



Touch of Courage . . . Connection

April 2015

TAKING ACTION – EDUCATING – ADVOCATING – MAKING A DIFFERENCE

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Beyond Pink – Now What?

*By Jay Ginther, MD
Cedar Valley Bone Health Institute*

This topic is personal. My mom died of Breast Cancer at age 59.

You have survived Breast Cancer. That is wonderful. You are continuing to take medications to make sure that Breast Cancer does not come back. That is smart. You hope to live long and problem free. That could take a little more work.

Aromatase Inhibitors (Anastrozol, Letrozol, etc) treat Breast Cancer by blocking ALL Estrogen. Blocking ALL Estrogen often leads to Bone Loss and Fractures. Defeating Breast Cancer, but having an early Hip Fracture, is NOT a good deal.

Early Fractures DO NOT need to happen. We now have medications which can be used to PREVENT Bone Loss and Fractures after successful Breast Cancer treatment. These meds were originally reserved for women who already had Osteoporosis. Now we can also use them to PREVENT Osteoporosis and Fractures after Breast Cancer treatment.

the women across the country, who should have gotten these medications, actually did get them. Almost half of the women, who were treated with Aromatase Inhibitors for their Breast Cancer, were not even tested to see if they should protect themselves from Fractures.

Not only can these medications prevent Bone Loss and Fractures; recent studies show that they can Delay, or even Prevent, spread of Cancer to Bone (Metastases). Even more amazing, there have been cases where adding these meds to other Breast Cancer treatments has resulted in beating the cancer in all tissues, not just in bone.

When my mother died of Breast Cancer, she had none of the options you have now. Take advantage of all the new options, including protecting yourself from Bone Loss and Early Fractures. Talk to your doctor about a Complete Bone Health Evaluation and the medications which can prevent the Fractures which can occur after Breast Cancer medications.

More information at: www.BoneDocBlog.com and www.CVBoneHealth.com.

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Losing this Battle Was Not an Option

By Trish Wegner, a breast cancer survivor

My journey begins in February 2014. It all started when I noticed a stinging pain in my right breast after my girls would give me a hug. I already had an

The opposite of fear is faith – I chose faith.

appointment set up the following week for my yearly physical and when I mentioned the pain to my doctor she suggested I have a mammogram, which then led to a biopsy. The next day (Valentine's Day), with my husband by my side, I found out I had breast cancer. I was 38 years old, a wife and mother of 3 girls ages 14, 12 and 8. The news was shocking. I was young and I had no family history of breast cancer.

It absolutely broke my heart when I had to tell my daughters. The memory of that moment is still very painful for me. They had seen too much cancer in their lives already. Their paternal Grandfather at that time was in and out of the hospital with advanced prostate cancer. He ended up passing away in the middle of my treatments, and they lost their paternal Grandmother to metastatic breast cancer in 2009.

One week after my diagnosis I had a double mastectomy. I had a 2 cm tumor with no lymph nodes affected, classified as Stage 2 Invasive Cancer. The next month I started 4 rounds of chemo, and on December 3, 2014, I had my final reconstruction surgery. My tumor was ER+ so I will take tamoxifen for at least five years. Since I have three daughters, I decided to do the BRCA test. My test was negative for the BRCA gene.

I would not make it through this journey without my husband. From the very beginning, he made sure I knew that we were in this together and that we would beat it. He was at every appointment and now every follow up appointment. I also have a strong faith and prayed a lot. The opposite of fear is faith, and I chose faith. God has truly blessed me with lots

of wonderful people. I am forever grateful for the love, support, and prayers from my family and friends, and especially my parents.

I can honestly say that my cancer journey has made me a better mom, a better wife, a better person. There is nothing that I take for granted anymore, and the littlest of things bring me joy. I make sure I treasure every moment with my husband and daughters. They are mine and I am not ready to give them up. Losing this battle was simply not an option. I will grow old with my husband and I will get to see the amazing young ladies that I know my daughters will become.

Breaking News:

**Beyond Pink TEAM
Advocacy is Working!**

Senator Grassley proposes a commission to focus on ending breast cancer. Breast cancer would be eliminated by the end of the decade under legislation being introduced by Iowa Senator Chuck Grassley. It comes on the heels of a report released at the University of Iowa last week that names breast cancer as the number-one cancer to strike Iowa women and the number-two cancer killer.

"The bill would establish a commission to accelerate the end of breast cancer," Grassley says. "That's the title of the commission, the Commission to Accelerate the End of Breast Cancer, to help end breast cancer by a target date of 2020." It is the bill Beyond Pink TEAM Advocacy Council members have been working to pass. More information to follow in the June newsletter.

Young Cancer Survivors April Meeting

"Sexuality – After Cancer"

presented by Erin Sullivan-Wagner

Erin was diagnosed with anal cancer in 2008. Her cancer journey began with fear, confusion and the unique awareness her life would change in every way. Her five week treatment of radiation and chemotherapy had minimal negative trauma until her final week when she was hospitalized for eight days. Her journey wasn't over, and in many ways it had just begun. She was surprised, as was her medical team, to realize sexual dysfunction was a long term side effect of her treatment. This complication, though challenging physically and emotionally, proved to be both personally and professionally a growing experience. Today, Erin provides support for cancer patients, survivors and their caregivers through the challenges of the diagnosis, treatment and the emotional journey ahead. She has helped medical team and patients/survivors address the communication gap, as it relates to discussing and screening for sexual dysfunction after treatment.

Young Cancer Survivors is open to **ALL** cancer survivors and will be held on **Tuesday, April 21, 2015** at the Unitarian Universalist Church, 3912 Cedar Heights Dr, Cedar Falls. **Doors open at 4:30 pm** with light refreshments, mingling and socialization. **Speaker will be around 5:30 pm** with opportunity for questions after.

For further information, feel free to contact Gabbi DeWitt at 319-292-2225

Go GREEN !

By Cindy Harris, a Survivor



A Garden is Beneficial to Your Health

Hoping that spring will be here soon, I've been planning my garden. Figure how much room you have and what you are putting where for the amount of sun it likes. If you don't have a large space you can still get a lot of fresh vegetables. Put a pepper plant or tomato plant in a flower bed. Use a tall trellis and put in pole beans instead of bush beans as they grow UP not out and not much space is needed. You can fill pots on a deck or patio with vegetables. Whatever you do don't use chemicals on them so you have good food.

We need to avoid "genetically modified organisms" or GMO foods at all costs. So much of our food is now GMO (genetically or artificially modified in laboratories using chemicals) but isn't labeled that way. There is NO law that makes companies tell you it is a GMO product. The FDA has NO testing procedure for GMO foods. A Scottish study (the only actual study done) has shown that in rats the genes from GMO foods is transferred to their DNA in the bacteria in their digestive systems. Damage to immune systems and liver showed up in 10 days in these rats. We are the guinea pig or rat in the USA. So, in short, just grow your own or try to buy organic. You can freeze or can your own. Visit farmers markets and buy bulk to preserve for the winter if you absolutely don't want to grow your own. Yes, it may be work, but a garden can be fun, relaxing, educational for kids and very rewarding. And the health benefits are priceless!

Upcoming Events and Fundraisers benefiting the Beyond Pink TEAM!



June 1, 2015 with first pitch at **7:05 pm** join the **Waterloo Bucks** at their **2nd Pink Out game**. Pink Jerseys will be up for Silent Auction, 50/50 raffle, fun activities and games for families. Watch for more details as the date gets closer.



additional details in the July 2015 newsletter and BPT website.

Join the NEISCA for their annual **Pretty in Pink Horse Show** on Saturday, August 1, 2015 at the Cattle Congress grounds.

Look for



Thank you to the UNI Women's Basketball program for including breast cancer survivors and those who care in a pre-game reception and game at their annual Pink Out game in February.



Pink Ribbon Run

Saturday, October 3, 2015 will be the **9th Annual Pink Ribbon Run** in the Cedar Valley. This event is for survivors, families, friends and runners/walkers who want to show their support for all breast cancer survivors in the Cedar Valley. Proceeds will be given to the Beyond Pink TEAM to continue their financial support for all breast cancer survivors in treatment. In 2014, 71 individuals received a total of \$51,726.77 in financial support for medical, housing and transportation needs.

Making A Difference

Several BPT members will be attending the National Breast Cancer Coalition (NBCC) Advocacy Summit and Lobby Day in Washington, DC on May 2-5, 2015. For more information contact Christine Carpenter at 319-266-0194.

Support Group Meeting Dates

April 6, 1:30 p.m.

Touch of Courage
Breast Cancer Support Group
 2101 Kimball Ave, Waterloo
 Pat – 319-232-8691

April 7, 1:30 p.m.

Care & Share Cancer Support Group
 Covenant Cancer Treatment Center
 200 E Ridgeway, Waterloo
 Jeanne – 319-272-2816

April 13, 1:30pm

Look Good . . . Feel Better
Hair – Make-up – Nails – Skin
 Covenant Cancer Treatment Center
 200 E Ridgeway, Waterloo
 RSVP to ACS – 1-800-227-2345

April 21, 4:30-7:00 p.m.

Young Cancer Survivors
Meet – Mingle – and Learn
 Unitarian Universalist Church
 3912 Cedar Heights Dr., Cedar Falls
 Gabbi – 319-292-2225

May 4, 1:30 p.m.

Touch of Courage
Breast Cancer Support Group
 2101 Kimball Ave, Waterloo
 Pat – 319-232-8691

May 4, 4:45-6:45 p.m.

Grundy Area Cancer Support Group
Support for ALL cancers
 Grundy County Hospital – Grundy Center
 Kristi – 319-824-4129

May 5, 1:30 p.m.

Care & Share Cancer Support Group
 Covenant Cancer Treatment Center
 200 E Ridgeway, Waterloo
 Jeanne – 319-272-2816

May 14, 5:00-7:00 p.m.

Splash of Color – Women of Color
Breast Cancer Support Group
 Waterloo Public Library, Waterloo
 Cathy – 319-493-8857

June 1, 1:30 p.m.

Touch of Courage
Breast Cancer Support Group
 2101 Kimball Ave, Waterloo
 Pat – 319-232-8691

June 2, 1:30 p.m.

Care & Share Cancer Support Group
 Covenant Cancer Treatment Center
 200 E Ridgeway, Waterloo
 Jeanne – 319-272-2816

July 6, 1:30 p.m.

Touch of Courage
Breast Cancer Support Group
 2101 Kimball Ave, Waterloo
 Pat – 319-232-8691

July 7, 1:30 p.m.

Care & Share Cancer Support Group
 Covenant Cancer Treatment Center
 200 E Ridgeway, Waterloo
 Jeanne – 319-272-2816



Looking for a Speaker . . .

If you are interested in having a Beyond Pink TEAM representative speak at your Church, organization or group, please contact Lori Seawel at lori.seawel@seawel.com

Want to do a Fundraiser for BPT . . .

If you would like to host a fundraiser to benefit the Beyond Pink TEAM, please contact Marty Mullnix at mapanix@cfu.net

Volunteer for BPT . . .

If you are interest in volunteering for the Beyond Pink TEAM, please visit our website at beyondpinkteam.org or contact Marty Mullnix at mapanix@cfu.net

American Cancer Society Relay For Life Events in the Cedar Valley



April 10, 2015 – Relay For Life of UNI McLeod, UNI Campus – Cedar Falls

June 6, 2015 – Relay For Life of Tama County South Tama High School – Tama

June 12, 2015 – Relay For Life of Grundy County Grundy High School – Grundy Center

June 12 2015 – Relay For Life of Bremer County Wartburg College Football Field – Waverly

June 19, 2015 – Relay For Life of Black Hawk County Hawkeye Community College – Waterloo

June 20, 2015 – Relay For Life of Fayette County Oelwein High School – Oelwein

June 27, 2015 – Relay For Life of Buchanan County Independence Jr / Sr High School – Independence

July 10, 2015 – Relay For Life of Butler County Butler County Fairgrounds – Allison

To learn more how to participate in any of these team fundraising events, go to RelayForLife.org to find event you are interested in.

Beyond Pink TEAM Goes to Capitol Hill to End Breast Cancer

By Kristin Teig Torres

BPT members Lori Seawel and I met with Iowa's Congressional delegation after attending the National Breast Cancer Coalition Board meeting in Washington DC in January. The Congressional visits went well and both Lori and I were thrilled to get the opportunity to meet with all three of Iowa's new Congressmen, even if just a short time with Senator Joni Ernst.

As a Beyond Pink TEAM member I have joined the Advocacy Council to do this work because I have learned breast cancer is a political issue. The federal government is the largest funder of biomedical research; laws regulate and support access to care and health care systems; and third party payers are subject to state and federal regulations. In fact, every aspect of breast cancer is touched by public policy. It is key that those who influence breast cancer public policy are educated and have no agenda other than to save lives and to end breast cancer. So with Beyond Pink TEAM's Advocacy Council members I am working to ensure that Iowa's Congressional delegation is supporting public policy that will help end breast cancer.

In each Iowa Congressional office we asked our elected officials to do three things: 1) endorse Breast Cancer Deadline 2020, 2) cosponsor the Accelerating the End of Breast Cancer Act, and 3) to continue funding the Department of Defense (DOD) Breast Cancer Research Program (BCRP) for fiscal year 2016. Breast Cancer Deadline 2020 asks organizations and public officials to get serious about knowing how to end breast cancer. That means we have to change the conversation and our behavior about the way we approach breast cancer. The Accelerating the End of Breast Cancer Act is a call to action for all stakeholders to focus efforts on knowing how to end the disease by the end of the decade. It defines an

important role the federal government must play in this effort. The DOD BCRP was created in 1992 to "eradicate breast cancer by funding innovative, high-impact research through a partnership of scientists and consumers."

After spending an afternoon and morning on Capitol Hill, Lori and I felt confident Representative Loeb sack and Representative King will continue to support Breast Cancer Deadline 2020, the DOD BCRP, and cosponsor the Accelerating the End of Breast Cancer Act. Senator Grassley supports Breast Cancer Deadline 2020 and did an amazing job of breaking Senate gridlock when the Accelerating the End of Breast Cancer Act was first introduced. While Senator Grassley usually writes a letter in support of the DOD BCRP, we would like him to sign the Dear Colleague letter to the Defense Appropriations Committee this year.

Lori and I felt we made good progress in educating Representatives Blum and Young about our priorities for ending breast cancer. We do feel we're going to want to try really hard to meet personally with Senator Ernst in particular when we return in May, as we had just a short amount of time with her for our January visit. We did let all offices know we plan to return in May to provide updates and follow up on our January requests for support. We addressed our personal stories with the new offices, including information to draw attention to our different breast cancer subtypes (with the intent of helping them to see how breast cancer is not one disease). I spoke specifically to how the DOD BCRP helped me personally because of Herceptin. And with all offices, we reiterated the transparency, accountability and role of consumer advocates in peer review within the DOD BCRP. We also shared a



Lori Seawel and Kristin Teig Torres with Representative David Young

number of the Iowa breast cancer incidence and death statistics. All offices really paid attention when they heard these were Iowa statistics, particularly when we noted the Iowa incidence rate is greater than the national average.

We introduced the importance of ending breast cancer to each of Iowa's new Congressional offices. Now we need you to let them know how important this is to all Iowans. Please send an email to the following legislative directors in Senator Ernst's office and in Representatives Blum's and Young's office. Tell them your name, address and:

Please join the voices of all the public officials who are saying, "I stand behind Breast Cancer Deadline 2020 and knowing how to end breast cancer by January 1, 2020." Please endorse Breast Cancer Deadline 2020.

Senator Joni Ernst's Legislative Director:
Ryan.Berger@ernst.senate.gov

Representative Rod Blum's Legislative Director:
Peter.Mihalick@mail.house.gov

Representative David Young's Legislative Director:
Adam.Pradko@mail.house.gov

Please help us increase the impact Iowans make on these important issues by joining our grassroots advocacy Facebook Group, the [Iowa Breast Cancer Deadline 2020 Action Network](https://www.facebook.com/groups/217433641780809) (<https://www.facebook.com/groups/217433641780809>), and inviting your friends and family to join as well.

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

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.cancer.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.stopbreastcancer.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 preventions, detections, treatment and long-term survivorship as well as reliable, up-to-date health information. www.dslrf.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

Touch of Courage • • • Connection

Cedar Valley Cancer
Committee
4756 Charolais Dr
Waterloo, IA 50701
www.beyondpinkTEAM.org

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.

Name _____

Address _____

City State Zip

Phone _____ E-mail _____

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

- Willing to write a survivor story for the newsletter
- Volunteer: *(Check all that apply)*
- Assist with Support Groups Education (Health Fairs/Presentations)
- Development (Publicity) Advocacy – Deadline 2020
- Events (Fundraisers, Annual Luncheon, Projects and more)
- Willing to write letters or make phone calls to legislators for breast cancer issues, through the Iowa Breast Cancer Advocacy Network.
- Interested in making a donation. Make checks payable to: Beyond Pink TEAM
(all donations are tax deductible)
- BPT Fund NBBC Scholarship Fund Area of Need