



Touch of Courage . . . Connection

October 2016

TAKING ACTION – EDUCATING – ADVOCATING – MAKING A DIFFERENCE

IN THIS ISSUE

Neo-Adjuvant Treatment for Breast Cancer

by Mary Kremer, CN-Bi, R.T. (R)(T) Certified Breast Cancer Navigator

Newer approach to breast cancer treatment for Her2 positive cancer.

In the last several years there has been new management in the treatment of breast cancers that are Her2-neu positive. While examining the sample obtained during a breast biopsy, the pathologist evaluates for expression of a certain protein called Her2-neu, if the diagnosis is a breast cancer.

Her2 or "human epidermal growth factor receptor 2" is a gene that helps control the growth and repair of cells. This is a protein that appears on the surface of some breast cancer cells. Breast cancers that are Her2 positive have overexpression of the gene indicating that the gene is making too many copies of itself. Extra copies of Her2 genes tell breast cancer cells to grow and multiply.

For most breast cancers, surgery is the first line of treatment. After healing of the surgical wound in about 4 – 6 weeks, then other forms of treatment tend to follow. However, for Her2-neu positive cancers, the oncologists and surgeons may consider certain medications before surgery which is called neoadjuvant therapy. Two agents that have been used in neoadjuvant

regimens are Herceptin and Perjeta. Treatment recommended after surgery is called adjuvant therapy.

A benefit of neoadjuvant treatment is that it prevents delay of administering chemotherapy to treat and prevent breast cancer spread beyond the breast, as it is given in these cases, before surgery. In patients who tend to heal slowly after having a lumpectomy or mastectomy, their treatments could be delayed, as doctors typically wait for the surgical wound to heal before administering chemotherapy. Additionally, since neoadjuvant chemotherapy could shrink the size of cancer, the patient may now be able to have a lumpectomy with radiation, instead of a mastectomy, hence allowing breast conservation.

Not every woman who has been diagnosed with a Her2 positive breast cancer may require neoadjuvant treatment. There are many factors that the medical team considers before deciding on a course of treatment. Doctors will take into consideration multiple different factors to decide on the appropriate regiment for treatment. Some of the factors may include age, overall performance status and other medical issues which could make

Neo-Adjuvant Treatment, continue page 4

I'm Fine . . . Not!

A Survivor's Story
Page 2

Upcoming Events

Pink Ribbon Run – Annual Celebration –
Delivering Fashion Event – Health Fairs –
Pink Sporting Events
Page 3

Go Green

Time For Canning
Page 4

Support Group Meeting Dates

October – November – December –
January
Page 4

Unsung Hero Award

Page 5

Want to Ignite the Cancer Conversation?

Page 5

Congress Should . . .

Page 5

Resources

Organizations for support and education
Page 6

Support and Volunteer Opportunities form

Page 6

I'm Fine NOT!!!

By Marina Steffner, a cancer survivor

I was 34 years old when I was diagnosed. My kids were ages 1, 4, 6 and 9. My daughter Roni had turned 1 in November, and I was just finishing up breast feeding in December or January. In February, I found a lump by accident. I thought nothing of it. I just thought I was still drying up from nursing, but I decided to have my doctor take a look at it just in case. My doctor suggested I get an ultrasound. The ultrasound doctor said it was not filled with fluid but it was a mass and suggested I go to a surgeon.

I literally had no idea what anything meant because no one gets cancer at 34....right? I was oblivious. But I just went from one appointment to the next. Nothing really hit me until the oncologist (literally the cancer doctor) told me I was going to get chemo. I said to her, "Ummm...I'm just here for radiation." As it turned out, I wasn't just there for radiation. Over the next 12 months, I was scheduled for a surgery to implant a port for the chemo, then endured 6 rounds of chemo and 32 radiation treatments. My breast cancer was Stage 2. One standard test during cancer treatment is a bone scan. My bone scan showed several tumors throughout my body, so they started to check for bone cancer. They were looking for Stage 4 bone cancer...that was very scary. They did hideous bone biopsies but thankfully they turned out to be benign tumors.

I write about this, not to bore you with my medical history, but to give you a general feel for where my head was at during that time. It also speaks to how I feel about the Pink Ribbon Run. Through the first six months, I never thought a thing about my cancer. I kept saying I was totally fine. I was just thankful my kids didn't have cancer. I was in complete denial. So, I completed four rounds of chemo, worked 40 hours per week and raised four kids, like everything was totally normal. I was so sick and really tired. After I completed four rounds of chemo and all the radiation treatments, I was supposed to go to back for two more

rounds of chemo, Taxol. I had heard that Taxol was the worst. My hair was just starting to grow back. I was feeling normal, rocking my short hair; I had even stopped wearing a bandana. I was preparing to go in for my weekly doctor appointment with the oncologist and I was feeling strong. Super confident. I had convinced myself that I did not need to finish my treatments, I was still "fine" and I was going to tell her I wasn't going to do it. I prayed, out loud, all the way to the doctor appointment. It was a super strong conversation with God, praying for strength and guidance to get through this appointment, a "help me through this" kind of prayer. It was a good conversation. I walked into the office, confident and strong, ready to go. I sat in the waiting room of her office.....it was also the waiting room for the "chemo room."

This is the turning point in my story. A woman came out of the chemo room and sat down right next to me and started a conversation with me. I know she was an angel. I can't tell you word for word what she said to me but she was younger, in her 40's and she had had a relapse. She was talking to me about fighting and never giving up, and how no matter what you are faced with you have to be strong and know you can do it. I never told her what I was planning to say to my doctor, but every word she said was exactly what I had asked God for...I had wanted to quit, and the message back was: I needed to fight.

The woman went back in the chemo room and I just sat there with tears just streaming down my face, I wasn't crying out loud, just silent tears. I went into my appointment with my doctor and started bawling... a lot. She rubbed my back and called a counselor and set up an appointment for me. She said, with her Indian accent, "You go to counseling, it's ok." So, I went to counseling, and it was amazing. But, I never went to a young cancer survivor group. I never had anyone to talk to about what I was going

through. I never connected to another person going through what I was going through. That was 11 years ago.

My first Pink Ribbon Run was in 2013. We have gone for the past three years. This is the time of year I celebrate how thankful I am for my life and every year I am so amazed at how happy I am. I cannot believe how many people are in my life now and how thankful I am that I fought through the tough times. The Pink Ribbon Run 5K is very special because I am surrounded by women who have gone through the same thing I have gone through, even though we don't talk in depth about our stories. It is seriously the first time I have been around survivors. Not reaching out to a survivor group is my biggest regret, I feel like I missed out on a sisterhood of support.

When we are all together for the big picture, sometimes we make funny comments that would only be funny to someone who has had cancer. For example, the year of the spray painted sign someone said, "we survived chemo, a little paint fumes aren't going to kill us." With other survivors it is okay to say cancer. People get so afraid to talk about it, and I get it, no one knows what to say, and certainly does not want to offend or make us feel bad. But it's nice to be with survivors, to be a little sarcastic and funny. I love the survivor picture, it makes me feel a part of the sisterhood. I feel like I belong to something bigger than cancer. I love my pink shirt that says Survivor, and I love the pink beads, I feel fancy...and special. 😊

At the Pink Ribbon Run, we celebrate our lives and the time we have as a family. The kids and I run together as a family; as a celebration. We all get dressed up in pink, crazy socks, make tutu's, have fun with it. I love the Memorial signs that are along the course, too. I cry every time I walk by one. I am thankful every day. I am still here, watching my kids grow, and the first weekend in October is when I remember and celebrate all these things. I will be there every year to celebrate my life and be an inspiration to the women who are still fighting. And to the survivors who are attending their first race? Come join us.

Upcoming Events and Fundraisers

10th ANNUAL
PINK RIBBON RUN
2016

Saturday, Oct. 1, 2016

8:00 a.m.

**Start and finish in front
of Cedar Falls Library**

Register at

www.beyondpinkteam.org



See & Learn about Beyond Pink TEAM at the following Health & Wellness Fairs

Wednesday, October 5, 2016 – 7-10 a.m.

YWCA of Black Hawk County – Gymnasium
425 Lafayette Street, Waterloo

Wednesday, Oct. 12, 2016 – 11 a.m.-2:00 p.m.

UNI Employee Benefits & Well-being Fair
Maucker Union Old Central ballroom

Wednesday, October 19, 2016 – 10 a.m.-1 p.m.

Hawkeye Community College

Health Education and Services Center

SCHEELS.

"Delivering Fashion"

Sunday, October 2, 2016 – 7-9 p.m.

Purchase tickets prior to the event at Customer Service. Cost \$10.00 and at event receive \$10 Scheels Gift Card.

October is considered "Breast Cancer Awareness" month. So many want to show their support of breast cancer survivors by hosting fundraising events to bring awareness and raise funds. The Beyond Pink TEAM is honored to be a recipient of many of these monies.



We would like to thank these groups,
Businesses, and individuals at the

Beyond Pink TEAM

Annual Celebration of Accomplishments

on Thursday, October 20, 2016 from 5:00-6:30 p.m.

at the Community Foundation of Northeast Iowa,

3737 Greenhill Circle – Cedar Falls.

Survivors and the community welcome to attend this celebration. See what Beyond Pink TEAM is all about.

Sporting Events hosting Pink Outs

UNI Soccer

Tuesday, October 11, 2016

7:00 pm vs. Drake

Cedar Valley Soccer Complex

Ridgeway/DeWitt Road

UNI Volleyball

Friday, October 21, 2016

7:00 pm – McLeod Center

Breast Cancer Survivors get

in FREE – *contact Marty at*

319-269-7176 or email

mapanix@cfu.net for more information

Blackhawk Hockey – TWO Nights!!!

Saturday, October 22, 2016

7:00 p.m. – Young Arena

50/50 Raffle

Friday, October 28

7:00 p.m. – Young Arena

Pink Jersey Auction

Go GREEN !

By Cindy Harris, a Survivor



Time for Canning!

It is time for all of us to start canning and freezing. All the fresh fruits and vegetables will soon be gone. The canned goods at the store are cans lined with plastic, laden with salt and preservatives and who knows what other additives. Canning is not hard, just a little time consuming but it is worth the time. If you don't have a garden, visit the farmers markets and buy in bulk.

I freeze my peppers to cook with all winter. You can do stuffed peppers with frozen peppers too. Freezing corn doesn't take a lot of time and the taste is wonderful. I can my green beans but I do freeze some too. Tomatoes can be canned or frozen too. I grow black beans, when they are ready I put them in glass jars. At the end of the season I cook them and can them too for chili, salads whatever. You can freeze, can or even pickle broccoli, cauliflower, carrots a variety of things.

You can buy books on how to or just go online and get all the easy instructions. You can buy all kinds of spices for this. If you are adventurous, try canning meat. It is really good and very simple too. So, keep healthy and eat healthy and save money too.



Support Group Meeting Dates

October 3, 1:30 p.m.

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

October 4, 1:30 p.m.

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

October 10, 1:30-3:30 p.m.

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

November 7, 1:30 p.m.

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

November 8, 1:30 p.m.

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

November 13, 5:00-7:00 p.m.

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

December 7, 1:30 p.m.

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

December 8, 1:30 p.m.

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

January 3, 1:30 p.m.

***Care & Share Cancer
Support Group***
Covenant Cancer Treatment
Center
200 E Ridgeway, 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 9, 1:30-3:30 p.m.

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

January 17, 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

Neo-Adjuvant Treatment, cont'd from pg 1

some patients unable to tolerate potential side effects of certain treatments.

In summary, neoadjuvant chemotherapy is available in treating specific cases of breast cancer which are Her2-neu positive which allows shrinkage of the breast cancer and treatment of cancer beyond the breast, prior to surgery. This has additional benefits of changing surgical management from mastectomy to lumpectomy, which allows breast conservation. Recent advances in research have led to a patient-centered approach where treatment is tailored to each patient based on multiple relevant patient factors.

Unsung Hero Award



By Christine Carpenter

Alan Levin is a Beyond Pink TEAM unsung hero. Over 15+ years ago when Beyond Pink TEAM (BPT) saw the need for a website, Alan Levin volunteered to host it. Ever since then, he has hosted our website at no charge. Additionally he has annually paid to register our domain names. Over ten years ago Alan and his wife Jane moved to the Savannah GA area. He continued to host and pay for all expenses connected with Beyond Pink TEAM's website. Any time we decided to overhaul our website, Alan would work with our new webmaster to transfer all materials and make it work right. I cannot recall our website ever being down. In fact, because of Alan's intelligent web hosting skills and quiet volunteerism, we often forgot about all he was doing for the Beyond Pink TEAM and our mission.

Alan has decided to retire and shut down his web hosting business. Even now he is selflessly and competently working with Dave and Lori Seawel to transfer the Beyond Pink TEAM website to a new web host. He truly is a Beyond Pink TEAM Unsung Hero!



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.

Want to ?

If you want to bring diverse communities together and activate the conversation that will initiate and develop concrete steps to conquer all cancer, you are welcome to join Ignite the Cancer Conversation's (Ignite) Team. The Ignite Team has laid out a path to continue our work in the Cedar Valley and beyond. Our goal is to bring all those wanting to search for common topics to address in future mini programs. Our hope is to schedule from 2-4 small events for 2017 – "Lunch and Learns" or later in the day appetizers and education sessions. Bring your ideas and help us choose which topics you want to learn more about.

- How do I write, call, and email by legislators?
- Which websites, blogs, and social media should I follow?
- Should I have my water tested for carcinogens?
- Should I have my home/school/work place tested for radon?
- Which farm and garden chemicals cause cancers?
- How do I determine truth from hype when the media reports about cancer?

Contact Kristin Teig Torres, kteigtorres@yahoo.com to learn more.

Congress should –

support legislation? And/or to fight breast cancer?

By Christine Carpenter

In the United States, it is estimated that more than 40,000 women and 440 men will die of breast cancer this year. Over the past few decades, this nation has invested billions of dollars in breast cancer research and technology, but the statistics have not changed significantly. We continue losing the women (and men) we love to this dreadful disease.

As a breast cancer advocate, I believe in the power of public policy action. There is a bill in Congress called the Accelerating the End of Breast Cancer Act (H.R. 1197) that would go a long way toward ending this disease once and for all. It focuses on identifying strategies for the primary prevention of breast cancer and identifying methods to prevent breast cancer metastasis, or the spread of breast cancer to other parts of the body.

Metastasis is responsible for over 90 percent of breast cancer deaths. H.R.

1197 is bipartisan, noncontroversial, does not require additional federal funding and will accelerate the progress already made towards ending breast cancer.

In the House, H.R. 1197 has 273 bipartisan co-sponsors including all of Iowa's Representatives: Blum, Loeb sack, Young, and King. That means that 273 members of Congress say they want this bill to become law. It is unheard of to see such strong bipartisan support in today's political climate. Does their word mean anything? Congressman Fred Upton, chair of the Energy and Commerce Committee and House Majority Leader Kevin McCarty have the power to bring this bill to a vote.

Call Congressman Fred Upton (202) 225-3761 and Majority Leader McCarthy (202) 225-2915 and tell them, "We need a vote on H.R. 1197 so we can know how to end breast cancer. The women and men of Iowa are watching and we are running out of time."



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.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:

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