



Cedar Valley Cancer Committee

Touch of Courage . . . Connection

Newsletter

April 2022

Celebrating over 30 years in the Cedar Valley

IN THIS ISSUE

Page 2

Living Green

**Where Are They Now
Survivor Story -**
Kathy Baethke

Page 3

Survivor Story -
Sarah Diesburg

Fundraisers

Page 4

Donations

**Beyond Pink TEAM All
Cancer Notice**

**NBCC - Take Action in
Action Center**

Page 5

**Beyond Pink TEAM Support
Groups - What Are They**

Support Group Dates
April - May - June - July

Look Good...Feel Better

Page 8

**Resources, Support and
Volunteer Information**

Financial Toxicity – It's Effect on a Cancer Patient's Treatment Costs

Source - National Cancer Institute

Financial toxicity often called financial distress, is used to describe how out-of-pocket costs can cause financial problems for a cancer patient. These out-of-pocket costs are what a person pays for medical care that is not covered by health insurance. Some of these costs could include:

- Copayments – The amount a patient pays for a healthcare service such as doctor appointment or a prescription.
- Deductible – What you need to pay for medical care before your health insurance plan begins to pay.
- Coinsurance – A percentage of medical costs you will be responsible for before your insurance covers. For example, you pay 20% and your insurance pays 80%. Some of these costs can be for hospital stays, outpatient services, medical appointments, and prescription drugs. Cancer survivors usually report higher out-of-pocket spending than people who have not had cancer. Some cancer survivors report spending more than 20% of their annual income on medical care.

Cancer is one of the most expensive medical conditions to treat in the United States. This is because cancer patients receive multiple types of treatments, including surgery, radiation therapy, and systemic treatment, and may be hospitalized. They receive more expensive chemotherapy, immunotherapy, and other new types of treatments. Prescription drugs maybe higher priced drugs or brand names (versus generic drugs) and may increase over time. Cancer patients may be paying for ongoing cancer treatments or care for late effects from their treatment. Even with health insurance these costs, along with higher health insurance premiums may cause financial toxicity.

Several factors in the household affect risk of financial toxicity

You and your family may have less income and assets, more debts because of the cost of your cancer care, trouble paying for housing, food, and bills because of your cancer diagnosis.

Financial Toxicity, continued page 6 and 7

Living Green

Save Our Insects!

By Dawn Keller

When I was a kid, I loved going outside on summer nights and catching lightning bugs. I would put them in a jar and watch them light up while wondering how they were able to do this, then let them go when it was time to go in. Now, some 40 years later, I would have a hard time doing that outside of my own lawn. Why? What has happened?

Insect populations are in trouble worldwide, with estimates of at least 75% loss in total insect abundance since my summers catching lightning bugs. Habitat loss, pesticide use, and mismanaging lawns are some of the reasons why we have lost so many of these organisms that we depend on. What can you do to help? First, don't use pesticides in your yard. Next, leave so-called weeds in your yard—especially those that show up early like dandelions. Insects rely on these early species for food. Finally, create habitat. It doesn't have to be a large garden. Even a small pot of flowers can help. And spread the word to neighbors, family, and friends. If many people do one small thing, it will add up!



Not Just a Unicorn, but a Survivor

By Kathy Baethke

I consider myself to be a unique individual, a unicorn one might say. The reason I, many of my friends and family, call me a unicorn is because in the last fifteen years of my life, I have had three cancers. All of which have been different from the original one. With this being said, my story begins fifteen years ago.

In September 2006, I had an abnormal lump in my wrist that was causing my fingers to turn purple. I called the doctor and made an appointment to figure out what the lump was. They did an MRI and decided it was best to send me to the Iowa City University hospital since this lump was literally integrated around the structures in the wrist. I had a small biopsy done, and what they had taken out was all benign. We then proceeded to have surgery to remove what we could from the wrist. It was a very meticulous process as it was only supposed to take an hour or two, it turned into over four hours. A week later I was then informed via phone call from a student resident that the lump was actually a liposarcoma. With this new little bit of information, and since the surgeons couldn't get clean margins, I was informed that thirty-six radiation treatments were the best course of action.

Thinking all was good, on April 1, 2011, a day for silly pranks begins the next chapter in my unicorn life. On that day I discovered a pea size lump in my left breast during my self-check. I thought it might be an infection or something so I figured that I could wait a bit and just keep checking. A month later after the



lump had significantly grown to about the size of a quarter, I went to see my family doctor. The next day an ultrasound was performed. From the images of the ultrasound, and the gut feeling within me, I felt that I needed to do more than just wait for a phone call of the results. The nurses set up an appointment with a breast surgeon. The next day the doctor checked the ultrasound, and we discussed the options. We decided to do a lumpectomy and it was scheduled for four days later. The biopsy results were invasive ductal carcinoma, and it was triple negative. A nine out of ten for tumor aggression. Thankfully, the lymph nodes were not involved.

Now I get to see the oncologist to discuss what further treatments were needed. I did six rounds of chemotherapy and thirty-six radiation treatments. On my first day of chemo, I got to the cancer treatment center and was able to choose a breast cancer blanket. This blanket was special to me for it was handmade with love and care and given to those who are going through chemo. I got my own private room which had an awesome recliner. I spent a good amount of time in that room while getting numerous medications via port. Thank God for a port as I am terrible with needles. I did these every three weeks. The treatments made me nauseous, and most of my food tasted weird.

Hope After a Metastatic Diagnosis

A Survivor Story of Sarah Diesburg

It was a cold day on March 6th, 2020. I was teaching two classes that day as a professor at the University of Northern Iowa, and I was trying to squeeze a well-needed hair appointment into my busy schedule. I was also entering the third trimester of my second pregnancy.

That's when I had the seizure – the first sign that my early-stage breast cancer, treated almost five years ago, had returned, and spread to my brain. Later, after giving birth to a healthy baby girl, I was diagnosed with stage 4 metastatic triple negative breast cancer at the age of 37.

A metastatic diagnosis means that cancer has spread beyond where it was originally diagnosed, and it is truly a terrifying place to be. We found my cancer had spread to three small places in my brain, lung, and chest lymph node. Average life expectancy of someone with the triple negative metastatic breast cancer subtype ranged around 2-3 years.

I had a newborn baby and a toddler at home, as well as a loving husband. I couldn't leave them. I started on a newly approved combination of chemotherapy and immunotherapy as soon as I recovered from brain surgery to remove the tumor from my brain. I also started reading everything I could about this disease, and I made a vow to myself to do *everything* I possibly could to stay alive. I ate a healthier diet. I started exercising a lot. I worked on my stress, even though that seemed ridiculous at the time.

As I write this article, I'm coming up on my two-year anniversary of that fateful date. And, amazingly, I have no evidence of disease (NED), which means cancer cannot be identified on current scans. I am one of the small handful of people with solid tumors for which immunotherapy, along with targeted radiation, has been able to keep me in NED status. For the last 16 months, I have been on maintenance immunotherapy alone, which luckily for me has no side effects.

Immunotherapy is so new in this space that my doctors do not know how long my NED status is likely to last, but they are getting cautiously optimistic that it could last a very long time. Maybe even a very long time. I'm also not stopping any of the healthy habits I picked up along the way to help support my body and immune system.

I wish I could send this article back to myself two years ago. I searched those first few dark months after being diagnosed stage 4, and I found very few stories of hope. I'm still here, and I'm full of hope and determination for a long and happy life.



The Diesburg Family

CBE Donates a check to BPT from their "Casual for a Cause" fundraiser



Thank You, Fundraisers!



Scheels donates \$2,000 to the BPT

DONATIONS

The following donations received December 1, 2021, through February 28, 2022.

Thank you so much for your generosity.

Hannah Borton
 CBE Group
 CF Public Safety
 C David & Glenda Christensen
 Krista Dougherty
 Carol Duffy
 Flowerama
 Fredsville Lutheran Church
 Mary Lou Gutting
 Grace Hernandez
 Jean Hoy
 Adrian Johnson
 Mary Jo Juel
 Brooke Kolder
 Amber Krebsbach
 Lincoln Savings Bank
 Walter McCausland
 Jodie Muller
 Panera Bread
 Martha Paprocki
 Jan & Kevin Parker
 Lori Seawel
 Rhonda Shaw
 St Athanasius School
 Tammy Theis
 Beth Thompson
 UNI Volleyball
 Sandy Warmuth
 Doris Webber



MEET, MINGLE AND LEARN EVENT

Topic: Nutrition Doesn't Have to be Complicated
Speaker: Dr. Andrew Nish, John Stoddard Cancer Center
Date: Tuesday, April 19 2022
Time: 5:00-7:00 PM (speaker begins at 6 pm)
Location: Zoom (call Angela to have a link emailed to you)

This is a **FREE EVENT** and open to all women living with cancer. Dr. Nish is the medical director of the John Stoddard Cancer Center in Des Moines. His passion is to educate the public about true health and well-being and how this can be achieved through lifestyle changes. He will speak on how a healthy diet doesn't have to be complicated. Come and go as your schedule allows.

CALL ANGELA AT 319-231-3143 FOR MORE DETAILS

Take Action in the Action Center



Metastatic Breast Cancer Access to Care Act:

Passage of legislation to waive the 24-month waiting period for Medicare and the 5-month waiting period for Social Security Disability Insurance benefits for eligible individuals with metastatic breast cancer.

Senator Grassley and Representative Hinson are the only Iowa Congressional delegation who still need to cosponsor this important legislation. We need your voice. You can show your support for the Metastatic Breast Cancer Access to Care Act (S.1312/H.R.3183) by sending personalized messages to the Iowa Members of Congress. Visit the NBCC

Action Center and urge our members to cosponsor this lifesaving legislation with just a few clicks.



BPT Support Groups - What They Are?

Whether newly diagnosed or living with cancer, the Beyond Pink TEAM is here for you! Living with cancer is a challenge and living through a pandemic has added even more to that challenge. Our support groups adjust to the safety needs of our community in determining whether a Zoom meeting or in-person meeting should be held.

All Cancer Support Group (ACSG) - this group meets on the third Tuesday of January, April, June, and September from 4:30-7:00 pm. These meetings are a time to socialize, keep in touch, and learn from other survivors and guest speakers. We hold virtual Zoom meetings as needed and are looking forward to in-person meetings once again. The Zoom link is sent through the private Facebook group, or you can reach out to Angela Hamilton at 319-231-3143 to have the link emailed to you. The in-person meetings are held at the Cedar Valley Unitarian Universalists building on Cedar Heights Drive in Cedar Falls.

Touch of Courage - this breast cancer support group meets the first Monday of every month at 1:30 pm at the Community Foundation of NE Iowa on Greenhill Road in Cedar Falls. New members are always welcome and there is an abundance of caring and sharing of experiences in this group. Contact Pat Buls at 319-232-8691 with questions.

Support Group Dates

As of this writing both BPT Support Groups (Touch of Courage and All Cancer Support Group) have met in-person outdoors. Please call first before attending any group. Wear a mask if indoors, and do not attend if you have been exposed to COVID-19.

April 4, 1:30 p.m.

Touch of Courage Breast Cancer Support Group

IF MEETING IN PERSON, MASK REQUIRED
Community Foundation of NE Iowa
3117 Greenhill Circle, Cedar Falls
Pat – 319-232-8691 for meeting info & location

April 5, 1:30 p.m.

Care & Share Cancer Support Group

IF MEETING IN PERSON, MASK REQUIRED
MercyOne Waterloo Cancer Center
200 E Ridgeway Ave., Waterloo
Jessica – 319-272-2816 for meeting information

April 19, 1:30 p.m.

BPT All Cancer Support Group – Meet, Mingle and Learn

IF MEETING IN PERSON, MASK REQUIRED
Cedar Valley Unitarian Universalist Church
3912 Cedar Heights Dr., Cedar Falls
Angela – 319-231-3143 for meeting information

May 2, 1:30 p.m.

Touch of Courage Breast Cancer Support Group

IF MEETING IN PERSON, MASK REQUIRED
Community Foundation of NE Iowa
3117 Greenhill Circle, Cedar Falls
Pat – 319-232-8691 for meeting info & location

May 9, 1:30 p.m.

Care & Share Cancer Support Group

IF MEETING IN PERSON, MASK REQUIRED
MercyOne Waterloo Cancer Center
200 E Ridgeway Ave., Waterloo
Jessica – 319-272-2816 for meeting information

Date to Be Determined

Splash of Color – Women of Color Breast Cancer Support Group

Call Cathy Ketton - 319-504-2703 for details

June 6, 1:30 p.m.

Touch of Courage Breast Cancer Support Group

IF MEETING IN PERSON, MASK REQUIRED
Community Foundation of NE Iowa
3117 Greenhill Circle, Cedar Falls
Pat – 319-232-8691 for meeting info & location

June 7, 1:30 p.m.

Care & Share Cancer Support Group

IF MEETING IN PERSON, MASK REQUIRED
MercyOne Waterloo Cancer Center
200 E Ridgeway Ave., Waterloo
Jessica – 319-272-2816 for meeting information

June 21, 1:30 p.m.

BPT All Cancer Support Group – Meet, Mingle and Learn

IF MEETING IN PERSON, MASK REQUIRED
Cedar Valley Unitarian Universalist Church
3912 Cedar Heights Dr., Cedar Falls
Angela – 319-231-3143 for meeting information

July 5, 1:30 p.m.

Care & Share Cancer Support Group

IF MEETING IN PERSON, MASK REQUIRED
MercyOne Waterloo Cancer Center
200 E Ridgeway Ave., Waterloo
Jessica – 319-272-2816 for meeting information

July 11, 1:30 p.m.

Touch of Courage Breast Cancer Support Group

IF MEETING IN PERSON, MASK REQUIRED
Community Foundation of NE Iowa
3117 Greenhill Circle, Cedar Falls
Pat – 319-232-8691 for meeting info & location

Look Good Feel Better

At this time, these sessions have not met in person. However, the American Cancer Society offers live virtual workshops. These provide a safe, convenient way to experience Look Good Feel Better from home, featuring their national trainers.

Check out –
lookgoodfeelbetter.org



Unicorn, continued from page 2

Almost like a metallic taste. I learned that plastic silverware was my friend. Watermelon was the only thing that tasted good to me. Chemo caused my hair to fall out which was fine as its only hair, and I got to wear a lot of cute hats. Chemo fog is a real thing as well as a struggle to this very day.

Nine years later... February 2020. I assumed after that length of time the chances of cancer returning were slim. My body however decided to throw a curveball. I had some blood coming from my left nipple when I showered, so I went to the breast clinic to have it checked. A mammogram was performed, and it was clear. Instead of leaving it there, my doctor decided it was best to do an MRI. That showed I had a couple of spots that were concerning in both breasts. So now it is time to do an MRI assisted biopsy, which let me tell you, is not a fun thing to go through. Then began everyone's least favorite game, the waiting and what if game. Everyone tells you to stay positive, but it is hard to do when you have battled this before. It is even harder knowing in your head and heart that the cancer was back.

When I went to see my breast care navigator for the results, she informed me that it was invasive lobular carcinoma and HER2 positive in the right breast yet benign in the left. Everyone was shocked that I had made the decision immediately to do a double mastectomy. I already made this decision while battling breast cancer the first time in case it ever decided to rear its ugly head again in the future. So, in March, during the chaos of Covid-19, my surgery for the double mastectomy and

reconstruction was scheduled. It was frightening to think my surgery could be cancelled at any time because of Covid-19. Thankfully, it wasn't canceled, and the surgery went well. However, after surgery I learned very quickly how moving, like laying down and sitting up affected your chest muscles. It got better little by little, day by day. This round of treatments, because it was HER2 positive, I will only take a prescription for the next five years. Radiation was out because I did the double mastectomy and again because it was HER2 positive, chemo wasn't necessary. This particular cancer was a one out of ten on the tumor aggression scale.

My oncologist told me that although my biopsy was only positive in the right breast, when the pathology report from surgery came back, it stated that it was invasive lobular carcinoma in the right but also lobular carcinoma in situ in the left. He informed me that I had made the correct decision to do the double mastectomy. Because of this, we did tests to see if the cancers were genetic. It was important to be tested because I have children. I wanted to be assured that it wouldn't be passed down and affect them. Thankfully, the tests came back with no predisposition of cancer, it was simply luck of the draw to have three separate types of cancer. If there has been one thing, I have learned throughout my crazy journey it is this: Always pay attention to your body, if something seems weird or different, get it checked. You are your best advocate. At the end of the day when it is all said and done, I am not just a unicorn, I am a Survivor!

Financial Toxicity, continued from page 1

Having cancer may make it hard for you to do the physical and mental tasks for your job. You may miss time at work, or not be able to work at all. One study showed that working people who are getting cancer treatment missed about 22 more workdays a year than those who did not have any cancer treatment. Not being able to work may affect your employment-based health insurance (this is when part or all your premium is paid by your employer).

You may also worry and stress about paying medical bills related to your cancer. It's reported cancer patients worry about wages lost for sick time or going to medical appointments. They may also have difficulty and stress when trying to understand complex medical bills.

Patients with advanced-stage cancer, recurrent cancer, cancer with a poor prognosis, more than one type of cancer and a chronic disease (such as heart disease or diabetes) in addition to cancer can have a higher risk of financial toxicity. This is partly because their cancer and treatment may keep them from having a job.

Studies show a younger age at the time of cancer diagnosis increases the risk of financial toxicity because of a lack of savings and assets, other financial responsibilities, such as raising children, and not having health insurance (patients under age 65 are not eligible for Medicare) or having a high-deductible health insurance plan with high out-of-pocket costs.

Younger cancer patients and survivors also have a higher risk of bankruptcy than older cancer patients and survivors and people without cancer.

Financial Toxicity, continued next page

Financial Toxicity, continued from previous page

Survivors of childhood cancer may be more likely to have financial problems. A cancer diagnosis during childhood may disrupt education and limit job opportunities. Childhood cancer survivors may have higher out-of-pocket costs than their siblings due to the risk of second cancers and lasting effects of their cancer treatment.

Some studies have shown that people who belong to a minority race, are from a lower-income household, losing a job, change in job status (switching to part-time or taking extended leave), difficulty returning to work, and general loss of productivity all are a risk for debt and bankruptcy.

Health insurance or lack of can affect your risk of financial toxicity

If you do not have health insurance you have a high risk of financial toxicity, especially because cancer costs are rising. However, even if you have health insurance, you may still have high out-of-pocket costs for your cancer care.

If you are enrolled in Medicare, you can also enroll in additional plans that can help reduce your out-of-pocket costs. You can choose to get supplemental insurance that can help cover medical costs that your regular insurance plan does not cover and you can enroll in Medicare Part D, which is a Medicare plan that covers prescription drugs.

One study found patients with public health insurance (Medicaid or Medicare) have a higher risk of financial toxicity compared to patients who have private health insurance. Patients with public health insurance may also have fewer

savings and assets, which is a risk factor for financial toxicity.

Effects of Financial Toxicity (Financial Distress) on Cancer Patients

Some patients have reported skipping doses or taking less medicine than prescribed, to make their prescription last longer and save money. Patients have also reported not filling a prescription because of the cost. The higher the copayment, the less likely patients are to take their medicine as directed.

Studies have shown that patients who have financial toxicity reported having a lower quality of life, more symptoms, and more pain. In addition, they have poor physical health, poor mental health (including feeling depressed), being unsatisfied with social activities and relationships, and worry their cancer may come back. Another study showed that patients who file for bankruptcy may be more likely to die than those who do not file for bankruptcy.

What you can do to help pay for your medical care

To help pay for your medical care, you may need to use your savings, borrow money, spend less on leisure activities, food, clothing, and utilities. You may also need to sell your stocks, investments, possessions, or property or move to lower-cost housing.

Informal caregivers often share in the experience of financial toxicity

Family members and friends may provide informal care for cancer patients. They often spend money on

food, medicine, and other things the patient needs. They may also need to take time off from work to provide care for the patient. These actions may lead to a higher sense of burden, lower quality of life, and poorer mental health for the caregiver.

Ways to Reduce Financial Toxicity (Financial Distress)

The following are being studied as possible ways to reduce financial toxicity:

- Meeting with a financial navigator who will teach you about the health insurance plans and cost-saving methods for treatments that you are eligible for.
- Hospitals posting their prices so that healthcare professionals and patients know the costs when making decisions about which tests and treatments to use.
- Introducing value-based pricing so that patients can choose higher-value treatments with lower out-of-pocket costs.
- Reforming health insurance by passing policies that help cancer patients.

To read the entirety of the National Cancer article go to:
<https://www.cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-hp-pdq>

The Beyond Pink TEAM provides financial grants to people receiving treatment for a breast cancer diagnosis. To check availability, contact your social worker or go to the Beyond Pink TEAM website, click on Financial under the Support tab.



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:

- Writing a survivor story for the newsletter
- Become part of the Breast Cancer Advocacy Network
- Volunteering: *(check all that apply)*
- Assist with Support Groups
- Development (Publicity)
- Events (Fundraisers, Projects and More)
- Making phone calls and sending emails to policy makers for breast cancer issues
- 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.
- Education (Health Fairs/Presentations, Newsletters)
- Advocacy – Contact Congress/Ignite the Cancer Conversation
- Donate. Make checks payable to Beyond Pink TEAM. *(All donations are tax deductible)*
- BPT Fund
- Advocacy Fund
- Area of Need

Touch of Courage . . . Connection

Quarterly Newsletter of Beyond Pink TEAM

Cedar Valley Cancer Committee
 Dba Beyond Pink TEAM
 3453 Kingswood Place
 Waterloo, IA 50701
www.beyondpinkteam.org