

Touch of Courage

. . . Connection

October 2017



Living My Dream

A Survivor's Story
Page 2

October Events

Page 3

BPT Celebration of Volunteers and Donors

Page 4

Where Are They Now?

A Survivor's Update
Page 4

Fundraising Thank You's

Page 4 and 5

Splash of Color 3K Walk

Page 5

Living Green

Page 5

Support Group Calendar

October – November – December
– January
Page 6

Breast Cancer and BPT Advocate Message

Page 6

Resources, Support and Volunteer Information

Page 8

WHAT IS CANCER REHABILITATION?

By Jennifer Nus, DPT

Oncology Rehabilitation Specialist, Taylor Physical & Occupational Therapy

When a person is diagnosed with cancer they will have a variety of treatment options which may include surgery, chemotherapy, radiation, and targeted therapies. The disease itself, as well as the treatment options, can cause a wide range of side-effects which can include fatigue, pain, decreased range of motion, weakness, fibrosis, incontinence, lymphedema, cognitive changes, swallowing /speech issues, and impaired balance/gait.

Cancer rehabilitation can include physical, occupational, or speech therapy and is designed to address the functional impairments that can be associated with cancer. Therapy can be helpful to address the specific needs of individuals who are undergoing or have completed treatment for cancer. Therapists use a variety of techniques to treat these symptoms including manual therapy, exercise, manual lymph drainage, balance and gait training.

One specific side effect that can be very prevalent is cancer-related fatigue. This is described as a persistent ongoing fatigue that is not proportionate to activity level. It is not likely to be relieved by rest and

interferes with normal daily activities. Patients may often describe a feeling of general weakness, heaviness in their arms and legs, and fatigue lasting hours after completing an activity. Exercise has been found to be beneficial at treating cancer-related fatigue. Exercise helps decrease loss of muscle mass, reduce fatigue, and improve physical performance and functional independence.

Another common side effect of chemotherapy can be chemotherapy-induced peripheral neuropathy. This is a set of symptoms caused by damage to the nerves that carry sensations to the brain and control movements in the arms and legs. Many chemotherapy drugs are linked with neuropathy. Patients may experience pain, loss of sensation, numbness, trouble using fingers or grasping objects, and balance problems. Therapy can help with desensitization techniques, sensory retraining, education on fall prevention, and exercises to improve balance and walking.

Continued on page 7, column 3

Living My Dream

By Magda Renenauer, a survivor, wife, and mother

On a February 18th, 2016 I was sitting at the breast care center waiting my turn for my first (and as it turned out later, also my last) mammogram. I have heard horror stories, about the pain and discomfort, so I was freaking out. I was sent for one, along with an ultrasound because I had some dark discharge. Within an hour, my world came tumbling down, when the word biopsy came up. They tried to calm me down. It might be nothing... but come on, who was going to believe that... this place sees plenty of cancers, so they know what to look for. They took not one but three samples, including one from a lymph node.

The next day with my husband, my worst fears were confirmed. That day I did break down, and cried like I have never cried before. But I didn't allow myself to dwell on it, because now it was time to fight... my official diagnosis was stage IIIA Her2+ and ER+ breast cancer. Mentally the toughest part was telling my family, friends and coworkers that I was sick, and pretending I was okay in front of my two small (3 years old and almost 1) children was pretty draining. At 36 years old I was facing cancer again. Because 8 years before this, I had melanoma, and this one was going to be a tougher fight.

The next couple of weeks passed in a fog. I don't recall too much from all the testing and doctors' appointments. It was hard keeping things straight, since I had so many of them. Thankfully I had my husband with me to keep track of everything. That whole time I was waiting for someone to wake me up from this nightmare.

My treatment plan was designed specifically for me. It was to administer chemo before the mastectomy to try and shrink the cancer. First was a port followed by three treatments of 4 drugs. After that a bilateral mastectomy and three more chemo treatments. I chose to have a reconstruction, and that was started at the time of my mastectomy. Since I am so young with absolutely no family history of breast cancer, I had genetic testing for BRCA as well as genetic testing for melanoma. All came back negative, which was both a relief and confusion. A relief, because that meant my girls do not have the gene.

Chemo was unknown, therefore scary. But I had to live through it and it sucked. I was tired, lost my taste, and developed a horrible taste in my mouth. It took two treatments for me to start losing my hair. To be honest, once I got a nice wig, I was not too upset about going bald. I didn't like it but it was easier than I expected. I do believe getting the right kind of wig was what helped me keep it together.

While on chemo, I remember feeling ok for the first couple of days, then have a weekend from hell (every three weeks). By the time I would start feeling human again (the weekend before my Tuesday treatment) I would get upset because I knew I was starting all over again. Eating and drinking was a struggle, but I tried pushing for it, to make sure I didn't end up in a hospital.

My coworkers were super understanding and work was a nice escape. It was easy to pretend at work things were normal... except I

would be missing for a day every three weeks. Home life was tough. My husband had to cover for me a LOT as I had no energy. You realize how useless you are when you are in bed before your 3-year-old daughter.

My surgery was the scariest thing I have lived through. I was terrified... terrified of what they would find, terrified of how I would feel (that unknown part is awful), terrified of not waking up. But, I'm still here... the good news was, the biopsy of the removed tissues showed ZERO cancer cells. I was declared cancer free. I guess feeling like crap has paid off.



Magda "living her dream" with her family.

After surgery, I was at home for six weeks. The first couple weeks were pretty bad...was on heavy pain meds, had drains in my body, and had to sleep in the recliner. One thing that made it easier, was my own personal nurse, my sister, who stayed with me for 3 weeks. I don't think I would've been able to take care of myself, if she hadn't been there.

Continued on page 7, column 1, Survivor

October – Breast Cancer Awareness Month and Fundraisers Supporting BPT



Join us on Saturday, October 7th, for the Pink Ribbon Run in downtown Cedar Falls. The Survivor tent, team sites, and other festivities will be held in the parking lot of the Cedar Falls Public Library and Community Center. Packet Pickup is Friday, October 6th from 4-7 p.m.

Didn't get registered? Come to Packet Pickup on Friday or before the race on Saturday to register. No t-shirt guarantee after September 22nd.

(see list of 2017 PRR Sponsors page 5)



On October 4th at 5:45 p.m., join Cedar Valley Cyclists for a ride to support and bring awareness to breast cancer. Contact Angie at angie@ridecvc.org for details.

SCHEELS.

Delivering Fashion – Sunday, October 15, 2017 from 7-9 p.m. at 402 Viking Plaza Drive, Cedar Falls. Advance tickets required and may be purchased at the Scheels Store.



UNI is a great supporter of breast cancer awareness and the BPT. Check out these events:

Maucker Union – October 9-20 will be selling **PINK** ribbons to patrons.

UNI Soccer – Thursday, October 26th at 4:00 p.m. Join the UNI team and BPT as together we share breast cancer information and watch an amazing team!

HOCKEY PINK OUT – 2 Days

Friday and Saturday, October 27 & 28, 2017 with drop of the puck at 7:05 p.m.
Young Arena, 125 Commercial Street, Waterloo

PINK Player Game Jerseys will be auctioned

50/50 Drawings each night



Stop and Checkout BPT at:

YWCA Wellness Fair – Tuesday, October 3, 7-9 a.m., 425 Lafayette, Waterloo

Grundy Girls Night Out – Thursday, October 5, 5-7 p.m. downtown Grundy Center

UNI Wellness Fair – Wednesday, November 15, 11-am-2 p.m., Maucker Union, UNI Campus

The Community Continues to Fundraise for the Beyond Pink TEAM

Thank you to PDCM Insurance for the donation from their "Pie in the Face" fundraiser.



Join Us for an Open House

Learn more about the
Beyond Pink TEAM

or

How to get involved

As we honor

Volunteers and Donors

Thursday, November 2, 2017

5:00 – 6:30 p.m.

Community Foundation of Northeast Iowa

3117 Greenhill Circle

(east of Cedar Heights Drive)

Cedar Falls, Iowa



Volunteer Awards - Donor Recognition

Fundraising Presentations - Refreshments

Where Are They Now? . . . *In 2017, we will be sharing with our readers how survivors are doing years after their diagnosis. This story is an inspiration of a breast cancer survivor who has known cancer in other ways. Because of this she has become an "angel" to many other cancer survivors. Here is Grace Hernandez's story.*

I was diagnosed with breast cancer about 1 ½ years ago. My 2 children and 6 step-children stepped up to support me during my diagnosis and treatment. When I was diagnosed, I thought back to when my son was diagnosed with cancer at the age of 19. I learned a lot from my son on how to approach cancer. He was determined to remain positive. He was told he would have a "one in a million" chance of ever having children. We all feel so fortunate that he is now 43 years old, healthy, and has two beautiful boys! I have had several family members who have had cancer or are currently dealing with cancer, including my son, husband, mother and three brothers. We have all supported each other!

I am a retired nurse, having cared for patients at UnityPoint Allen Hospital for 43 years. When I retired 8 years ago I knew I wanted to continue caring for others. That is why, every Monday, I volunteer at the Community Cancer Center, sharing my homemade baked treats with patients and their families and friends. I greet and welcome patients coming into the Community Cancer Center. I enjoy making people more comfortable when they are scared. I let them know that I was also scared when I found myself on a cancer journey. I share with patients that good things can come of this situation. Being around the patients at the Community Cancer Center has helped me get through my cancer.

The patients and their support people have also become part of my support system.

I continue to have preventative screens and I see my oncologist every six months. I am in my first year of being cancer free! I feel blessed. I am thankful every day. I enjoy my life.

We are all survivors!



 **Splash of Color (SoC)**
Breast Cancer Support Group 3K
Fundraiser Walk 



SATURDAY, OCTOBER 14, 2017

Registration: 7:30 A.M. Program: 8:00 A.M.

Walk: 8:30 A.M. Sharp!

Sullivan Park, Waterloo

\$20-\$22 Adult, \$10 student

**SPONSORS: YOUR TAX DEDUCTIBLE
 DONATION OF \$100 OR MORE WILL GET
 YOUR NAME ON THE BACK OF THE
 EVENT T-SHIRT. MAKE CHECK PAYABLE
 TO/MAIL TO: SPLASH OF COLOR, 541
 SHERMAN AVENUE, WATERLOO, IA 50703
 B/4 9/29/17.**

Contact: Mrs. Cathy Ketton
@cathy_ketton@yahoo.com or 319/233-2819
for more information.

Living Green

Shared By Deanna Hughes

Berry Wash



Imagine no more spoiled strawberries, raspberries, blue and black berries the day or two after you just purchased them. Here's a wash that will help keep them fresh longer.

1 part vinegar (such as $\frac{1}{4}$ cup)

3 parts water (such as $\frac{3}{4}$ cup)

Soak berries for a few minutes, drain and rinse well. Dry them on paper/dish towel or in a salad spinner. Store in **GLASS** container with a lid that seals!

The vinegar will kill bacteria so the berries should last for a week in the refrigerator.

A huge thank you to the Pink Ribbon Run sponsors!

Presenting

Oakridge Realtors
 University of Iowa Community Credit Union

Survivor Sponsor

Community Auto Group

Bibs 'N Banner Sponsor

Nagle Signs Inc.

Award Sponsor

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 Nucara Breast Care Center
 CUNA Mutual Group Xpressions

Survivor Cheer Sponsors

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Sartori Hospital Avalon Plastic Surgery
 Lincoln Savings Bank
 UnityPoint Health Allen Hospital-Community
 Cancer Center
 Cedar Falls Tourism and Visitors Bureau

Supporters

Culligan Martin Bros. – Food Market

Often we receive information from individuals, groups, organizations, or businesses that would like to donate to or fundraise for the Beyond Pink TEAM. We are always excited to partner with the community in this way. We have drafted guidelines to facilitate these opportunities which can be found on our website at www.beyondpinkteam.org to make the process easier or you can contact Lisa Ellermann at mamgrl.lw@gmail.com.

This is the first of 2 articles sharing the role, insight, and vision of Gowri Bertrabet Gulwadi, a breast cancer advocate for BPT and YOU!

National Breast Cancer Coalition - NBCC

By Gowri Bertrabet Gulwadi

The team in Iowa has strong roots in advocacy thanks to the efforts of Christine Carpenter and her dedicated team of volunteers who have been attending the National Breast Cancer Coalition (NBCC) Advocate Leadership Summit for the past several decades. Recently I was honored to be a part of this group and began to figure out my own voice in this process. The two fundamental questions I began to understand and learn were: 1) Why is there a need for advocacy in breast cancer research and 2) What makes a good advocate?

I attended the NBCC summit in 2015 and 2017 and also recently attended a very intensive workshop called Project LEAD coordinated by the NBCC. Through these experiences, I realized that our risk of breast cancer has gone up, not down, despite our advances in research and technology, our efforts in building awareness, and our innovative, sophisticated screening mechanisms.

There is a need for advocacy because not all the research is relevant, focused in the right areas, or able to be translated into action. There is a need for advocacy because there are multiple groups of researchers who have not found the ways to speak with each other. Breast Cancer is a systemic disease that needs a systemic approach to treatment and eradication. However, we have siloed approaches which are successful in making some advances, but often not in conversation with each other.

There is a need for advocacy because decisions are made at very high levels that impact a person's daily experience when living with cancer. There is a need for advocacy to emphasize a critical need for research on environmental factors that might play a role - not only the environment that surrounds a single cell - the cancer cell, but the environment that surrounds us people - pesticides, cosmetics, etc. Even though there is anecdotal evidence, we cannot take action unless the research is sound, valid, ethically conducted, and translatable. There is a need for advocacy because people must be educated on what good research is.

So, what makes a good advocate? A good advocate understands the science behind cancer, understands what happens to the cell when cancer begins to grow, understands the deep potential yet deep limitations of screening, understands that detection does not equal cure, and understands that a strong voice is necessary so that the advocate can be heard by not only the scientific researchers, clinicians, and patients but the politicians who impact this complex system.

Support Group Meeting Dates

October 2, 1:30 p.m.

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

October 3, 1:30 p.m.

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

October 9, 1:30-3:30 p.m.

Look Good ...Feel Better
Hair – Make-up – Nails – Skin
Covenant Cancer Treatment Center
200 E Ridgeway Ave., Waterloo
To reserve a seat call 1-800-227-2345

November 6, 1:30 p.m.

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

November 7, 1:30 p.m.

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

November 9, 5:00-7:00 p.m.

Splash of Color – Women of Color
Breast Cancer Support Group
Waterloo Public Library
Cathy – 319-504-2703 for details

December 4, 1:30 p.m.

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

December 5, 1:30 p.m.

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

December 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
To reserve a seat call 1-800-227-2345
Jessica – 319-272-2816

January 2, 1:30 p.m.

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

January 8, 1:30 p.m.

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

January 16, 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

Survivor Story, Continued from page 2

The good news of no cancer did not alter my treatment plan, and I had to continue my chemo, for three more treatments.

To say my summer was shot, is an understatement. Once I was done with the chemo (except for Herceptin) I started radiation. This invisible thing didn't seem to bother me much, for the first 5 of 6.5 weeks... until it hit me all at once. The burns were bad and painful. I was eating ibuprofen like candy... but in the end I got through it.

Up until radiation, I was able to keep my spirits up. I didn't have time to think too much about my situation, I was too scared and felt sick, I didn't concentrate on what was happening to my body. And then, things slowed down, and I got in a rut. Not that I never cried before, but usually I got myself out of that dark place. But all of a sudden I couldn't. I was PISSED. Why the heck was this happening to me? What did I do to deserve it? I'm a good person, why? I know those are stupid questions, because I know cancer doesn't discriminate, but you can't help what you feel.

Once my radiation was over, my husband took me on a trip to Boston. I spent a long weekend without a wig, as my hair was growing back. Of course, as my hair started growing back, my eyebrows and eyelashes started falling out. I never completely lost my brows, which was very helpful with drawing them on. And then came the biggest surprise of them all... I lost all of my toenails, and my fingernails were detaching from the nail bed. It is an unusual side effect, but, it happens... I'm still waiting for proper nails. And let's not

forget chemo brain... I hope, one day it will finally go away.

I had to finish out the 12 months on Herceptin, but that was easy. I didn't have any side effects from it. Regular echocardiograms showed that my heart was tolerating it well.

This year on March 7th I got to ring the bell of a last chemo. A week later I had my port removed. The last step was the reconstruction. I had my implant placement surgery on July 24th. This time around, surgery and recovery were much easier.

What got me though this...? My family. My husband stood by me, no matter how hard it got. He had to pick up where I couldn't care for my children, he shaved my head as needed (not exactly an activity specified in our vows). And mostly, I needed to stick around for my girls. I wanted them to have a mom.

Today, I am living my life, trying to pretend it didn't happen, but there are enough scars on my body and my mind to always remind me. I am still not at full capacity, but I am getting better. I still cry on occasion, and at times I get mad, but I am doing my best not to let cancer rule my life. I could let myself fall into a dark hole and never get out... but I guess it's not in my nature. I'm a fighter, whether I like it or not, and giving up is not part of my vocabulary.

It has been 18 months since that fateful day, where I thought my life was over. I have taken on this war. I won! I am a SURVIVOR! What did cancer teach me? That I am pretty damn awesome and strong, even if I don't always give myself the credit. That I can pull off a wig, and I have a pretty nice looking head. And most importantly, none of us are guaranteed a tomorrow. So when

people ask me how I am, I always respond with "living the dream". Most assume I'm being sarcastic, but you know what, I'm alive, therefore I AM living my dream.

Rehabilitation, Continued from page 1

Radiation fibrosis can occur as a result of radiation treatments. Tissue trauma and inflammation can lead to the formation of scar tissue which can contribute to tightness and loss of mobility in the area of radiation. A patient going through treatment for breast cancer may develop tightness and difficulty moving their arm, which may in turn cause them pain. Manual therapy techniques and exercises can be helpful to improve tissue flexibility, range of motion, strength, and postural control to restore function and decrease pain.

Radiation, chemotherapy, and anti-estrogen medications can cause incontinence and sexual dysfunction. Both can have a huge impact on a person's life. Pelvic floor disorders can occur when the muscles that support the pelvic organs becomes weak or damaged. This can lead to issues with incontinence and pelvic pain. Our staff includes physical therapists that specialize in treating these issues through pelvic and core stabilization exercises, manual therapy, postural education, and functional training.

It is important to discuss any side effects or concerns with your healthcare provider to find out if cancer rehab may be appropriate. The goal of cancer rehab is to improve function and quality of life for patients throughout the continuum of their cancer diagnosis, treatment, and recovery.



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, counselin, 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

National LGBT Cancer Network works to improve the lives of LGBT cancer survivors and those at risk. www.cancer-network.org

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 the 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)
- Make a donation. Make checks payable to Beyond Pink TEAM. *(All donations 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