



Cedar Valley Cancer Committee

# TOUCH OF COURAGE

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## CONNECTION NEWSLETTER

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## BEYOND BRCA: HEREDITARY BREAST CANCER GENETIC TESTING

*By Athena Puski, MS LGC*

*Licensed Genetic Counselor*

*Holden Comprehensive Cancer Center*

*University of Iowa Hospitals and Clinics*

You've probably heard of BRCA1 and BRCA2, or "the BRACA genes," which increase the risk of getting breast and ovarian cancer. But have you heard of PALB2, CHEK2, or ATM? Many are surprised to learn there are 11 additional genes besides BRCA1 and BRCA2 that are known to increase the risk of getting breast cancer, and many more genes are still being researched for their possible association with hereditary breast cancer.

A mutation in any of these "other" genes increases the chance of getting breast cancer. Some increase the risk for breast cancer just a little bit, while others increase the risk a lot. These genes can also increase the chance of getting other cancers besides just breast cancer. For example, CHEK2 mutations slightly increase the risk for breast cancer and colon cancer, while PALB2 mutations slightly increase the risk for pancreatic cancer, ovarian cancer, and breast cancer.

Knowing if you have one of these genetic mutations can impact medical care for you and your family members. There are often steps that can be taken to detect cancer at an early and more-treatable stage, or even prevent cancer. How this is done depends on the specific gene in which there is a mutation. It may include screening for cancer more often, such as doing a mammogram and a breast MRI every year. Sometimes surgery can be used to prevent cancer, such as by removing the ovaries or both breasts. Medications can also sometimes be used to lower the chance of getting cancer. In some cases, targeted cancer treatments, such as PARP inhibitors, can be used as part of the treatment for breast cancer.

These hereditary causes of cancer are not common—only about 10% of all breast cancers are estimated to be due to an inherited genetic mutation (about half of which are due to a mutation in a gene other than BRCA1 or BRCA2). Those with a genetic mutation often (but not always) have a strong family history of cancer. Some things that can

BEYOND BRCA, CONTINUED PAGE 2

indicate you might have a hereditary breast cancer condition and may want to consider genetic testing include the following:

- You or someone in your family had breast cancer before the age of 45
- You or someone in your family has had triple-negative breast cancer, ovarian cancer, pancreatic cancer, male breast cancer, or metastatic prostate cancer
- At least three members of your family have had breast cancer or prostate cancer at any age

If genetic testing is something you are interested in learning more about, talk with your doctor or a genetic counselor. Even if you had BRCA1 and BRCA2 genetic testing in the past, additional testing for mutations in other genes may be appropriate. This type of genetic testing is called “update testing” or “panel testing.” Genetic testing can usually be done with a blood sample or sometimes a saliva sample. Nowadays, insurance coverage for genetic testing is often very good. However, even if insurance won’t

cover the cost of testing for you, there are routes available to get genetic testing for about \$250, even without insurance.

Genetic testing isn’t right for everyone, though, and that’s okay. It is scary to learn you and family members have an increased chance of getting cancer; not everyone is ready for this information. Others may welcome the information learned from genetic testing so they can take proactive steps against their cancer risk. A genetic counselor and your doctor can help you determine what is best for you. FORCE (<https://www.facingourrisk.org/>) is also great resource to learn more about genetic testing and genetic mutations.

Whether or not you decide if genetic testing is right for you, knowing your family history is key. The upcoming holidays are a great time to talk with family members and gather their medical history. Here is a guide to help you through the process about asking family members about their health history: [guide-to-family-health-history.pdf](#) ([geisinger.org](https://www.geisinger.org)).

## WHERE THEY ARE NOW | JOY THORSON'S STORY

### JOY THORSON



I was happy to write a bit about my breast cancer journey, but I wasn’t sure what to include since it’s been a very long journey. So, I decided to focus on the most recent chapter, but I thought I should give you a bit of background first.

In October 1999 I was diagnosed with HER2-negative breast cancer.

Within 3 days I had a single modified radical mastectomy and because of lymph node involvement I also had chemotherapy, radiation, followed by medication and no plan for reconstruction.

In 2004, I was feeling good and decided to consider reconstruction. I hadn’t retained any extra skin at the time of my mastectomy, so I needed an “expander” implanted to encourage that skin to expand enough for the implant. This was a very difficult and painful process because that radiated skin did not want to expand. Then I received a silicone implant.

In March 2017 after multiple tests, I was given the news that I had metastatic breast cancer in a rib and a vertebra...certainly NOT what I expected to hear. I was devastated. After all these years that darn

cancer decided to show up again!!!

As you know, Metastatic Breast Cancer is not curable and is considered Stage 4. In June of 2017, I began taking Kisqali, a CDK-inhibitor drug, that I take every day for 3 weeks, then get a week off and I would need to take this for the rest of my life. It seems to be doing its job keeping my cancer at bay as the last 5 PET scans (I have them twice a year) have basically been clear! Hallelujah! Other than being a VERY expensive drug I am tolerating it very well.

I was thrilled to be the recipient of BPT grant funds one year which helped to cover a couple of months of my Kisqali prescription. It is very hard for me to ask for help, but I was treated with great respect, kindness, and care from the BPT. Their scholarship program for financial assistance is a wonderful part of the BPT!

The past couple of years I have been experiencing extreme fatigue for unknown reasons. I’ve had blood tests and I learned that I am not anemic, my thyroid is under control, I do not have Lyme disease or lupus. The doctor told me I have “chronic fatigue”. It’s difficult to accept as I love being active and doing more than 1 or 2 things a day! One day I happened to watch

## MY SON IS WHY I WAS DIAGNOSED WITH BREAST CANCER

### **SURVIVOR STORY – KIM KOCKLER**

In April of 2020, my husband and I welcomed baby #2 into our family. Rylan joined big brother Gavin at home. Fortunately or unfortunately, however you look at it, Rylan is the reason I was diagnosed with breast cancer.

Just four short months after birth, I was having severe pain and felt a lump in my right breast. I thought for sure it was a clogged milk duct, so I tried all the methods to find relief. Nothing seemed to work so I went to my doctor for some help. Little did I know, that “clogged milk duct” would turn out to be breast cancer. I was diagnosed with Invasive Ductal Carcinoma(IDC). I was also triple negative.

The week of diagnosis was a whirlwind. I'm a teacher. It was the start of a new school year. We were in the mist of the Covid-19 pandemic. Teachers were told to be very flexible because rules/regulations were changing daily. I went to my initial visit with my oncologist. Due to my compromised immune system while on chemo and the unknown of the coronavirus, my team of doctors made the suggestions of taking a medical leave of absence for the school year. Only a few days into the school year, I was going to be leaving my students to begin fighting my battle with cancer.

My medical team decided that I would do chemotherapy first and then have surgery to remove any remains of the tumor. Fortunately for me, my cancer had not spread and was contained to my right breast.

I did 20 rounds of chemo from September 2020 to February 2021. In February, I made the decision to have a double mastectomy, with reconstruction. Mastectomy recovery was rough. It was painful. I also had two boys at home that I wasn't able to interact with because of weight restrictions and just the fear of them hitting my chest.

In July of 2021, I was able to have my expanders taken out and my breast implants put in. That surgery was a breeze compared to the mastectomy surgery. The recovery was much easier.

Five weeks after surgery, I started back to work for the 2021-2022 school year. I was determined to go back to work at the start of the year. Physically, I was ready. I wasn't at my full strength, but anything I needed to do as a teacher, I could handle. However, looking back I was mentally not ready to be back to work. The first semester was tough. I cried a lot. My body had changed a lot in the past year and I hadn't fully realized that. I was under a lot of stress for a lot of different reasons. I was able to get some medical help, and second

semester went much smoother.

As I write this reflection, I am a year and a half cancer free. It is a fantastic feeling! Instead of spending the summer recovering from surgeries, this year, I am spending quality time with my 5- and 2-year old. We are keeping busy with the typical summer activities, but I am also taking all the snuggles, hugs and kisses I can get, since I couldn't experience them last year.



## LIVING GREEN | DOING SMALL THINGS DO MATTER

### **DAWN KELLER**

I've been an environmental science professor for over 20 years. I'm not going to lie, it has taken a toll on me. Why? It's hard to continue to teach topics that continually get worse. Very little has improved environmentally during my teaching career. What do I do when I lose hope that things can get better? I focus on a small thing that I am doing.

I know that growing a garden and mowing my yard less won't do much in the big picture, but I do know that I'm providing food sources and habitat for

organisms that may not survive if it wasn't for me. Lately I've taken to really watching hummingbirds visit my feeders while on their way south. I don't know how many hummingbirds have visited, but I do know those that have are in need of food. Watching them feed reminds me of the following, paraphrased from the Talmud, “Whoever saves one life saves the world entire.” It gives me some hope knowing that those small, feathered friends have a better chance of making it because of me.





## FUNDRAISERS

### Buck's Game

Buck's jerseys were auctioned off at the July 29th Pink Out Game and earned over \$3,000 for the Beyond Pink TEAM.

Survivor Christine Grimmeth threw the first pitch of the game. Read her story in the January 2023 Touch of Courage newsletter.



### CV Women Ride-Run event

The Spokes Women, Fearless Women of Dirt, Trail Sisters, and SingleSpeed Brewing were able to raise over \$221.65 for the Beyond Pink TEAM with the July 12th event. Here is a picture of all who participated, along with BPT representatives.



## UPCOMING EVENTS

For the month of October, round up your bill and support the Beyond Pink TEAM at the Cedar Falls Texas Roadhouse.



### BREAST CANCER AWARENESS BICYCLE AND MOTORCYCLE RIDE

to support the *Beyond Pink TEAM!*

**WEDNESDAY, OCTOBER 5**

Starting and ending at the Amvets Post 49  
Wheels down at 5:45 p.m.  
Potluck afterward

**Costumes encouraged – wear PINK!**

Suggested donation/registration is \$25, but every dollar helps.  
All proceeds go to the Beyond Pink TEAM.



### BEYOND PINK DANCE PARTY!!

Let's dance as one family for breast cancer awareness.

**DANCE PARTY LEAD BY:  
PENIE AALDERKS & KARYN ROBERT**

**OCTOBER 26, 2022 | 5:00-7:00PM  
CEDAR VALLEY SPORTSPLEX**

**\$5 SUGGESTED DONATION  
WALK UP REGISTRATION ONLY**

# 16<sup>TH</sup> ANNUAL PINK RIBBON RUN | 2022

## 2022 PINK RIBBON RUN SPONSORS

### FRIDAY, SEPTEMBER 30

3:00PM-7:00PM - Packet Pick Up

Community Main Street, 310 East 4th St., Cedar Falls

### SATURDAY, OCTOBER 1

#### PRE-RACE

6:30-7:30AM - Packet Pick Up

Community Main Street, 310 East 4th St., Cedar Falls

7:45AM - Survivor Photo

8:00AM - Welcome

8:05AM - Survivor Spotlight

8:15AM - Race Announcements

#### LINE UP

8:30AM - Race Start

#### POST-RACE

9:30AM - Thank you, Lisa's Story, Awards & Team Prizes

**All Pre- and Post-Race activities will take place  
at the River Place Plaza, 100 E 2nd St., Cedar Falls**

### Warrior



### Strength



### Courage



### Hope



### Faith

UnityPoint Health  
Cedar Valley Breast Care Center  
John Deery Motors  
The VGM Group  
PDCM Insurance  
Lincoln Savings Bank  
Advanced Heat Treat Corp.  
Kimball & Beecher Family Dentistry

### Support

Carolann Seeds  
Mudd Advertising  
Avalon Plastic  
Surgery Center

### In-Kind Donations

Transcend Defy Limits  
Urban Pie  
NuCara  
KJ & Kompany  
Here's What's Poppin  
Nagles  
PDCM

Community Auto Group  
Farmer Agency  
Bambino Cookies  
Pump Haus  
Martin Brothers  
Culligan  
Eagle View Hospitality Partners

Scoopskies  
Tea Cellar  
The Runner's Flat  
Get Roasted Coffee Company  
4 Queens  
George's  
Second State Brewing

## WHY IS VOTING IMPORTANT FOR BREAST CANCER?

You ask why is Voting so important? It is important because breast cancer is a political issue. Policy makers determine almost every aspect of breast cancer, such as funding for breast cancer research, access to quality care, and regulations affecting health care systems. That is why voting is so important to ending breast cancer.

Our elected officials are charged with making important breast cancer policy decisions every year. Before you vote on November 8, please consider how our Iowa Congressional delegation voted on important breast cancer issues.

Congressional Support	DOD Breast Cancer Research Program	Metastatic Breast Cancer Access to Care
Dist. 2 Ashley Hinson	No	No
Opponent-Liz Mathis	Yes	Yes
Dist. 4 Randy Feenstra	Yes	Yes
Opponent-Ryan Meltona	Yes	Yes
Senator Chuck Grassley	No	No
Opponent-Mike Franken	Yes	Yes

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

\* DOD BCRP - Signed or agreed to sign the Dear Colleague letter in support of the Department of Defense Breast Cancer Research Program for FY 2023.

\*\* Mets Access to Care - Cosponsored or agreed to cosponsor the Metastatic Breast Cancer Access to Care Act.



### WHERE THEY ARE NOW, CONTINUED FROM PAGE 2

a documentary about hip replacements and issues with the metal used causing cognitive challenges. I haven't had a hip replacement, but it did cause me to start looking at complications caused by breast implants. I read more about Breast Implant Illness (BII) and learned that the top symptom is "chronic fatigue." I began to research reliable websites and read about other symptoms, many of which I'm experiencing...hair loss, changes in skin, dry eyes, bone & joint pain, on and on. It was time to take the next step and speak with a breast surgeon about having the implant removed. November of last year I met with Dr McMahon who then referred me to a plastic surgeon for further consultation. I saw Dr Barnard and he agreed that the implant was causing a lot of issues. While neither surgeon would say my symptoms would go away if I had the implant removed, I was confident that my quality of life would improve with it out of my body. I was also tired of trying to make my breasts be similar in size/shape and always worrying about breast cancer recurring, so I decided to have a mastectomy of the remaining breast. On April 28, 2022, Dr Barnard and his team removed the breast implant, its capsule, and as much scar tissue as possible; then Dr McMahon and his team performed the mastectomy. I was excited and anxious at the same time!

Now that I am about 3 months out from that surgery, I know it was absolutely the right decision for me. My quality of life has improved incredibly. My energy is returning, my pain and range of motion is improving with Physical Therapy (I believe everyone having surgery would benefit from PT), my hair stopped falling out, I feel like myself again! I am back to yoga and Zumba and my attitude regarding a healthy lifestyle has returned!

**The most important "take-away" I want you to consider is that we must be our own advocate for ourselves and our bodies.** You are the only one who really knows your body and when something doesn't feel right, doesn't make sense, or you don't understand, ask questions! And do your research. Of course, it's important to use reliable sources but gather as much information you can and ask questions.

If I hadn't pursued more information about breast implants and their complications, I would still be dealing with chronic fatigue and all the other health issues. Being advocates for our own health journey is a vital part of living each day to its fullest!

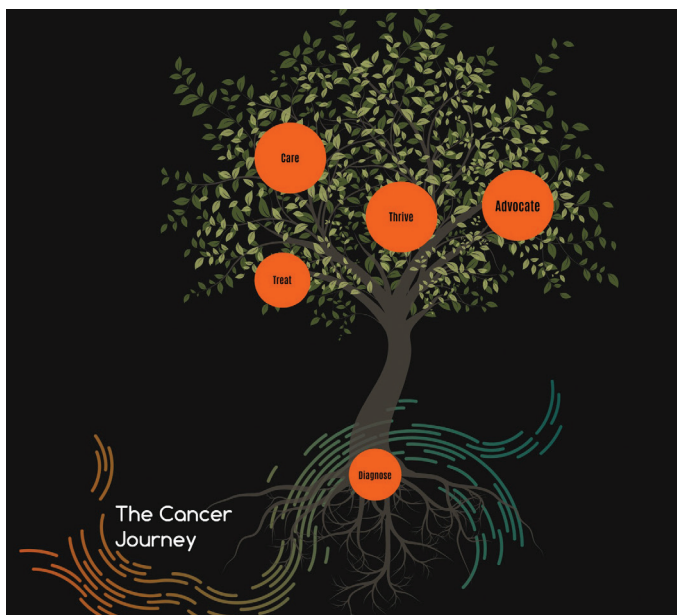
I love life, I love my family, I love hearing each of your stories. I wish you all the very best in your journey and I hope you won't be afraid to ask questions.



## THE CANCER JOURNEY

There are many reputable sources to go to for more information when a person is first diagnosed with cancer--but there are so many it can be overwhelming. Ignite the Cancer Conversation, Beyond Pink Team's advocacy and education arm, is preparing a resource that brings a visual order to these helpful information videos. Organized according to the journey from diagnose to treat, care, thrive, and advocate, this prez presentation allows people to move among various videos in which patients, medical experts, and caregivers share their experiences and advice. The videos are short, generally 3-5 minutes, and offer compassionate insights into the many questions people have and the resources available for help. Thumbnail pictures represent videos in each category. Some are offered in Spanish as well as English.

This central hub for information videos will be available from the Beyond Pink Team website later in the fall.



## DONATIONS

**DONATIONS AND MEMORIALS  
RECEIVED FROM JUNE 1, 2022  
THROUGH AUGUST 31, 2022**

### Donations

Anne Barloon  
Claludette Butler  
Jen Chase  
Dawn Del Carlo  
Pam Dowie  
Pat Homeister  
Christine Kaczmariski  
LPL Financial  
Taylor Risius  
Helen Steffen

### Memorials

*In Memory of Lisa Wilson*  
Anne Bader  
Bryan Destival  
Janet Destival  
Gladys Diehl  
Janet Erpelding  
Kelly Flege  
Melinda Pitt  
JoAnn Smith  
Rebecca Uhlenhopp  
Tracy Wilson

## 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.

**October 3, 1:30 pm**

**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 info & location

**October 4, 1:30 pm**

**Care & Share Cancer Support Group**

If meeting in person mask required  
MercyOne Cancer Treatment Center  
200 E Ridgeway Ave, Waterloo  
Jessica 319-272-2816 for meeting info

**November 1, 1:30 pm**

**Care & Share Cancer Support Group**

If meeting in person mask required  
MercyOne Cancer Treatment Center  
200 E Ridgeway Ave, Waterloo  
Jessica 319-272-2816 for meeting info

**November 7, 1:30 pm**

**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 info & location

**December 5, 1:30 pm**

**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 info & location

**December 6, 1:30 pm**

**Care & Share Cancer Support Group**

If meeting in person mask required  
MercyOne Cancer Treatment Center  
200 E Ridgeway Ave, Waterloo  
Jessica 319-272-2816 for meeting info

**January 2, 2023, 1:30 pm**

**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 info & location

**January 3, 1:30 pm**

**Care & Share Cancer Support Group**

If meeting in person mask required  
MercyOne Cancer Treatment Center  
200 E Ridgeway Ave, Waterloo  
Jessica 319-272-2816 for meeting info

**January 17, 2023, 4:30-7:00**


**BPT All Cancer Survivor Group**

If meeting in person mask required  
Cedar Valley Unitarian Universalists Church  
3912 Cedar Heights Drive, Cedar Falls  
Angela 319-231-3143 for info & location

# 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. [beyondpinkTEAM.org](http://beyondpinkTEAM.org)

 You can also find us on Facebook.

**Living Beyond Breast Cancer** includes a helpline, newsletter, and information. [LBBC.org](http://LBBC.org)  
Survivors Helpline: 888-753-5222

**Cancer Care** is a national nonprofit organization offering counseling, support, financial assistance, and education to individuals with cancer and their families. [cancercares.org](http://cancercares.org)

**Iowa Cancer Consortium** offers cancer information and links to resources in Iowa. [canceriowa.org](http://canceriowa.org)

**American Cancer Society** offers cancer information and services. [cancer.org](http://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. [stopbreastcancer.org](http://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](http://NCCN.org/patients)

**National LGBT Cancer Network** works to improve the lives of LGBT cancer survivors and those at risk. [cancer-network.org](http://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**. [cancer.gov](http://cancer.gov)

**National Cancer Institute** for NCI dictionaries of cancer terms, genetics terms, and cancer drugs. [cancer.gov/publications/dictionaries](http://cancer.gov/publications/dictionaries)

**Young Survival Coalition** connects with other young women diagnosed with breast cancer. [youngsurvival.org](http://youngsurvival.org)

**CancerChoices** is an independent, science-informed resource, helping you make sense of your choice in integrative cancer care. [cancerchoices.org](http://cancerchoices.org)

**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.

**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 3rd 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"/> Advocacy – Contact Congress/Ignite the Cancer Conversation  |
| <input type="checkbox"/> Development (Publicity)   | <input type="checkbox"/> Education (Health Fairs/Presentations, Newsletters)   |
| <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  |  |

Mail To:  
Cedar Valley Cancer Committee  
Dbas Beyond Pink TEAM  
3453 Kingswood Place  
Waterloo, IA 50701

Scan here for more information on the Beyond Pink TEAM.



**BeyondPinkTEAM.org**