Dean Witwer
Joann Meihost Estate
Cedar Heights School
Pura Vida Salon
Lorelee Coulter
LaVonne Friedly
Vanessa & Larry Rosauer
Marina Steffener & Craig Nahnsen
Kevin & Jennifer Custer
Gary & Janice Rosauer
Jim & Becky Mudd, Jr
Shawn & Brenda Bartz
Larry Anfinson
Timothy & Kari Fernholz



SPASH OF COLOR NOTICE

The February 16th Splash of Color support group meeting will be a bowling party! The group will meet at the Maple Lanes Bowling Center, 2608 University Avenue, Waterloo. Bowling begins at 5:00 p.m. For additional details call Cathy Ketton at 319.493.8857.



MISSION – Beyond Pink TEAM is a nonprofit organization whose mission is to provide breast cancer prevention, education, support and advocacy for comprehensive, quality health care for ALL in the Cedar Valley and surrounding communities.

Resources – Information, support, counseling, and educational materials are available from the following:

Beyond Pink TEAM is a local breast cancer organization providing a variety of services. Our website lists services we provide as well as other services available in the Cedar Valley. www.beyondpinkTEAM.org

Living Beyond Breast Cancer includes a helpline, newsletter and information. Survivors Helpline: 888-753-5222 www.LBBC.org

Young Survival Coalition connects with other young women diagnosed with breast cancer. www.youngsurvival.org

Cancer Care is a national nonprofit organization offering counseling, support, financial assistance and education to individuals with cancer and their families. www.cancercare.org

Iowa Cancer Consortium offers cancer information and links to resources in Iowa. www.canceriowa.org

American Cancer Society offers cancer information and services. www.cancer.org.

National Breast Cancer Coalition The NBCC's mission is to eradicate breast cancer by focusing the government, research institutions and consumer advocates on breast cancer. It encourages advocacy for action and change. www.breastcancerdeadline2020.org

National Comprehensive Cancer Network® (NCCN) provides state-of-the-art treatment information in easy-to-understand language to people with cancer and their caregivers. NCCN.org/patients

Dr. Susan Love Research Foundation offers clear, comprehensive information on breast cancer prevention, detection, treatment and long-term survivorship as well as reliable, up-to-date health information. www.dsirf.org/breastcancer/

National Cancer Institute's website offers information about cancer, breast cancer, clinical trials, cancer statistics, research and funding, and the latest news. They will also answer your questions by calling 1-800-4CANCER. www.cancer.gov

Connect with us . . . Your support financially or through volunteering is both needed and appreciated. Please feel free to complete the following and forward to Cedar Valley Cancer Committee at address listed below.

Name _____ Phone _____

Address _____ City _____ State _____ Zip _____

Email _____

I would like to participate with the Beyond Pink TEAM by:

- Writing a survivor story for the newsletter Making phone calls and sending emails to policy makers for breast cancer issues
- Become part of the Breast Cancer Advocacy Network
- Volunteering: *(check all that apply)*
- Assist with Support Groups Education (Health Fairs/Presentations)
- Development (Publicity) Advocacy – Deadline 2020/Ignite the Cancer Conversation
- Events (Fundraisers, Annual Luncheon, Projects and More)
- Making a donation. Make checks payable to Beyond Pink TEAM. *(All donation are tax deductible)*
- BPT Fund Advocacy Fund Area of Need

Touch of Courage . . . Connection

Cedar Valley Cancer Committee
1753 W Ridgeway Ave, Suite 104
Waterloo, IA 50701
www.beyondpinkteam.org