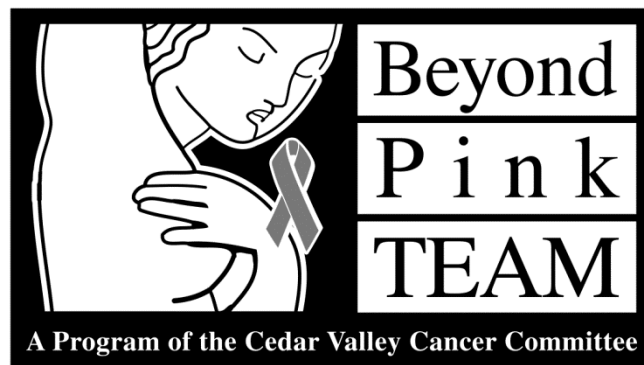


Touch of Courage

. . . Connection

April 2019



Celebrating 30 years in the Cedar Valley

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Mindfulness Meditation

What it is – How it Works – What are the Benefits

At Young Cancer Survivors' January meeting, local meditation instructor, Carol Teare, led us through a beginner's practice of mindfulness meditation.

What it is

Mindfulness meditation is based on being mindful or having an increased awareness and acceptance of living in the present moment. In mindfulness meditation, you broaden your conscious awareness. You focus on what you experience during meditation, such as the flow of your breath. You can observe your thoughts and emotions but let them pass without judgment.

Mindfulness-Based Stress Reduction studies have shown many mindfulness techniques improve common psychological problems such as anxiety, stress and depression in cancer survivors and improve overall quality of life.

According to the National Cancer Institute, up to half of cancer patients have trouble sleeping. Insomnia is the most common sleep disturbance, affecting up to eighty percent of

patients. Emotional distress, side effects from medications, and pain all contribute to difficulty falling asleep. But insomnia is not mere inconvenience. Getting adequate deep sleep lowers stress hormones like cortisol, boosts immune function, reduces inflammation, and promotes the body's healing mechanisms.

Dr. Linda Carlson* teaches her patients a breathing exercise that has been successful in helping them relax and fall asleep. Based on what she calls "2 to 1 breathing," this exercise is best done while in bed, in a dark room, in preparation for sleep.

How it Works

Begin by lying on your back. Breathe in for a count of 4, exhale for 8. Do this 8 times.

Turn to your left side. Breathe in for 4, out for 8. Do this 16 times.

Turn to your right side. Breathe in for 4, out for 8. Do this 32 times.

Meditation, continued col. 2, page 7

A Survivor Shares . . . Never Lose Faith

A survivor's story by Cheryl Thayer

My journey started in September of 2010. I had off and on muscular back pain so when my left breast started to feel achy and swollen my family doctor just thought it was the muscle pain associated with that.

After a month the feeling had not subsided so I called my OB-GYN in Ames to have it checked out. I had been in for my yearly physical just six months prior. They scheduled me for a mammogram, had me wait, and was called back for more views. I started to think this was not good. Sure enough they saw something and scheduled a biopsy the next day. The following day I got a phone call no one wants, "It was Breast Cancer."

I was shocked, angry, and couldn't understand. I exercised, watched what I ate, didn't smoke or drink. Why me? Two years later I got my answer.

I was scheduled with a surgeon who suggested the lump was caught early and wasn't large. I decided to do a lumpectomy which was done in November 2010. A week after surgery I went back for a check-up with the surgeon. He wanted me to see an oncologist, which was scheduled the next week. I was shocked when I was told I needed chemotherapy and radiation. I didn't understand. All you hear is "Catch it Early" (which I had done); surgery and pathology showed no signs of cancer. They had gotten it all during the biopsy.

He explained that with the type of cancer I had that this was the only treatment. If it came back it was terminal. Needless to say I was in shock, felt like I had been kicked in the stomach. We caught it early - I thought I was good to go! No one

ever explained to me I had Triple Negative Breast Cancer, a lack of three receptors that fuel most breast cancers: estrogen, progesterone and human epidermal growth factor. This type is very aggressive. The surgeon had said this was negative and to me negative was a good thing! One thing I have learned, ask questions! I had no idea there were so many different kinds of cancer. Be your own health advocate, if something doesn't seem right keep asking questions!

The next few days were a whirl wind, got my port in, and started chemotherapy December 17, 2010. I was scheduled to have four rounds simultaneously of Taxotere and Cytoxan every three weeks. After each round I ended up in the hospital with some reaction. But once I was released, I went back to work the next day. I had to use my vacation and sick time, but as long as I got in at least 30 hours a week my employer was good with it. I was tired but kept on going.

I had 20 radiation treatments in March. Finally, I was done with treatments. I was tired for a long time, I remembered my nurse in the hospital saying that it would take a good year before you may feel somewhat normal. Once I had finished treatments I had an adjustment period of feeling like I needed to keep doing something to keep this away. I lived an hour from Ames and the only support group met at 7 p.m. That was too far away to go to that late, so my support was my husband and children. You just have got to keep going. I tried walking as much as I could in between treatments. I would walk on my treadmill for even five minutes and build from there. I felt like I was doing

something to reduce my stress and building my strength back up.

I feel like I got my answer of "Why me?" two years later when my daughter had gone in for her check-up. She had just moved back to Waterloo and had to find a new OB-GYN doctor. She proceeded to ask her physician when she should get a mammogram as her mom had breast cancer. She said she could wait until 40 as she was only 32 and she proceeded with her physical. The doctor felt something. My daughter was sent for a mammogram, followed by an ultrasound. They told her they were 98% sure it was just fibroid and they would check again in six months. My daughter knew I would be freaking out, so she opted for a biopsy. Low and behold it was cancer. She was also diagnosed with Triple Negative. She was checked for the BRCA gene and found she carries the gene. My middle daughter also did genetic testing, finding out she carries it also, as well as my son. My middle daughter opted for a preventative mastectomy and hysterectomy. My son can be proactive and watch for symptoms as well. As it turned out the BRCA gene came from their father's side of the family.

I feel as if I had never had breast cancer it might have been too late before the cancer was detected in my daughter. I feel that I got Breast Cancer to save my children's lives!!

I do believe everything happens for a reason. God works in mysterious ways . . . Never lose the Faith!

Beyond Pink TEAM Turned 30!

October 2018 marked the 30th Anniversary of the Beyond Pink TEAM. The first decade of the Beyond Pink TEAM was highlighted in the January 2019 issue of this newsletter. If you missed that, you can view on our website, www.beyondpinkteam.org. This issue we will feature our very active second decade.

1998-2008

In December 1999, a small group of Beyond Pink TEAM members met with Senator Chuck Grassley. We asked him to take the lead on introducing the Breast and Cervical Treatment Act to congress. The bill was passed in 2000 and women diagnosed through the Breast and Cervical Early Detection program were now eligible to receive treatment through Medicaid. To this day, we still advocate to retain this legislation so all women and men have access to quality treatment.

In 2005, the Beyond Pink TEAM became an organizational member of the National Breast Cancer Coalition (NBCC). The NBCC mission is to eradicate breast cancer so no person has to suffer with this disease.

2006 was a busy year. We changed our name from the Cedar Valley Committee for Breast Cancer Awareness to the Beyond Pink TEAM. The name represents that we have gone beyond pink ribbons and trinkets to **T**ake action, **E**ducate, **A**dvocate and **M**ake a difference.

In April 2006, we held a Meet, Mingle and Learn for young women with breast cancer. Meant to be a one time event for them to meet each other, they asked that we continue holding these events. Young Cancer Survivors now meets in January, April, June, and September.

In 2006, we received a \$1,000 donation from the Allen College Student Nurses Association and used it to start the Beyond Pink Fund at the NE Iowa Community Foundation. Also, the first Pink Ribbon Run in downtown Cedar Falls was held the first Saturday in October. The Beyond Pink TEAM was fortunate to be chosen by Cedar Falls Community Main Street Association to receive the proceeds.

The Pink Ribbon Run, along with many other donations, was added to our Beyond Pink Fund. In 2008 we were able to award the first grant to pay medical bills and/or essential living expenses for those in breast cancer treatment.

Stay tuned in July as we share where Beyond Pink TEAM is now.



You shop. Amazon gives.

Amazon donates 0.5% of the price of your eligible AmazonSmile purchases to the charitable organization: Cedar Valley Cancer Committee.

Support Beyond Pink TEAM by starting your shopping at smile.amazon.com



Living Green

By Patty Wandschneider

NATURAL LAUNDRY DETERGENT

Ingredients

4 – 4 oz bars Kirk's Original Coco Castile Soap Fragrance Free (16 ounces total)

4 lbs Baking Soda

3.7 lbs Arm & Hammer Super Washing Soda (1 box)

3 lbs OxiClean Baby (1 container)

28 oz Epsom Salt (optional)

Instructions

Grate Castile soap into very small bits. (Can use a food processor to grate the soap with a grater attachment.)

To turn the grated soap into smaller bits pulse it with the food processor blade. I found that processing one bar at a time and adding 1/4-1/2 cup baking soda to soap during the pulsing stage helped the soap separate into smaller bits.

Mix all ingredients in a large container and stir. (Do not breathe in the dust.)

How to use the laundry detergent: Measure 1 or 2 Tablespoons into the laundry per load. (There are no fillers in this detergent so it takes less than commercial laundry detergent.) It can be used in regular and HE machines.

Recipe Notes

**Warning: Use your food processor at your own risk! I was willing to try because Castile soap is very pure and non-scented. The soap has not injured my food processor at all. It washes out easily and does not leave a scent. (Fels-Naptha, which I don't recommend anyway, may leave a strong scent.)*

Celebrations – Fundraisers – Events Supporting Beyond Pink TEAM

Thank you to all individuals, businesses, organizations, and communities who gave of their time and talents for breast cancer awareness!

Beyond Pink TEAM had a presence at the February UNI Women's Pink Out Basketball game. The weather didn't deter us – much like cancer isn't deterred by much. Let's keep fighting for a Cure!



A huge thank you to Veridian Credit Union for their gift to the Beyond Pink TEAM from their "Jeans Day" event. This gift was just a portion of what the Veridian staff raised. Truly this group gives back to their community. Thank you.



Thank You Donors!!!

The Beyond Pink TEAM would like to thank the following individuals, organizations, businesses, and groups for their donations from December 1, 2018 through November 30, 2019. Your generosity, no matter the size, is greatly appreciated.

Karen Beneke
Bossard North America
Cedar Falls Police-City of Cedar Falls
Cedar Falls Police Protective
Association
C David Christensen
Flowerama
Fredsville Lutheran Church

Jean Hoy
Isle Casino-Waterloo
Jordan Kettner
LeRoys – Mark Dahling
Donna O'Brien
Ocwen Loan Servicing
Rob & Rhoda Olson
Trish Pederson

Bonnie Sadler
St Peter Lutheran Church
Scheels
Ashley Shultz
Robert & Jammi Welter
Post 49 Junior Amvets
Jeanne Olson
Doris Webber

Check out these upcoming events and activities to either support the BPT or learn more about who we are!

Saturday, April 6 – Main Street Sweets donations to BPT as part of Community Main Street Fundraiser

Saturday, April 27, 9-11 a.m. – Waverly Wellness Fair at the "W"

Thursday, September 19 – Singlespeed Bike Ride

Saturday, October 5 – 13th Annual Pink Ribbon Run, downtown Cedar Falls

Details for these and other upcoming events/activities will be on Facebook or our website: www.beyondpinkteam.org



LOOK

Where They Are Now!

By Theresa Britt - Survivor

My name is Theresa. I'm the mother of two, grandmother of two, and a radiation therapist of 33 years. I treat cancer patients with radiation as a career. And I'm a breast cancer survivor of 8 years!

My diagnosis was in two parts, a week apart. The diagnosis on my right breast was July 15, 2010 and on my left breast, after routine studies, July 21, 2010. Yep, felt the lump on my right and thanks to a MRI of my breasts we saw everything...multiple tumors in both breasts. I even had two different pathologies.

I remember, so vividly, my daughter – just 18 at the time, saying, “mommy it isn't fair! You have to take care of the people that get cancer, you shouldn't have to have it, too.” (I now actually feel it has been a blessing in disguise.)

Those words are pretty hard to hear and maybe even harder when you work around cancer and know what to expect. It sure knocked me off my feet. Now I would have to practice what I preach. I had to have a double mastectomy with reconstruction and chemotherapy. I didn't have any positive nodes so I was able to forgo radiation treatments.

For me, the nausea and loss of appetite were probably the hardest to deal with physically. And now I choose my words carefully when giving advice to my patients about eating more.

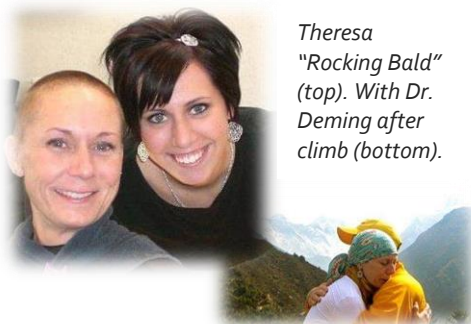
Having my daughter shave my head was pretty tough, too, but that was short lived. I rocked the bald!!!

More than the physical, though, was the emotional and mental anguish – from the drastic change in body image, to thinking of the future of my kids without a mom, to when is it going to come back. Man, some days and nights never seemed to end. It was so hard to shut my brain and thoughts down.

Now 8 years later, I am using my 'blessing' to help my patients, which in turn helps me...it's good for my soul. I can truly appreciate what some of them are going through. I can also help them to know, and see, that there are better days ahead...you regain your appetite, your hair grows back, you get your strength and confidence back, you get a new lease on life and regain control.

For me, it has made me stronger. It's reminded me how fragile and precious life is. I don't take as many things for granted. I try new things and look for new adventures. I try not to sweat the small stuff. I make sure I tell people I love them and give out as many hugs as I can every single day.

I love, live, eat, pray, give thanks, and hug daily. I celebrate every birthday and embrace each morning I can get out of bed, put my feet on the floor, and breathe.



Theresa
"Rocking Bald"
(top). With Dr.
Deming after
climb (bottom).

Beyond Pink TEAM at Work in DC for YOU!



In February Beyond Pink TEAM advocates Lori Seawel and Christine Carpenter visited the offices of Iowa's U.S. Senators and Representatives in Washington DC. They asked Senators Grassley and Ernst and Representatives Abby Finkenauer, Dave Loebsack, Cindy Axne, and Steve King to sign the letter to the Defense Appropriations Subcommittee in support of \$150 million for the Department of Defense (DOD) Breast Cancer Research Program (BCRP) for fiscal year 2020. For at least a decade all of Iowa's U.S. Representatives have supported the DOD BCRP by signing the letter each year. We are pleased Iowa Democrat and Republican Representatives support this program year after year when we ask them to. Beyond Pink TEAM advocacy works. Please join others in the Cedar Valley to influence Congress by joining our Facebook page: Iowa Breast Cancer Deadline 2020 Action Network. We need your voice.

Advocacy Updates

NBCC's Artemis Project: What is the latest?

The National Breast Cancer Coalition (NBCC) was formed in 1992 to end breast cancer through the power of grassroots action and advocacy. Since that time, NBCC has built a strong coalition of advocates and organizations that support its mission. Beyond Pink TEAM is a member organization. In 2010, NBCC launched a strategic plan of action and set out with a blueprint to identify the knowledge, approaches and tools, needed to end breast cancer. The campaign includes a research component, known as the Artemis Project, a collaboration that involves researchers, advocates, and other key stakeholders who set priorities and design and implement research plans that focus on two areas:

- Primary Prevention: how do we stop women and men from getting breast cancer?
- Prevention of Metastasis: How do we stop them from dying of breast cancer?

The following is an update on the Artemis Project for a Preventive Vaccine:

Work continues in two areas: 1) cost estimates to manufacture a multi-antigen vaccine for the prevention of breast cancer and 2) implementation of the protocol for a Phase 1 Safety Trial to test the vaccine in humans. The safety trial is scheduled to begin in early 2020. The protocol is written and the principal investigator is ready. The trial will recruit patients with low-burden metastatic disease to test safety and efficacy (whether it works or not) of the vaccine.

The following is an update on the Artemis Project for the Prevention of Metastasis:

Over 27,400 people who have had their DNA tested through home genetic tests such as 23 and Me, Ancestry DNA, etc. have given consent and completed a questionnaire about their own breast cancer history. All this information was turned over to NBCC. The goal and focus now is to bring together an advisory group to help NBCC develop a structure for the database and research protocol looking at the genetics of those breast cancers that metastasize and those that do not. Additionally, Dr. Cyrus Ghajar, breast cancer researcher at Fred Hutchinson Cancer Center in Seattle WA, is researching tumor dormancy (*Tumor dormancy* is a recognized clinical phenomenon in which disseminated tumor cells (DTCs) remain asymptomatic and undetectable over a prolonged period of time) and the immune response to disseminated tumor cells. Work continues to progress and there is excitement around the results conducted in his lab in culture. The next step will look at doing the same research in mouse models.

Breast Cancer Patient Equity Act Re-Introduced in Congress

Nikki Jensen, vice president
Essentially Women, a division of the VGM Group, Inc

Representatives on both sides of the aisle re-introduced the Breast Cancer Patient Equity Act bill that, if passed, will expand Medicare coverage to include custom breast prosthesis as an option for women recovering from mastectomy surgery. We believe

women deserve to have **ALL** choices available to them, whether it be reconstruction, off the shelf breast prosthesis, custom breast prosthesis or to go flat.

The Breast Cancer Patient Equality Act bill was introduced by both the Senate and House February 26, 2019. The bipartisan bills S. 562 and H.R. 1370 were co-sponsored by Senators Tammy Duckworth (D-IL) and Lisa Murkowski (R-AK), along with Representatives Judy Chu (D-CA) and Jackie Walorski (R-IN).

Women come in all shapes, sizes and skin tones. Providing Medicare coverage for custom breast prosthesis gives women the options they need and will let them decide what's right for them.

The female breast is one of the only body parts not covered by Medicare as a custom replacement. A similar bill to the Breast Cancer Patient Equity Act was introduced in 2018, however it didn't gain enough support to pass. Medicare already has a billing code and fee schedule but doesn't recognize custom breast prosthesis for coverage eligibility. Since many insurance companies follow Medicare guidelines. This legislation has the potential to impact women of all ages throughout the country

Having the bills introduced is just one step in the process. Now, we need you to help drum up grassroots advocacy support. Essentially Women is launching our new campaign, Let Her Decide, to advocate for the Breast Care Patient Equality Act. Toolkits are available at www.essentiallywomen.com/AdvocacyResources.

Support Group Dates

April 1, 1:30 p.m.

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

April 2, 1:30 p.m.

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

April 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

May 6, 1:30 p.m.

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

May 7, 1:30 p.m.

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

May 10, 5:00-7:00 p.m.

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

June 3, 1:30 p.m.

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

June 4, 1:30 p.m.

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

June 15, 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

July 1, 1:30 p.m.

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

July 2, 1:30 p.m.

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

Meditation, continued from page 1

The Benefits

- Reduced insomnia
- Increased relaxation
- Less anxiety
- Decreased feeling of being overwhelmed

Why it Works

This 2:1 breathing exercise combines gentle, diaphragmatic breathing with an extended exhalation, which shifts the autonomic nervous system from sympathetic “fight-flight” response to the body’s “rest-and-digest” parasympathetic response.

Switching sides mimics alternate nostril breathing in yoga. You always end on your right side because that compresses the right nostril which forces you to breathe more through the left nostril which stimulates the right brain for more relaxation and prepares people for sleep. The other reason it works is it keeps your mind really busy with all the counting, and people usually fall asleep before they’re done!

Follow BPT-Young Cancer Survivors on Facebook for announcements of local classes. Ask to join BPT-Young Cancer Survivors on Facebook.

**Dr. Linda Carlson holds the Enbridge Research Chair in Psychosocial Oncology, is an Alberta Innovates-Health Solutions Health Scholar, Full Professor in Psychosocial Oncology in the Department of Oncology, Cumming School of Medicine at the University of Calgary, and Adjunct Professor in the Department of Psychology. She is the Director of Research and works as a Clinical Psychologist at the Department of Psychosocial Resources at the Tom Baker Cancer Centre.*

KINDNESS
is
RARE
and
BEAUTIFUL

Thank you for Yours!

I have a daughter and granddaughter – Getting the genetic test after my insurance turned it down is a blessing I’ll never forget!

DH

Because of the generosity of individuals, businesses, groups, and organizations the Beyond Pink TEAM is able to help individuals with grants through the Pink Fund. In 2018, the BPT was able to ease the burden for 81 individuals in Black Hawk County and 10 surrounding counties with \$66,568.67 toward medical bills and/or essential living expenses. You can help by donating to the Beyond Pink Fund at Community Foundation of Northeast Iowa, 3117 Greenhill Circle, Cedar Falls, Iowa 50613

*Thank
 You*



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.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.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:

- | | | |
|---|--|---------------------------------------|
| <input type="checkbox"/> Writing a survivor story for the newsletter | <input type="checkbox"/> Making phone calls and sending emails to policy makers for breast cancer issues | |
| <input type="checkbox"/> Become part of the Breast Cancer Advocacy Network | <input type="checkbox"/> Become a member of the Beyond Pink TEAM -Complete this form, send with a check for \$5 to Jeanne Olson, BPT Treasurer, to address at bottom of this page. | |
| <input type="checkbox"/> Volunteering: ((check all that apply)) | | |
| <input type="checkbox"/> Assist with Support Groups | <input type="checkbox"/> Education (Health Fairs/Presentations, Newsletters) | |
| <input type="checkbox"/> Development (Publicity) | <input type="checkbox"/> Advocacy – Deadline 2020/Ignite the Cancer Conversation | |
| <input type="checkbox"/> Events (Fundraisers, Projects and More) | | |
| <input type="checkbox"/> Make a donation. Make checks payable to Beyond Pink TEAM. (All donations are tax deductible) | | |
| <input type="checkbox"/> BPT Fund | <input type="checkbox"/> Advocacy Fund | <input type="checkbox"/> Area of Need |

Touch of Courage . . . Connection

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