



Cedar Valley Cancer Committee

Touch of Courage Connection

Newsletter

July 2021

Celebrating over 30 years in the Cedar Valley

IN THIS ISSUE

Page 2

Living Green - Composting

**Beyond Pink TEAM
Volunteer Wins Award**

Page 3

**Survivor Story - Tiffany
Ahren**

Waterloo Buck's Pink Out

Page 4

**Look Where They Are Now
- Jeanne Olson**

Donor Thank You

Beyond Pink Fund

Page 5

Pink Ribbon Run

Support Group Dates
July - August - September -
October

2021 Fall Ignite Event

Page 6

**Support Group Meeting
Guidelines**

Iowa Senator Takes Lead

Support Group Meetings

Page 7

**Iowa Cancer Health
Disparities**

Page 8

**Resources, Support and
Volunteer Information**

Iowa - A Leader in Saving Lives

By Christine Carpenter and Lori Seawel

Did you know Iowa has played an integral role in breast cancer research that is saving lives right here in the Cedar Valley? Some of our own Beyond Pink TEAM members credit the Breast Cancer Research Program as the reason why they are alive today. And they have retired Iowa Senator Tom Harkin to thank.

Fran Visco, President of the National Breast Cancer Coalition, explained in a 2014 interview with the Philadelphia Inquirer (October 18), "You know, there are many runs and races and dinners that raise money for breast cancer research - and they're all important. But real money, year in and out, comes from federal appropriations. So, we said that's what we're going to focus our efforts on. We were successful [winning some \$300 million in their first congressional appropriation], but Sen. Tom Harkin, who was then the chair of the Appropriations Committee, said to me, 'I can't do all of it in the domestic budget.' So, we got \$210 million in the defense budget."

As a result, the Breast Cancer Research Program (BCRP) was created in 1992 as the first program

under the umbrella of the Congressionally Directed Medical Research Programs (CDMRP). You may ask how breast cancer research is relevant to military health. The December 2020 BCRP Report explains, "Female active-duty Service members have a 20%-40% higher incidence rate of breast cancer than the public. The incidence rate of breast cancer for active-duty women is seven times higher than the average incidence rate of fifteen other cancer types across all Service members. The outcomes of BCRP-funded research will ultimately benefit military Service members, Veterans, military beneficiaries, and the general public."

The BCRP, a unique partnership among the public, Congress, and the military, has become a model program. The CDMRP has grown to encompass more than thirty-five similar targeted programs. Funds for the CDMRP are added to the Department of Defense (DoD) budget each year. Support for the Breast Cancer Research Program is allocated from those funds via specific guidance from Congress. Foundational to the program is the involvement of breast cancer survivors, alongside scientists, to decide how the money gets spent.

The BCRP has awarded \$3 billion in grants since 1992 to highly innovative research. In fact, the breakthrough drug, Herceptin, was discovered

through the Breast Cancer Research Program. Herceptin is used for the treatment of HER2+ early-stage and metastatic breast cancers.

Beyond Pink TEAM advocates Jill Hansen, Jacque Bakker, and Kristin Teig Torres attribute the BCRP's initial research funding to develop Herceptin for saving their lives. Jill Hansen notes, "Herceptin was and still is a game changer [for me and] for so many women and men that has allowed us to survive and thrive past this horrible disease that continues to take the lives of our mothers, daughters, friends and other family members that we cherish."

"In 2009 I [Jacque Bakker] was told by my oncologist that I had HER2+ breast cancer, a type of breast cancer with a deadly prognosis. Then I was told that I would be given a targeted therapy called Herceptin, a drug improving and prolonging the lives of men and women with HER2+ breast cancer. I remember feeling like I could breathe after hearing this."

Kristin Teig Torres, a 10+ year survivor of HER2+ breast cancer, realized "breast cancer continues to take far too many lives. The large numbers are intolerable. Breast cancer is a political issue that remains an urgent health crisis. It will take action to prevent breast cancer and prevent death from breast cancer."

All three are thankful for retired Senator Tom Harkin's work to create the BCRP and have joined Beyond Pink TEAM and the National Breast Cancer Coalition to advocate to keep this program funded. All Beyond Pink TEAM advocates lead busy lives with already jam-packed schedules of work, family, church, and volunteering commitments. The thought of one more commitment – or one more meeting – is intimidating

for us. Yet they realized their health, and the health of their daughters and granddaughters, is at risk. So, they do what they can with the time that they to End. This. Disease. Will you join them?

Citations for interview referenced in second paragraph and the BCRP report/program booklet referenced in the third paragraph:

The Interview: Fran Visco. (2014, October 18). Retrieved March 25, 2021, from https://www.inquirer.com/philly/news/20141019_The_Interview_Fran_Visco.html

Breast Cancer Research Program (Publication). (2020, December). Retrieved March 25, 2021, from Department of Defense – Congressionally Directed Medical Research Program.

Congratulations to Devin O'Loughlin!



Devin, an avid BPT volunteer recently received the YWCA's Women of Persimmon Award for Young Women of Tomorrow.

Her nominators stated, "With talking with others, we were surprised at how often we hear Devin has voluntarily stepped up to make the world a better place. Everyone speaks of Devin in glowing terms, and she continues to participate, as a college student, with the Beyond Pink TEAM."

Composting

By Dawn Keller



Many people think that when their garbage is taken to a landfill, it decomposes. However, in a properly working sanitary landfill, the goal is the opposite: Waste should not break down, as water and oxygen are kept out. What does this mean for you?

If you want to be more environmentally friendly when it comes to waste, you can compost to reduce the amount of biodegradable waste you are sending to a landfill. There are different ways to compost at your home, including an outside bin that you can purchase or build, or you could make an indoor bin that uses redworms to break down waste.

Many items can be composted, from coffee grounds and filters to fruit cores and peels, to eggshells and the leftovers that were forgotten in the back of the fridge. If it is biodegradable, it can be composted. Once you have a system that works for you, you can use the compost on your house plants or in your garden, not only reducing your waste but turning it into a valuable resource!

Survivor Story

Cancer Felt Like an Interstate Pile-up, But Now Clear Roads Ahead

By Survivor, *Tiffany Ahren*

For most people, cancer is an obstacle in a long and winding course. For me, it was more like a pile-up on the interstate. I was diagnosed with invasive ductal carcinoma in late January of 2020, following my sister's diagnosis several weeks earlier. My diagnosis was further complicated a week later when I confirmed my pregnancy. Talk about getting the best and worst news of your life in the same week! I was floored, overwhelmed, and scared out of my mind. I had tried so hard to have a baby, and would my HR+ cancer diagnosis change it?

Luckily, I was told that I could have my cancer and my baby too, which was a huge relief. I worked with doctors down at the University of Iowa Hospital who took great care of me and my impending baby. At 11 weeks I had a bilateral mastectomy, at 15 weeks I started 2 chemo drugs that were safe in pregnancy (I didn't know you could do chemo while you were pregnant, talk about a surprise!) After 4 chemo treatments every other week for 8 weeks I had been treated as much as was safe in my pregnancy. I got to take a treatment hiatus until November, about 6 weeks after my baby's arrival. On October 1 I delivered the most perfect 6-pound 1 ounce baby girl, named Joy to celebrate the beauty in a really tough year. 6 weeks after Joy was born, I went back into chemo for another 8 weeks for the last drug I couldn't have in pregnancy. Six

weeks later I was transferred to the MercyOne cancer center for 25 radiation treatments, which concluded in March. I am currently cancer free and loving my life as a wife, teacher, and new mom.



Tiffany and her daughter

While cancer isn't the path, I would have chosen for myself, I am so thankful for the journey. I have learned so much about my own strength and have seen for myself the amazing village of people who have held me up during one of the hardest times of my life. I had a year where my life felt like an interstate pile up, but I feel like it is clear roads from here on out.



Join the Bucks July 17 for their **Pink Out** game and festivities

The Bucks will be wearing and auctioning off **Pink** jerseys in support of those who have been affected by breast cancer. Stick around after the game for a fireworks show! Proceeds from jersey sales will benefit the Beyond Pink TEAM. Jerseys courtesy of Great Clips, SCHEELS, and Brass Tap.

Game starts at 6:35 pm

Tickets Prices

	Day of Game	Advance
Box Seats	\$12.00	\$10.00
Reserved	\$ 9.00	\$ 7.00

Wear **PINK** to support those affected by breast cancer!

See you at the game!



Where They Are Now!

In August 2008 I was diagnosed with a Stage 0 breast cancer, I had surgery and completed five years of oral anti-estrogen therapy. I was an RN working in the ENT field at that time.

I was approached in 2010 and had the opportunity to work as an RN/manager at the Breast Care Center, providing physical and emotional care to many women (and men) going through breast cancer. During this time, I became active with the Beyond Pink TEAM. I took over as Treasurer in 2017. The Breast Care Center annually sponsored a breast cancer event with Waterloo Black Hawks Hockey. With the help of many volunteers, it became a successful fundraiser.

Through my daily work, I found much reward in assisting the Breast Center

Jeanne Olson - *a Survivor, RN, Volunteer, and Caregiver*

patients, through their diagnosis, surgical treatment, referrals to oncology and radiation, and continuing to see them in the clinic in follow-up. I was also able to write grants to the Beyond Pink Fund to assist those in financial need. Being able to address their financial concerns provided one area of relief for them.

I worked at the Breast Care Center for ten years, retiring in December 2020. One of the contributing factors to my retirement decision, was my sister being diagnosed in September 2020 with breast cancer that required chemotherapy before surgery, but was complicated by infection, abscess, and sepsis. She lives in Idaho, and I needed to be there in person to provide the care she needed.

I continue as BPT treasurer and find reward in fulfilling the Beyond Pink Fund grants



Donations received from March 1, 2021, through May 31, 2021.

Iver & Aileen Anderson
Lorraine Axtell
Stacey Belk
Cameron & Heidi Blinn
Julie & Paul Bruss
Bunger Family Foundation
Brian & Janet Christensen
DJ & Reid Corson
Rose Freitag
Susan Girsch
Vicki Hanson
David & Julie Harbaugh
Jean Hoy
Marty & Dee Hughes
Mike & Linda Hughes
Darion Hutchinson
Dori James & Steve Musson
Rick & Mary James
Virginia James
Pamela Jensen & Family
Josh & Sara Kelly
Wayne & Melissa Kerby
Duane & Barb Kuenstling
Janet & Gerald Magnuson
Doug Miller, Integrity Welding
Donna O'Brien
Kennard Pohlman
David & Joyce Riley
Alan & Carol Satterlee
Pete & Janet Schuster
Jacque Simon
Loyce Stout
Lanny & Ann Strausser
Superior Welding, Mark Hughes' Co-Workers
Sandy Townsend
Garry & Lynne Truman
Doris Weber
Mary Ann Weber
JR & Candis Wolff

BEYOND PINK FUND

The Beyond Pink Fund provides financial assistance for breast health/breast cancer-related expenses to persons who live in Northeast Iowa and are not eligible for reimbursement from another source. Assistance is provided as payor of last resort and on a funds available basis only. The Cedar Valley Cancer Committee – Beyond Pink TEAM is a non-profit organization whose mission is to increase cancer awareness throughout the Cedar Valley (Northeast Iowa ONLY), thereby empowering people to make informed health care choices. Task Force members include representatives from health care organizations, public health, local businesses, and consumers.

As of May 1, 2021, 70 individuals have received \$58,870.27 in assistance. To donate to the Beyond Pink Fund, go to:

<https://www.beyondpinkteam.org/donate-to-bpt.html>



We are excited to announce the 15th Annual Pink Ribbon Run

Saturday, October 2nd, 8:00 a.m.

NEW THIS YEAR

🎗️ Event will be both in-person and virtual.

🎗️ Event festivities will begin at Community Main Street Office, 301 E 4th Street, and end at the Plaza - 2nd and State Street, downtown Cedar Falls

🎗️ 15 Year Sponsor Recognition

Registration opens August 1st on-line. Check out BPT website for link and more information.



Presenting Sponsors



PLEASE CALL BEFORE ATTENDING ANY SUPPORT GROUP AS SOME HAVE GONE TO INPERSON OR LOCATION HAS CHANGED

Support Group Dates

July 5 1:30 p.m.

**Touch of Courage
Breast Cancer Support Group**

Location to be Determined
Pat – 319-232-8691 for information

Call Ahead

July 6, 1:30 p.m.

**Care & Share Cancer Support
Group**

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

Call Ahead

September 7, 1:30 p.m.

**Care & Share Cancer Support
Group**

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

September 13, 1:30 p.m.

**Touch of Courage
Breast Cancer Support Group**

Location to be Determined
Pat – 319-232-8691 for information

Call Ahead

September 21, 4:40-7:00 p.m.

**BPT All Cancer Support Group -
Meet, Mingle and Learn**

Cedar Valley Unitarian Universalist
3912 Cedar Heights Dr., Cedar Falls
**Angela – 319-231-3143 for meeting information
(Outdoors or virtual)**

October 4, 1:30 p.m.

**Touch of Courage
Breast Cancer Support Group**

Location to be Determined
Pat – 319-232-8691 for information

Call Ahead

October 5, 1:30 p.m.

**Care & Share Cancer Support
Group**

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

August 19

**Splash of Color – Women of Color
Breast Cancer Support Group**

Call Cathy Ketton - 319-504-2703 for details



Ignite 2021 October 19th

Our featured speaker, Dr. Cyrus Ghajar, will share his research of metastasis, or the spread of cancer cells to distant sites, and how the microenvironments of these sites (including bones) can put cancer cells to sleep – or wake them up.

This event will be virtual. Details for registration will be coming soon. Check the Beyond Pink TEAM website, www.beyondpinkteam.org and/or watch for Facebook announcements.

SUPPORT GROUP MEETINGS

As we begin to emerge from the pandemic and wonder what are the appropriate procedures, we want to share some guidelines for our meetings.

As of this writing, *Touch of Courage* has met in-person at a park. Hopefully, in August or September, they can begin to meet at their new location in the Community Room at the Community Foundation of Northeast Iowa, 3117 Greenhill Circle, Cedar Falls.

The *BPT All Cancer Support Group* met in person for their June meeting. This was held at a park in Cedar Falls. Please call Angie at 319-232-8691 for details of next meeting.

Care and Share Group is **NOW** meeting in person. Participants will need to wear a mask and have their temperature taken upon arrival. These meetings are the first Tuesday of each month at 1:30 p.m. in the first-floor conference room of the MercyOne Waterloo Cancer Center, 200 E Ridgeway, Waterloo.



Ask to join *Iowa Stop Breast Cancer* on Facebook. We need your voice asking Senator Grassley and Representatives Ashley Hinson and Randy Feenstra to cosponsor this important bill.

Iowa Senator Joni Ernst Leads



Thank you, Iowa Senator Joni Ernst for being the Lead Republican sponsor of the Metastatic Breast Cancer Access to Care Act. In April, Senators Joni Ernst (R-IA) and Chris Murphy (D-CT) introduced the bipartisan Metastatic Breast Cancer Access to Care Act. This legislation will reduce pain and suffering from metastatic breast cancer by waiving all waiting periods for Medicare and Social Security Disability Insurance (SSDI) benefits based on disability.

There are too many women and men in this country who must deal with how to pay for treatment and how to support their families while they are living with metastatic breast cancer. Passing this bill would improve lives because metastatic breast cancer survivors will not have to wait to get the Medicare and SSDI benefits they are entitled to.

The Metastatic Breast Cancer Access to Care Act

Background – Individuals diagnosed with metastatic breast cancer automatically qualify for disability benefits from the Social Security Administration (SSA) if they apply and meet the SSA's technical qualification rules. An individual must have been employed within the last ten years, and currently, be unable to work due to her disability to earn Social Security disability insurance benefits (SSDI). Once an individual is approved for SSDI, there is a five-month waiting period to begin receiving benefits. Following approval of SSDI, individuals with metastatic breast cancer are eligible

for Medicare coverage based on their disability.

Eligibility for Medicare includes individuals over the age of 65, those with disabilities, and those with two specific diseases, End-Stage Renal Disease, or Amyotrophic Lateral Sclerosis (ALS). Individuals under age 65 with disabilities other than End-Stage Renal Disease (ESRD) or ALS must have received Social Security Disability Insurance (SSDI) benefits for 24 months before gaining eligibility for Medicare. These eligibility rules include individuals diagnosed with metastatic breast cancer.

Metastatic breast cancer is cancer that has spread from the breast to the bones, lungs, or other distant parts of the body. 90% of breast cancer deaths are because of metastatic disease. There are treatments, some of which have extended survival for women and men with metastatic breast cancer. There is no cure.

Extended Coverage is Based on Federal Precedent

The Beyond Pink TEAM and the National Breast Cancer Coalition urge Congress to enact The Metastatic Breast Cancer Access to Care Act, (S. 1312) introduced by Senators Joni Ernst (R-IA) and Chris Murphy (D-CT) and H.R. 3183, introduced by Representatives John Katko (R-NY) and Kathy Castor (D-FL). This legislation would amend the

Ernst, continued next page 7.

Ernst, continued from page 6.

Social Security Act to eliminate waiting periods for disability insurance benefits and Medicare coverage for individuals with metastatic breast cancer.

In 2001, Congress passed a bill to add Amyotrophic Lateral Sclerosis (ALS) as a qualifying condition for automatic Medicare coverage, thus creating a federal precedent. Based on the limited life expectancy of individuals with metastatic disease, an average of 3 years, NBCC believes the 24-month waiting period waiver should extend to these individuals. More recently, legislation has been introduced which would build on that precedent to allow patients with ALS who qualify for SSDI to immediately be eligible for SSDI (thus waiving the five-month waiting period), making them automatically eligible for Medicare as well. NBCC believes that both automatic SSDI and Medicare coverage should also apply to metastatic breast cancer patients who qualify.

Coverage accommodations for individuals diagnosed with breast cancer were also made with the passage of legislation in 2001 to allow states to offer women diagnosed with cancer in the National Breast and Cervical Cancer Early Intervention Program automatic eligibility for treatment under Medicaid.

Beyond Pink TEAM advocates are so pleased Senator Ernst listened and said “yes” when we asked her to be the Lead Republican Sponsor. As Jena McNeill, Senator Ernst’s Legislative Director said, “It’s a good bill.” Thank you, Iowa Senator Ernst!

Cancer Health Disparities in Iowa

The special section in the Cancer in Iowa 2021 report featured racial/ethnic cancer disparities in Iowa. As background, the Iowa Cancer Registry/State Health Registry of Iowa has collected data on cancer incidence (new cases of cancer diagnosed each year) and mortality (deaths due to cancer each year) for the state of Iowa since 1973. This year we examined the cancer experience of Iowans according to racial/ethnic groups: non-Hispanic (NH) White, NH Black, other races including NH Asian/Pacific Islander and NH American Indian/Alaska Native, and the Hispanic population.

Advancing age is the most important risk factor for cancer. While the White population in Iowa has higher rates of cancer because it is older, Iowa’s Black population bears the greater burden of cancer when we account for their differing age distribution.

Of all racial/ethnic groups, the Black population had the highest rate of cancer for those ages 50-79 whereas the White population had the highest rates for those 80 and older. Cancer is striking the Black population at a much younger age than the White population.

When looking at mortality data, aside from suicide and liver disease, the Black population in Iowa also has the highest mortality rate in all causes of death, including cancer. Consequently, the life expectancy is only 74.8 years in the Black population in Iowa compared to 79.3 years in the White population.

Among all 50 states, Iowa has one of the highest cancer mortality rates among the Black population, and one

of the largest differences in the mortality rates between Black and White populations. Some of the largest differences in mortality between Iowa’s Black and White populations include prostate, lung, and liver cancers. Iowa’s Black population also has higher colorectal and breast cancer mortality rates compared to other racial/ethnic groups.

Cancer mortality rates are higher in the Black population compared to all other racial/ethnic groups for both males and females. The rates have been decreasing, however, for all racial/ethnic groups. The greatest decline in mortality rates has been seen in Black males and the difference in mortality rates between Black and White males is narrowing.

While the difference is narrowing, there is more work to be done. This report is an important step in furthering the discussion of health disparities in the state of Iowa. The full report, including more discussion on causes of inequalities, can be found at <https://shri.public-health.uiowa.edu/wp-content/uploads/2021/03/2021-cancer-registry-annual-report-FINAL.pdf>.

This project was funded in whole or in part with Federal funds from the National Cancer Institute, National Institutes of Health, Department of Health and Human Services, under Contract No. HHSN261201800012L.

NOTE:

The NH abbreviation was used so that we could specify that those in the Black, white, Asian/Pacific Islander and American Indian/Alaska Native only include those who did not identify as being Hispanic, whereas the Hispanic group includes people of any race who did identify as Hispanic.



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.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

National Cancer Institute for NCI dictionaries of cancer terms, genetics terms, and cancer drugs. www.cancer.gov/publications/dictionaries

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. Meetings are 3 rd Thursdays each month (except December) at 7:00 a.m. |
| <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 – Contact Congress/Ignite the Cancer Conversation |
| <input type="checkbox"/> Events (Fundraisers, Projects and More) | |
| <input type="checkbox"/> Donate. 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

Quarterly Newsletter of Beyond Pink TEAM

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www.beyondpinkteam.org