Touch of Courage

... Connection

April 2020



Celebrating 30 years in the Cedar Valley

A Survivor Shares - Kim Ehlers Page 2

Go Green - Natural Cleaners Page 2

Where Are They Now -Jacque Bakker Page 3

Sue Witwer Scholarship Recipient -Jodie Muller Page 3

Supporting BPT is Personal Page 4

Supporting BPT Pages 5

BPT All Cancer Support Group Page 5

Support Group Dates April - May - June - July Page 6

Ignite the Cancer Conversation Page 6

NBCC Pages 7

Resources, Support and Volunteer Information Page 8

Grief . . . What it is and How to Cope

By Nicole Alber, BSW Bereavement Coordinator, UnityPoint at Home Hospice

Grief is the emotional suffering you feel after someone or something is taken away. It is a natural and necessary response. The feeling may be overwhelming. Often, grief is associated with the death of a loved one. However, grief can be associated with any loss. Examples would include: loss of heath, such as a cancer diagnosis, serious illness of a loved one, divorce, loss of financial stability, miscarriage, retirement, death of a pet, etc.

What are the 5 Stages of Grief?

Elizabeth Kubler-Ross, a Swiss Psychiastrist, wrote her book On Death and Dying, where she introduced her five stage grief model. Since writing the book, Kubler-Ross notes that everyone may not experience all of these stages or any of these stages. In addition, she notes that these stages are not linear. Not linear, meaning this is not a process we move through in sequential stages. Grief is not something we start after a loss and reach an endpoint after we have gone through the states. Grief is always with us. **Denial** is the first stage of grief. We may go numb and the world becomes meaningless and overwhelming. During this stage, we are in a state of shock and denial. These both help us to cope and make survival possible. As time passes and you become stronger, the denial begins to fade.

Anger is the second stage in the five stages of grief. It is common to feel anger towards your friends, family, doctors, yourself, etc. It may be a necessary part of the healing process. Under the anger you feel, is the pain. It is normal to feel abandoned during this time.

Bargaining is the next stage and it can happen before or after the loss that is causing you grief. It is the 'what if' or 'if only' statements that begin to play like a record in our minds. For example, "What if we would have found that tumor sooner?" These thoughts cause us to find fault in ourselves.

Grief, continued on page 6, column 1

Faith, Humor, Positive Attitude, and Jig-Saw Puzzles

A Survivor Story by Kim Ehlers

I was pregnant with our 4th child and I felt a lump in my right breast. The needle biopsy came back negative. Yay! Fast forward 7 months. I felt another lump. On December 20, 2006 I had a lumpectomy...not for one lump, but FIVE!

At the age of 32 with a loving husband and now 4 kids, ages 6, 4, 2, and 7 months, I was diagnosed with HER2+, hormone receptive breast cancer. My lymph nodes were clear. Yippee! Based on the results, a double mastectomy was the best choice. I had always wanted a breast reduction (DDDs are heavy to carry around). Not exactly how I dreamed that would end up happening. But, when something tries to kill you, you eliminate the threat. (I should have been CIA.)

Things moved fast. By January 15, 2007 both breasts were gone. In February, I met with Dr. Masri. We chose an abdominal CT just to make sure the cancer wasn't in other areas. My lymph nodes were clear...I wasn't worried. Then the call came that Dr. Masri wanted to meet with me that same day. I'm sure my heart stopped. But, off I went to see the man who would help save my life. I thought for sure they were going to tell me the cancer was in my ovaries. Nope. Surprise! My cancer had metastasized to my liver!

With an encouraged second opinion, my treatment ended up being 6 months of chemotherapy and Herceptin. I had 2 masses in my liver. One vanished with chemo. The other shrank by half (and I didn't lose my

hair). In July 2007, I had radio frequency ablation that fried the remaining liver tumor. I also had reconstruction breast and а hysterectomy in 2007. During treatments, I continued to work as a labor and delivery nurse at Covenant Hospital (now MercyOne). I avoided working on the days that I knew I wouldn't feel well. I had family, friends, and colleagues who helped with the kids and my sanity, not to mention my amazing and supportive husband who stayed by my side through it all. In July 2007, I was classified as cancer free.

In 2013, I was diagnosed with breast cancer again. I felt a lump because I continued to do self-breast exams even though they were fake. This time, the cancer was only in the breast. Treatment consisted of chemo (not so lucky with keeping the hair this time) and then radiation. Oh, and I had to lose the breast implants. Again, family and friends rallied with me.

Through both fights, I used faith in God, humor and a positive attitude to get through. And, jig saw puzzles – they kept my mind from wandering to thoughts that would not help me heal or kick cancer to the curb. I am a breast cancer with mets to the liver survivor. Nothing scares me now except spiders.

For fighters and supporters, remain as positive as possible. Bad days will come. Just make sure they go.





NATURAL CLEANERS FOR YOU AND YOUR HOME

With all the COVID-19 pandemic, we are advised to wash our hands and keep surfaces clean. We are hearing about a shortage of hand-sanitizers. The truth is, that shortage isn't entirely unwarranted: While the Centers for Disease Control and Prevention maintain that the absolute best way to protect yourself is to frequently wash your handsfor at least 20 seconds; and before eating, after using the bathroom, and after sneezing or coughing—a second-best option is to use hand sanitizer with at least 60% alcohol, especially when you're not near soap and running water.

Here are a few recipes for some natural cleaning supplies for you and your home.

Homemade Hand Sanitizer

5-10 drops lavender essential oil 30 drops tea tree essential oil 3 oz rubbing alcohol 1 oz pure aloe vera gel 1⁄4 tsp. vitamin E oil (helps soften hands)

Mix essential oils and Vitamin E in a small bowl. Add alcohol to the oils and mix. Combine this mixture with the aloe vera gel and mix well. Shake gently before each use.

All-purpose Cleaner

1 quart of warm water ¼ cup baking soda 1 teaspoon vinegar



Where They Are Now!

Jacque Bakker's journey began ten years ago at the age of 46. She had set a personal goal to qualify and run the Boston Marathon. In October 2009, she was listed as a participant for the 2010 (114th) Boston Marathon! One month later her life changed when she was diagnosed with HER 2+ breast cancer.

Needless to say, Jacque did not run the marathon in 2010. Instead, she joined BPT's Young Survivors and began chemotherapy. In 2011, she joined the Beyond Pink TEAM and completed radiation as well as a targeted therapy called Herceptin. "I felt so fortunate to hear my oncologist tell me that this targeted therapy was making a big difference in patient's survival," Jacque said. "I want all patients to hear this when they are diagnosed with cancer."

It was this that led Jacque to joining the National Breast Cancer Coalition (NBCC) in 2012. Each year the BPT members travel to Washington DC to the NBCC Leadership Conference. This includes lobbying on Capitol Hill for research, access to healthcare and more. In 2013, she was in a phase 1 vaccine trial to prevent recurrence of HER 2 + breast cancer. And in 2015, she became an educated advocate when attending NBCC's Project LEAD.

"I know scientists, researchers and advocates are working together to end cancer. This is why the BPT 'Ignite the Cancer' Conversation (which was created in 2016) is so important to me," states Jacque. "This initiative was designed to engage our community in education and action to reduce cancer deaths. All of our voices make a difference."



"I am blessed with the support of a loving family, friends and community. I am blessed to have received the excellent care of doctors and nurses with immense support from the Beyond Pink TEAM organization (BPT). I've learned so much this past 10 years. I am stronger than I was before. "

Jacque did run the Boston Marathon with the amazing encouragement of family and friends in 2013, 2014 and thankfully again in 2019 as a 10-year survivor!

Jodie Muller Receives Susan Witwer Memorial Scholarship

"As someone who is on the Beyond Pink TEAM's (need-based grant) approval committee, I see stories regularly about financial hardships that are caused by this diagnosis, and this bothers me quite a bit. No one who is also trying to navigate a breast cancer diagnosis should have to worry about insurance (or lack of insurance). No one should have to worry if they can afford a life-saving treatment or drug. And NO ONE, including those with metastatic breast cancer should have to worry about losing their home because they are unable to work, and don't meet the standard criteria for disability."

That kind of passion led the Beyond Pink TEAM to choose Jodie Muller as the 2020 recipient of the Susan Witwer Memorial Scholarship to attend the National Breast Cancer Coalition (NBCC) Leadership Summit in Washington, DC. May 2-5,2020. Jodie, a breast cancer survivor and North Star Community Services Director of Donor and Public Relations, wrote in her application, "I want to feel like I may be helping so that someday our granddaughters and great-granddaughters will never have to deal with a breast cancer diagnosis."



Susan Witwer was also a passionate Beyond Pink TEAM breast cancer advocate and would have been pleased with Jodie's commitment. Susan channeled her anger, passion and considerable advocacy skills toward passing the legislative priorities of the National Breast Cancer Coalition. After Sue attended her first NBCC Advocacy Conference in 2003, she went on to attend NBCC Team Leader Training so she could speak knowledgably to Iowa's Senators and Representatives. She became a persistent and articulate breast cancer advocate; well-known and respected by the staff of the lowa Congressional staff. Sue died in December 2010. Her husband Dean, two sons and daughter-in-law generously funded the Susan Witwer Memorial Scholarship. Sadly, Dean Witwer passed away in April 2018, yet the family continues to fund this scholarship. Because of it the Beyond Pink TEAM has built a strong advocacy team representing all of us in the Cedar Valley in the quest to end breast cancer. Congratulations Jodie and thank you to the Witwer family.

Supporting Beyond Pink TEAM Becomes Personal for Many

High School Service Club Gives to Beyond Pink TEAM



BPT members, Marty M and Dee H accept check from Interact members, Ivan C, Zoe W, Emma R, Clair Q and staff sponsors, Kris W and Sadra R.

Interact, a New Hampton High School service club associated with the town's Rotary, held its first project this year. The club decided to do a pink out fundraiser because it was still October, and mostly everyone in a small town has been affected or knows someone who has been affected by breast cancer.

The project was a bake sale and selling pink bracelets. On the day of the sales, everyone wore pink shirts to spread more awareness about what the club was doing. The profits came to a total of 665! But what to do with the money?

While all this was happening one of the project leaders, Zoe W's mom, Karen N, was going through breast cancer treatments. *This project became personal.* The Beyond Pink TEAM helped pay bills and supported her family during a rough time. After Zoe's mom received one of the BPT's Touch of Courage quarterly newsletters, Zoe shared it with the club. Upon examination, it was agreed to donate the money to Beyond Pink TEAM to keep supporting the Cedar-Valley and surrounding communities. The Interact club hopes that the money raised goes to families in need outside of the Waterloo-Cedar Falls area.

NOTE: According to grant requests, of the 89 individuals provided with financial support in 2019 by the Beyond Pink Fund, 40 were outside of Black Hawk County.

To: The Beyond Pink TEAM

From: Bob Goodrich

On Jan 7 my wife, Carol, passed away with Alzhiemer's. She also was a breast cancer survivor.

I would like to donate a check for \$500.00 to the Beyond Pink TEAM. I have a great love for the Beyond Pink TEAM and the volunteers involved.

I head up the Fishing For A Cure in October and want to thank you for having us in your newsletter.

We have to end both (Breast Cancer & Alzheimer's).

This is personal for me!

Carol Menefee - A Thriver and Giver

Carol's cancer story began February 11, 2009 when diagnosed with Stage III breast cancer.

After finishing all her treatments and surgeries in 2014, she was happy things were beginning to feel a little more normal. Does it ever go back to a "before" cancer normal? But Carol was a "Survivor!" Not too quick - another cancer diagnosis came in 2016 when Carol was diagnosed with non-Hodgkin lymphoma which meant another round of chemotherapy and 2 years of Rituxan.

Carol has been an active member of an amazing group – "Young Cancer Survivors". This group of friends were a blessing as she went through another diagnosis!

Carol is a thriver and giver. For the past 9 years, Carol has had a team for the Pink Ribbon Run. This team doesn't just run/walk but fundraises before and after the run. To date, Carol's Crew Cares Bra Crawlers have raised



over \$2240.00. To her and her team this is personal!



Businesses, Groups, and Individuals who support the Beyond Pink TEAM





Dee H accepts a donation from Mark D, owner of LeRoy's in Aurora, IA. LeRoy's holds a series of events supporting the Beyond Pink TEAM. Wal-Mart-Waterloo manager, Ryan R shares with Dee H a grant given to Beyond Pink TEAM for support of breast cancer survivors.

The Beyond Pink TEAM All Cancer Support Group

This support group began as a way to reach out to "young cancer survivors." Michelle Dowie Friedley, was in her mid-30's and going through breast cancer treatment. She attended a traditional breast cancer support group, but didn't feel a connection, as most of the women were quite a bit older than she was, and at a different point in their lives. Michelle was a young mom, had a busy job, and was still working during treatment. She told her mother that she hoped people who did not have as much support as she had at home, were able to find support that met their needs.

After Michelle passed away in 2006, Cedar Falls Community Main Street rallied around her mom, by putting on the first Pink Ribbon Run in Michelle's honor. The money raised was given to the Beyond Pink TEAM and requested it be directed toward supporting young survivors. The first Young Cancer Survivors "Meet, Mingle and Learn" event was held in April, 2007.

Since then, the group has met on the 3rd Tuesday of January, April, June and September. - The group is designed to meet the needs of busy women, but still provide support and education. Topics can include nutrition, exercise, coping with feelings, managing side effects of treatment, etc. For members who need more support, there is a private FaceBook group for support, and some members get together socially outside of the group.

In 2020, the group renamed themselves the **Beyond Pink TEAM All Cancer Support Group**, to recognize that it was a group open to women with any cancer diagnosis, with no age limit requirement. Donors from December 1, 2019 through February 29, 2020 – Thank you for all your support!

First Congregational Church Mission Fund - Fredsville First Congregational Church -Waterloo Flowerama **Bob Goodrich** Jean Hoy Jordan Kettner LeRoy's **Carol Menefee & Family** Carol Miller **New Hampton Schools** Donna O'Brien Panera Rabobank Root **Bob & Peggy Sinders** Alex & Kristi Syhlman UNI Women's Basketball-3-Point Challenge - Cindy Stein, Tanya Warren, Dr. Sharon Duclos WalMart #1496 – Waterloo Robert & Jammi Welter West Buchanan Telephone Co-op Natalie Wulfekuhle



Grief, continued from page 1

Depression is the stage where our attention moves to the present. This stage often feels like it is going to last forever. Often, it feels like we are in a fog of sadness. We begin to withdraw from visiting loved ones, participating in activities we love, etc. It is important to know that depression is not a sign of mental illness as depression is normal when going through grief.

Acceptance is the stage about accepting the reality that someone or something has been taken away. It is about recognizing that this is a new normal. It is not to be confused with the notion of being 'okay' with what happened, or this new reality but instead, accepting it. At this stage, we may learn how to live with it. Many times, we feel that we are betraying our loved ones as we begin to enjoy our life again. Although our loved ones cannot be replaced, we are able to reach out to make new connections.

What are Common Symptoms of Grief?

Symptoms of grief can include physical symptoms, spiritual symptoms and social symptoms. Examples of these symptoms include: anger, anxiety, crying, difficulty sleeping, fatigue, feelings of detachment, guilt, headaches, loss of appetite, worry, etc.

What are Ways of Coping with Grief?

The most common methods of treating grief include counseling and medication. Counseling provides you with different coping strategies that help you deal with grief in an effective way. Counseling includes bereavement groups, individual counseling and support groups. Secondly, medication can be used to help you operate more fully during the day or sleep at night. Seek treatment from a health professional or mental health provider if you are having a hard time coping with your loss.

In conclusion, grief is just as unique as each of us. It does not come with a time frame or end on a certain day.

DUE TO THE COVID-19 VIRUS, PLEASE CALL BEFORE ATTENDING ANY SUPPORT GROUP

Support Group Dates

<u>April 6, 1:30 p.m.</u>

Touch of Courage Breast Cancer Support

April 7, 1:30 p.m.

Care & Share Cancer Support Grado MercyOne Waterloo Cancer South Line 200 E Ridgeway Ave., Waterloo Jessica – 319-272-2816

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

All Cancer Support Group – Meet, Mingle and Learn Cedar Valley Unitarian University (MNCBLLE) 3912 Cedar Heights Dr., Cedar Falle

Gabbi – 319-292-2225

May 4, 1:30 p.m.

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

May 5, 1:30 p.m.

Care & Share Cancer Support Group

MercyOne Waterloo Cancer Center 200 E Ridgeway Ave., Waterloo Jessica – 319-272-2816

<u>June 1, 1:30 p.m.</u>

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

June 2, 1:30 p.m.

Care & Share Cancer Support Group

MercyOne Waterloo Cancer Center 200 E Ridgeway Ave., Waterloo Jessica – 319-272-2816

June 16, 4:30-7:00 p.m. All Cancer Survivor Group -Meet, Mingle and Learn

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

<u>July 6, 1:30 p.m.</u>

Touch of Courage

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

July 7, 1:30 p.m.

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

Splash of Color – Women of Color

Breast Cancer Support Group Community support and resources available Upon request Cathy – 319-504-2703 for details

COMING SOON!!!*

Look Good . . . Feel Better

Hair – Makeup – Nails - Skin MercyOne Waterloo Cancer Center 200 E Ridgeway Ave., Waterloo *Call Jessica at 319-272-2816 for date & RSVP

Save the DATE

Thursday, November 12, 2020 Ignite the Cancer Conversation: Mind, Body, & Soul 5-6 p.m. – Registration & optional light dinner 6-9 p.m. – Event Hosted by Allen School of Nursing 1900 Heath Street, Waterloo

Watch BPT Facebook and website for more details.



6



National Breast Cancer Coalition

The NBCC Leadership Summit is the premier breast cancer advocacy event that offers discussion sessions with top researchers and advocates, as well as skill-building, message training, and strategic planning activities needed to energize advocates for the important work in the year ahead.

NBCC links hundreds of organizations and tens of thousands of individuals from across the country into a dynamic, diverse coalition that gives breast cancer a meaningful voice in Washington, DC, and state capitals, in laboratories and health care institutions, and in local communities everywhere.

NBCC increases federal funding for breast cancer research; monitors how research funds are spent; expands access to quality health care for all; and ensures that trained advocates influence all decision making that affects breast cancer.

2020 Legislative and Public Policy Priorities

Each year the grassroots NBCC Board of Directors, with input from our members, sets our public policy and legislative priorities for the coming year. The priorities for 2020 serve as the foundation of our legislative advocacy work throughout the year, and with grassroots mobilization efforts, provide the context for the action alerts sent to our network.

Please distribute NBCC's 2020 Legislative and Public Policy Priorities to your networks and keep them on hand to use in your NBCC legislative advocacy work. As we develop specific strategies to forward our priorities, your prompt attention and action on alerts will be critical to our success.

Legislative Priorities PRIORITY #1:

\$150 Million for the Department of Defense (DOD) Breast Cancer Research Program (BCRP) for FY2021: As a result of NBCC's grassroots advocacy, the DOD BCRP was created in 1992 to "eradicate breast cancer by funding innovative, high-impact research through a partnership of scientists and consumers." The DOD BCRP is widely viewed as an innovative, unique, and efficient medical research model which has proven to be accountable to the public and has produced extraordinary results. NBCC seeks continued funding for this successful program.

PRIORITY #2:

Metastatic Breast Cancer Access to Care Act: A bill to waive the 24month waiting period for Medicare eligibility and the 5-month waiting period for Social Security Disability Insurance benefits for individuals with Metastatic Breast Cancer. This legislation would waive all waiting periods for Medicare eligibility and Social Security Disability Insurance (SSDI) eligibility on the basis of disability for individuals with metastatic breast cancer.

PRIORITY #3:

Preservation of the Medicaid Breast and Cervical Cancer Treatment Program: Congress enacted the Breast and Cervical Cancer Treatment Act in 2000 after years of NBCC grassroots lobbying and influence. NBCC remains committed to ensuring all women and men screened and diagnosed with breast cancer through federal screening programs have access to the treatment they need.

Public Policy Priorities PRIORITY #1:

Guaranteed Access to Quality Care for All: Ensuring access to quality, evidence-based health care has been a top priority of NBCC for many years. Prior to the passage of the Affordable Care Act (ACA), the NBCC grassroots Board of Directors approved a Framework for a Health Care System Guaranteeing Access to Quality Health Care for All which built on NBCC's Principles for Quality Care. In 2010, NBCC endorsed and advocated for the passage and implementation of ACA which marked important steps forward in access to quality health care for individuals with, and at risk of, breast cancer. The Coalition opposes and will work to defeat any and all efforts to repeal the ACA or replace it with something less expansive.

PRIORITY #2:

Ensuring the Participation of Educated Patient Advocates in Science Research and all Levels of Health Care Decision Making: NBCC continues to work to ensure that educated patient advocates who represent a constituency, have a meaningful "seat at the table" in all levels of health care decision making which affects their lives.

facebook

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.

<u>Resources</u> – 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

lowa 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**

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

National Cancer Institute 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 vo and forward to Cedar Valley Cancer Committee at the addres		eel free to complete the following
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	 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. Meetings are 3rd Thursdays each month (except December) at 7:00 a.m. 	
□ Volunteering: ((check all that apply)		
□ Assist with Support Groups □	Education (Health Fairs/Presentations, Newslette	rs)
Development (Publicity)	Advocacy – Deadline 2020/Ignite the Cancer Conv	versation
Events (Fundraisers, Projects and More)		
□ Make a donation. Make checks payable to Beyond Pink TEAM. (All donations are tax deductible)		
BPT Fund Advoca	acy Fund 🗖 Area of Need	
Touch of Courage Connection Cedar Valley Cancer Committee		

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