



Cedar Valley Cancer Committee

Touch of Courage Connection

Newsletter

October 2020

Celebrating 30 years in the Cedar Valley

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Metastatic Breast Cancer and Advocacy

Little did Ellen Duffy know when she joined Beyond Pink TEAM, because her mother was a breast cancer survivor, that she would be diagnosed with the same disease a few years later. Ellen was diagnosed with breast cancer and before she completed her initial treatment it was discovered the breast cancer had spread to her bones. With metastatic breast cancer Ellen was unable to work at either of her two jobs: as a nurse for Covenant Hospital or as an assistant at a fitness center. After one year both of her employers let her go which left her with no job and no health insurance. While she applied for Social Security disability, she still had to wait more than 2 years to become eligible for Medicare [health care] and did not live long enough to receive it. Ellen was single, never married, and lived her final year extremely sick and in constant fear of losing her home because she could not pay her bills.



Jane Clark, left, and Ellen Duffy, right, at Lobby Day in Washington, D.C. in 2009. Ellen died in 2011 at the age of 47.

A diagnosis of metastatic breast cancer can be very frightening because it is considered incurable. Metastatic breast cancer occurs when breast cancer cells travel from the breast to another part of the body such as the bones, liver, lungs, or brain. Metastatic breast cancer is also referred to as Stage IV breast cancer.

We still do not understand why some cancers become metastatic, especially those that are diagnosed years after the first breast cancer. In the past, doctors believed that cancer progressed in a linear manner and that women with positive lymph

nodes were more likely to become metastatic. Now researchers are focusing more on genetics and the microbiology of breast cancer. They are trying to learn why some cancers behave more aggressively, what causes cancer cells to grow in different parts of the body, and what treatments can be developed to stop that process.

About 6% of women are initially diagnosed at Stage IV. They may already have symptoms such as pain or shortness of breath that cause the

Continued on page 2

doctors to suspect metastatic cancer. Or the metastasis may be discovered during a CT or PET scan as part of the initial workup for breast cancer.

Most women who become metastatic are diagnosed later, anytime from several months to years after they were initially treated for early stage cancer.

*SHARE NYC

<https://www.sharecancersupport.org/metastatic-breast-cancer/about-metastatic-cancer/>

The Metastatic Breast Cancer Access to Care Act (S. 1374/H.R. 2178)

The above law would improve the lives of people, like BPT's Ellen Duffy, living with metastatic breast cancer. We need your help in lending your voice to this nationwide effort.

Currently, individuals under age 65 with metastatic breast cancer who qualify for Social Security Disability Insurance (SSDI) benefits must wait 5 months before receiving SSDI benefits and after that an additional 24 MONTHS (2 YEARS) before being eligible for Medicare (health insurance).

**Currently the National Breast Cancer Coalition (NBCC) is asking Congress to enact a bill, S.1374/H.R. 2178, so individuals with metastatic breast cancer have access to the care for which they are entitled and deserve. One of NBCC's most important priorities is passage of our bipartisan Metastatic Breast Cancer Access to Care Act to eliminate waiting periods for social security disability insurance benefits (SSDI)

and Medicare coverage for eligible individuals with metastatic breast cancer.

Concrete Things You Can Do

It's now easier than ever to take action through the National Breast Cancer Coalition [Advocacy Action Center](https://www.stopbreastcancer.org/action-center/action-network).

<https://www.stopbreastcancer.org/action-center/action-network>

Success depends on the voices of breast cancer survivors, and other advocates and stakeholders across all 50 states.

Time is running out for legislative action in this Congress. We need you to **act today** to urge your members of Congress to cosponsor this legislation and get a vote as soon as possible.

An additional way you can help is to

Local Women Struggling

"L" - "I'm 38 years old, a wife, and a mother of 4 young children, 6 and under, living my life with stage 4 metastatic breast cancer."

"My name is Danielle and I have stage 4 breast cancer with Mets (metastasis) to my bones and my brain. I'm 38 years old and a mom of 3 children, ages 8,6,and 3. There have been many challenges during this journey, but the most important thing is my kids and trying to keep their lives as normal as possible for as long as possible."

Vote Breast Cancer! See page 7 for more information.

**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. To earn Social

Security Disability Insurance (SSDI) benefits, the individual 1) must have been employed within the last ten years, and 2) currently be unable to work due to their disability. 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, regardless of their age. However, there is a **24-month waiting period for Medicare coverage** (health insurance) once eligible.

Based on the limited life expectancy of individuals with metastatic breast cancer, an average of 3 years, Beyond Pink TEAM (BPT) and the National Breast Cancer Coalition (NBCC) believe both the 5-month and 24-month waiting periods should be waived. By law, the 24-month waiting period for Medicare is waived

for individuals with ALS (Lou Gehrig's disease) and End Stage Renal Disease (ESRD). Legislation has been introduced which would allow patients with ALS who qualify for SSDI to immediately be eligible for SSDI (thus waiving the five-month waiting period). NBCC believes both SSDI and

Medicare coverage should also apply to metastatic breast cancer patients who qualify.



Living Green

By Dawn Keller



Reducing Waste

When people are asked what they can do to better the environment, most will quickly reply, "Recycle!" Recycling has been ingrained in us for more than 40 years, due in part to the oft-used phrase "Reduce, Reuse, Recycle." Nobody knows the specific origin of that catchy saying, but what if you took it in order of importance? First, reduce the amount of waste you generate. Next, reuse when possible. Finally, recycle what is possible.

There are many ways to reduce the waste you generate. From simple things like taking reusable bags to stores and using travel mugs when you go out for coffee, to more involved efforts like making your own laundry detergent and household cleaners. One only needs to take a few minutes to think of the possibilities! When beginning such an endeavor, start simple and you will soon be thinking of new ways to reduce as you see the results of your efforts by having less to carry to the garbage and recycling bins and more money in your wallet. And you will never hear those three words in the same way again.



Donations from June 2, 2020
through August 30, 2020
Thank you for all your support!

Dee & Marty Hughes ✂
Donna O'Brien
Pi Kappa Sigma – Allen College ✂
James & Cheryl Thayer ✂
Doris Webber

✂ *Sponsor for Ignite Event*

Early Bird Registration
Ends October 12

Fifth Annual



Mind, Body & Soul

This event will educate patients, survivors, care givers, healthcare professionals (CEUs available), community members, leaders and advocates.

DR. SNEHA PHADKE
Oncologist and Professor
Will address "chemo brain"

ERIN SULLIVAN WAGNER
Certified Cancer Life Coach
Will discuss sexual health and intimacy
after cancer

REVEREND CAROL TEARE
Associate Region Minister
Will speak on the topic of mindfulness

DR. MICHELE DEVLIN
UNI Professor of Global Public Health
Will cover health disparities in Iowa

TRACI MCCAUSLAND
Gallup-Certified Strengths Coach
Will explain the relevance of following
your strengths when facing cancer

BEYONDPINKTEAM.ORG

THURSDAY,
NOVEMBER 12

5 - 9 PM

LIVE VIA ZOOM

TICKETS
\$15 - \$20



Early Bird Registration
Ends October 12



Thank you for the following sponsors of the 14th Annual Pink Ribbon Run.

Presenting Sponsors



Media Sponsors



Bibs "Mask" 'n Banner Sponsor

T-shirt Sponsor

Team Sponsor



Cheer Sponsors

Friend Sponsors

Supporting Sponsors



NuCara Pharmacy
Avalon Plastic Surgery
Cedar Valley Breast Care
Lincoln Savings Bank
Mudd Advertising
Cedar Falls Tourism and
Visitors Bureau

Culligan
VGM
The Pump Haus



The 14th Annual Pink Ribbon Run is going Virtual!

Cancer does not stop for COVID-19 and neither does the need in our community. Due to COVID-19 many fundraisers are being canceled. Every dollar counts to people facing a cancer diagnosis.

You have the option to participate virtually as an individual, or with a team, or can skip the walk and just raise funds. Either way, we appreciate you!

Thanks to our sponsors on previous page, your registration dollars go directly back to our community. The Pink Ribbon Run is presented by Oakridge Real Estate and GreenState Credit Union. Survivor Sponsor, Community Auto Group, will cover registrations for ALL breast cancer survivors.

To register go to: <http://runsignup.com/pinkribbonrun> or find link on BPT website: www.beyondpinkteam.org.

Packet pickup

Community Main Street Office
310 E 4th Street, Cedar Falls on:

- Tuesday and Wednesday, September 29 and 30
9 a.m. to 4:30 p.m.
- Thursday, October 1
9 a.m. to 7 p.m.

Optional Virtual Race Routes

- **2020 Pink Ribbon Run Race Route** – Start at the trail by CMS office (310 E 4th St), head south to Washington Park, turn left to hit the loop around Washington Park, exit loop when you cross the road in Washington Park and

VIRTUAL



travel to park entrance on road, exiting park you will cross railroad tracks and jump back on the trail heading south toward 12th Street, then turning east on the trail to go toward Pfeiffer Park where you take the trail over Kreig's Crossing and just into Gateway Park. Race Route is 3.25 miles.

- **Gateway to Big Woods – 5K.** This is an out and back and not around the entire loop at Big Woods. It would be to the park bench by the prairie when you head east entering Big Woods. (Spoiler, this is where we will put the PRR sign). Turn there and head back.
- **Prairie Lakes Loop – 5K.** Two loops around the large lake and add one loop around the small lake is just over 3 miles.
- **Do Your Own** – It takes approximately 2000 steps to make a mile. Grab your favorite step counting app and log 6200 steps. Then send us a picture!



Sam and Rachel,
Sherry's dad
and daughter,
at a PRR event.

“Be Happy Where You Are”

Sherry Schumacher, Survivor

At the 2019 Pink Ribbon Run, Sherry Schumacher's family shared Sherry's story.

These are Sherry's words from 2016... *“I was diagnosed with breast cancer in August of 2015. After discovering a lump, I went in for my (overdue) mammogram and then had a follow up biopsy at Waverly Health Center. From there I was referred to the Mayo Clinic for chemotherapy and mastectomy and finished my treatments with 6 weeks of daily radiation at the Covenant Cancer Treatment Center. I plan to have reconstructive surgery later this year. My family has participated in the Pink Ribbon Run almost from the beginning...I have always wanted to support women going through cancer, but I never expected to be one of them! This year's Run will be quite a different one for me. In fact, one thought that kept me going during treatment was that I wanted to be able to run this race in October and start collecting my beads! I think the Pink Ribbon Run is great for the community because it shows the strength of so many women and those who have been their support systems as they go through their cancer experience. It also raises awareness of research*

being done and reminds women to get their checkups and screenings done."

Sherry did collect her first strand of beads in 2016. In 2017, smiling brightly with 2 strands of beads, she was front and center in the Survivor's photo holding a sign with the number 938, the years of survival represented that year.

In March 2018, Sherry's cancer returned...this time in her liver. At that time Sherry and her husband, Mark, contacted the Beyond Pink TEAM and received assistance for transportation costs back and forth to Mayo. The fight was on again...but the outcome was quite different. Sherry lost her battle on April 11, 2018. She was a loving and devoted daughter, wife, mother, and friend and is missed every single day.

Sherry's faith was an important part of how she got through her cancer. Her family would like to share two notes found in her Bible:

The first next to Ecclesiastes 5:18 was "Be happy where you are."

The second next to Matthew 6:33-34 was "God will give us enough grace for today and fresh grace for tomorrow. Every day is a bonus!"

This gives some insight into how Sherry lived her life and fought her fight. She believed in promoting early detection and supporting those journeying through a cancer diagnosis. As a Team, we will continue to participate in the Pink Ribbon run and hold an annual fundraising garage sale as a tribute to Sherry's memory.

Written by family friend, Mary Rekers

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

Support Group Dates

October 5, 1:30 p.m.

Touch of Courage

Breast Cancer Support Group

2101 Kimball Ave., Bd Rm, Waterloo
Pat – 319-232-8691

Call Ahead

October 6, 1:30 p.m.

Care & Share Cancer Support Group

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

Call Ahead

November 2, 1:30 p.m.

Touch of Courage

Breast Cancer Support Group

2101 Kimball Ave., Bd Rm, Waterloo
Pat – 319-232-8691

November 3, 1:30 p.m.

Care & Share Cancer Support Group

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

November 12 - TBD

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

Call Cathy Ketton - 319-504-2703 for details

December 1, 1:30 p.m.

Care & Share Cancer Support Group

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

December 7, 1:30 p.m.

Touch of Courage

Breast Cancer Support Group

2101 Kimball Ave., Bd Rm, Waterloo
Pat – 319-232-8691

January 19, 4:30 p.m.

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

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

VIRTUAL

January 4, 1:30 p.m.

Touch of Courage

Breast Cancer Support Group

2101 Kimball Ave., Bd Rm, Waterloo
Pat – 319-232-8691

January 5, 1:30 p.m.

Care & Share Cancer Support Group

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



Beyond Pink TEAM advocates may not have traveled to Washington, D.C. this year, but they made a huge impact!

Below is a picture of the BPT attendees for the Virtual Lobby Day. What an impressive presentation they made, along with 3 local breast cancer individuals with metastatic breast cancer sharing their stories.



Featured in the Zoom photo from top left to bottom right:

Christine Carpenter, Lori Seawel, Kristin Teig Torres, Jodie Muller, Beth Drelich, Jacque Bakker, Julie Husband, Devin O'Laughlin, Gowri Betrabet Guilwadi, Barbara Christie-Pope, Traci McClausland, Sarah Corkery

Vote Breast Cancer!

Breast cancer is not only a women's issue; it is a political issue that remains an urgent health crisis. Every day elected officials across the country are tasked with making decisions that affect people diagnosed with breast cancer. These decisions include determining the amount of funding and resources allocated to this issue, how to prevent the disease, and how to ensure accessibility of treatment and care to their constituency. The breast cancer

policies being debated at the state and federal levels can mean life or death to you or your loved one with breast cancer. And all women are at risk.

However, breast cancer is not a partisan issue. Candidates on both sides of the aisle need to get behind the National Breast Cancer Coalition's mission to end breast cancer. We need elected officials who understand the urgency and importance of realizing this mission.

Our elected officials are charged with making important breast cancer policy decisions every year. Before you vote on November 3, please consider how our Iowa Congressional delegation and their opponents vote or have pledged to vote, if elected, on important breast cancer issues.

Remember, we control who sits in Congress representing Iowa. So, register to vote today – and VOTE BREAST CANCER!

	DOD BCRP *	ACA **	Mets Access to Care ***
President Donald Trump	NO	NO	NO
V. Pres. Mike Pence	NO	NO	NO
Senator Joe Biden	YES	YES	YES
Senator Kamala Harris	YES	YES	YES
Iowa Senator Joni Ernst	NO	NO	YES
Theresa Greenfield	YES	YES	YES
1st District Rep. Finkenauer	YES	YES	YES
1st District Ashley Hinson	NO	NO	NO
* DOD BCRP - Have signed or will sign the Dear Colleague letter in support of the Department of Defense Breast Cancer Research Program for FY 2021			
**ACA - Voted to or will vote to retain the Affordable Care Act that provides insurance coverage for many previously uninsured and does not allow insurers to discriminate against those with pre-existing conditions.			
*** Mets Access to Care - Co-sponsored or will co-sponsor the Metastatic Breast Cancer Access to Care Act.			



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.cancercaare.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 Thurs days 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

Cedar Valley Cancer Committee
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