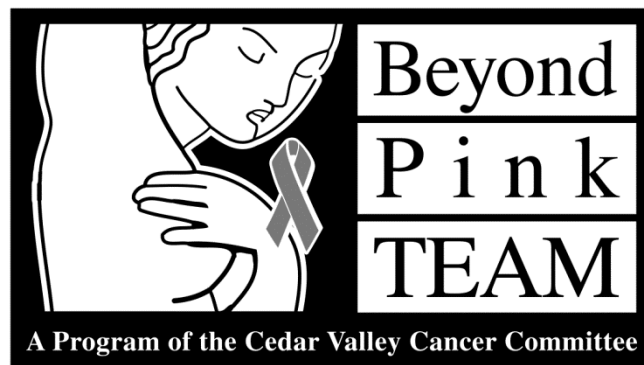


# Touch of Courage

. . . Connection

## October 2019



*Celebrating 30 years in the Cedar Valley*

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## Beyond BRCA Testing

By Jeanne Olson, R.N.

Genetic testing has expanded greatly in the past few years. BRCA1 & BRCA2 were the only genes tested for breast cancer in the past. Genetic testing panels are now standard. Only one out of ten (10%) women diagnosed with breast cancer have a genetic predisposition measurable by genetic testing.

Genes related to breast cancer development now include ATM, CDH1, CHEK2, PALB2, PTEN, STK11, TP53, NBN, NF1, in addition to BRCA1 & BRCA2. All of these genes have a different penetrance level, there are varying percentages of risk.

Cancer genetic panel testing also include the genes for cancers affecting colon/gastric, pancreatic, prostate, melanoma, ovarian/uterine and others. Most genes affect more than one body system.

The American Society of Breast Surgeons (ASBS) published a consensus statement this spring, stating all women with a diagnosis of breast cancer, regardless of age

should be genetically tested. For those women who were tested previously only for BRCA1 & 2, they should be offered updated panel testing. It is felt that of the 10% noted above, only half of those were being identified due to the restrictive insurance company policies.

Genetic testing is offered locally at the cancer treatment centers, as well as the breast centers, and some primary care offices. Samples of either blood or saliva can be submitted for DNA sampling.

If you were tested for BRCA1 & BRCA2 only in the past, check with your physician about having expanded panel testing.

Genetic testing results fall into three categories: A positive/pathogenic variant, a negative result and then variants of uncertain significance (VUS).

- For those with a positive/pathogenic variant, genetic counseling is recommended. Genetic counseling can be obtained by an in-person visit – typically in Cedar Rapids, Iowa City or Mayo Clinic.

*Continued on page 7, BRCA*

## *A Survivor Shares . . . I Cried, I Prayed, and I Listened*

*A survivor's story by Angela Hamilton*

My name is Angela Hamilton and I am a breast cancer survivor! My cancer was caught during a routine mammogram in July 2009. My next appointments were to have an ultrasound, biopsy, and a meeting with a surgeon. When I left that biopsy appointment, I could sense something was wrong and knew my life was about to change in a big way. But also knew that I had to keep my same routine so that I would not send shockwaves thru my family. See we had lost my mom to heart disease in 2001, my grandparents, a cousin and my dad to cancer in 2007. Too much loss and I wasn't ready to accept cancer into my family again.

Well, I did hear those dreaded words – “You have cancer.” I cried, I prayed, and I listened. During the time between my diagnosis and surgery I would take walks on the bike trail and one day as I was walking, I stopped at the bench my neighborhood had place in memory of Michelle Friedley. As I sat on that bench, I cried, I prayed, and I listened. It was at that point that I knew I had to be strong – not just for me but to prove to my kids that cancer was not a death sentence and I would beat this!

I had surgery followed by 37 radiation treatments. I did genetic testing and Oncotype DX testing to help determine if chemotherapy was needed – although no cancer was found in my lymph nodes, chemotherapy was still a possibility. Once again, I returned to that bench – to cry, to pray, and to listen. I decided no to the “traditional” chemotherapy and entered a clinical trial. During all of this I relied on the

support of my family and friends to help me get thru the physical aspects of this disease and its treatments.

I have the best support system – a patient and loving husband, two awesome kids, extended family, great friends, neighbors, and co-workers already to lend a hand. My friends organized meals and kept me exercising to fight against the fatigue. My co-workers were there to let me cry when I needed and to dig into my workload for me. I even had a friend tell me that if I had to lose my hair, the she would too – lucky for her I didn't go that route!!

Even with all these amazing people surrounding me I still felt lonely. Once again, I returned to the bench – to cry, to pray, and to listen. I had heard about the Beyond Pink TEAM, Touch of Courage, and the Young Cancer Survivors while going through radiation treatments but knew I wasn't ready at that time to share my story. I was still trying to accept and understand the diagnosis myself. I started reading and learning as much as I could and while reading, “Dear God They Say Its Cancer”, by Janet Thompson, I realized I needed the emotional support that could only come from someone who had heard those dreadful words.

So, in January 2010, I attended my first Touch of Courage support group and my first Young Cancer Survivors – both times shaking in my shoes and emotional. What I soon realized was that even though our stories may be different, the theme is still the same – lives interrupted, sleepless nights, racing minds and a “sisterhood” that I

really didn't understand until it became my own. Now I make it a priority to attend those meetings – partly to share my story and experiences but more in the hopes that it will help just one other person to get out of the loneliness of a cancer diagnosis and to keep learning.

I continue to return to that bench – sometimes to cry, but more to pray and to listen these days. Thank you to all who show support for those battling, those we've lost, and for your support of the Beyond Pink TEAM. Without them and the ladies in the Touch of Courage and Young Cancer Survivors, I think I would still be searching. Thanks to them I know that as I continue with my journey and survivorship I don't ever have to feel alone.

The bench Angela mentions is in memory of Michelle Friedley. In 2006, the Cedar Falls downtown merchants and Community Main Street held the first Pink Ribbon Run in honor of Michelle. Her mother, Pam Dowie suggested funds raised be donated to the Beyond Pink TEAM.

Pam had been attending Beyond Pink TEAM meetings, learning more about the organization and sharing Michelle's story and a need for a support group for young mothers and working women. Because of a need and a suggestion, the 13<sup>th</sup> Annual Pink Ribbon Run will be held on October 5.

# Activities - Events - Fundraisers

## Supporting the Beyond Pink TEAM



### Presenting Sponsors



Get your running shoes ready for the **13<sup>th</sup> Annual Pink Ribbon Run on Saturday, October 5!** For the 5<sup>th</sup> year, Oakridge Realtors and GreenState Credit Union (formerly University of Iowa Community Credit Union) are the Presenting Sponsors.

Breast cancer survivors are invited to participate with their registration covered by Community Auto Group, the Survivor Sponsor. A survivor group photo will be taken just prior to the run. Last year there were over 130 survivors celebrating 750 years of survivorship.

Here is the schedule for the event – All are held at the Cedar Falls Community Center

#### Friday, October 4

4:30-7:00 p.m. Packet Pickup – Day of Registration

#### Saturday, October 5

7-8 a.m. Day of Registration – Check-in – Packet Pickup

8:00 a.m. – Survivor Photo

8:15 a.m. – Opening Ceremony with Testimonials

8:30 a.m. – Race Begin

9:30 a.m. – Refreshments & Coffee – Door Prizes – Race Results – Awards

**LeRoy's "Keep the Cups Full"**  
benefit for the Beyond Pink  
TEAM. Festivities will be  
**October 12 & 13 in Aurora, IA.**

Watch for details on Facebook,  
Beyond Pink TEAM website,  
[www.beyondpinkteam.org](http://www.beyondpinkteam.org).



**Join the Waterloo Blackhawks**  
**November 15 & 16**  
for their annual **Pink Out**

**50/50 Raffle both nights**

**Auction of the hockey jerseys**  
– **Saturday night**

### 2019 Fishing For A Cure

October 13 and 14  
Lynxville, WI at Hoochies 2

7 am to 3:30 pm Sunday, Oct 13

7 am to 2:30 pm Monday Oct 14

Entry Fee - \$50 per person

Entry Deadline Monday, October 7

For more information call Bob Goodrich at 715-  
699-1141 or email [Kevin@ModernIowa.com](mailto:Kevin@ModernIowa.com)

### BREAST CANCER AWARENESS RIDE

To support the Beyond Pink TEAM

**Wednesday, October 2**

Wheels down at 5:45 pm  
from SingleSpeed – Waterloo

Wear **PINK**



Suggestion donation/registration \$25,  
but every dollar helps and stays in the Cedar Valley.



## 8<sup>th</sup> Annual 3K Walk/Run Fundraiser

Saturday, October 12

Sullivan Park, Waterloo

Registration begins at 8:00 a.m.  
or

Register online at  
[getmeregistered.com/Splashofcolor](http://getmeregistered.com/Splashofcolor)

For more information contact:  
Cathy Ketton – 319.233.2819 or  
[splashofcolor3\\_wloo@yahoo.com](mailto:splashofcolor3_wloo@yahoo.com)

## Thank You Donors!!!

The Beyond Pink TEAM would like to thank the following individuals, organizations, businesses, and groups for their donations from June 1, 2019 through August 31, 2019. Your generosity, no matter the size, is greatly appreciated.

Beecher Law Firm  
Cedar Falls Community  
Main Street  
Isle Casino – Waterloo  
Jeanne Olson  
Sydney Payton  
Post 49 Junior Amvets  
Cheryl Thayer  
UNI Department of Residence  
Visions Salon  
Robert & Jammi Welter

## FREE Mammograms!

Mammograms can be a life-saving screening. For those without insurance, the cost can be prohibitive.

MercyOne of Northeast Iowa will be offering free mammograms to women 40 and older who have cost-barriers to receiving a yearly mammogram. The hospital has partnered with the Black Hawk County Health Department's Care for Yourself program, MercyOne Waterloo Foundation and Check the Girls Foundation to make the "Free Mammo Nights" financially possible.

Appointments are required for the free mammograms since there are a limited number of openings available. People should call 319-292-2225 to find out more and to schedule.

### WHERE:

Waterloo Breast Center (formerly Covenant Breast Center) at MercyOne: Thursday, October 24, 3:30-8:00 p.m.

Cedar Falls Medical Center (formerly Sartori Hospital): Thursday, November 7, 1:00-7:00 p.m.

Transportation can be provided upon request.

**Bambinos**, a sweet, fluffy cookie creation is now offered locally at Hy-Vee, College Square. A portion of the sales comes to the Beyond Pink TEAM. Enjoy a treat and help the BPT!



## Support Group Dates

**October 1, 1:30 p.m.**

**Care & Share Cancer Support Group**

Covenant Cancer Treatment Center

200 E Ridgeway Ave., Waterloo

Jessica – 319-272-2816

**October 7, 1:30 p.m.**

**Touch of Courage**

**Breast Cancer Support Group**

2101 Kimball Ave., Bd Rm, Waterloo

Pat – 319-232-8691

**November 4, 1:30 p.m.**

**Touch of Courage**

**Breast Cancer Support Group**

2101 Kimball Ave., Bd Rm, Waterloo

Pat – 319-232-8691

**November 5, 1:30 p.m.**

**Care & Share Cancer Support Group**

Covenant Cancer Treatment Center

200 E Ridgeway Ave., Waterloo

Jessica – 319-272-2816

**December 2, 1:30 p.m.**

**Touch of Courage**

**Breast Cancer Support Group**

2101 Kimball Ave., Bd Rm, Waterloo

Pat – 319-232-8691

**December 3, 1:30 p.m.**

**Care & Share Cancer Support Group**

Covenant Cancer Treatment Center

200 E Ridgeway Ave., Waterloo

Jessica – 319-272-2816

**January 6, 1:30 p.m.**

**Touch of Courage**

**Breast Cancer Support Group**

2101 Kimball Ave., Bd Rm, Waterloo

Pat – 319-232-8691

**January 7, 1:30 p.m.**

**Care & Share Cancer Support Group**

Covenant Cancer Treatment Center

200 E Ridgeway Ave., Waterloo

Jessica – 319-272-2816

**January 21, 4:30-7:00 p.m.**

**Young Cancer Survivors –**

**Meet, Mingle and Learn**

Cedar Valley Unitarian Universalist

3912 Cedar Heights Dr., Cedar Falls

Gabbi – 319-292-2225

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

Community support and resources available  
Upon request

Cathy – 319-504-2703 for details



## Living Green

By Patty Wandschneider



### Non-toxic Homemade Deck Cleaner

#### Ingredients/items you will need:

Oxygen Bleach (e.g. Oxi-Clean\*)  
Water  
Bucket  
Deck brush

Mix about ½ cup of oxygen bleach with 2 gallons of warm water in a bucket until it dissolves. (More may be needed for larger decks.)

#### DIRECTIONS

1. Before applying DIY deck cleaner, rinse off and soak the deck with water to open the wood pores and make it easier to get rid of the dirt. This will also help to clean out any debris that may have gathered in the cracks between the boards.
2. Spread the oxygen bleach solution on the deck with the scrub brush.
3. Use a deck brush to spread the oxygen bleach cleaning solution over the deck. If your deck has a pretty thick layer of dirt and algae, you'll need to scrub a little to get it into the grooves.
4. Leave the solution on the deck for about 10 minutes.
5. Then wash it off with the hose or power washer. You can see the green coming off with the water! You may need to give a second treatment if you have some real dirty spots,

**NOTE** – This oxygen bleach cleaner also works well on patio furniture, siding, wood or poly-vinyl fences and pretty much any other outdoor surface that needs to be washed.

Works best on a not-too-hot, not-too-sunny day so that the water doesn't dry up before you have a chance to finish. If you have a large deck, you may want to clean sections of it at a time to make sure the oxygen bleach solution doesn't dry on the boards (it's not the end of the world if it does...it'll just mean more work for you to get it off).

## Ignite Rethinks Cancer

In 2016, members of the Beyond Pink TEAM along with sponsoring organization, hosted "Ignite the Cancer Conversation" - a discussion from awareness and early detection, to developing concrete steps to end ALL cancers event.

Today, Ignite's mission is – "To ignite the cancer conversation by going beyond discussions limited to awareness, early detection, and treatment." Below are ways you can be a part of the new mission.





## Where They Are Now!

## ROAD RACERS by Lynne Peters

*"The person who starts the race, is not the same person who finishes the race."*

*Unknown*

January 31, 2011 was the day I heard the words, "You have breast cancer." This was the proverbial gun shot that started a race that I never dreamed I would be running. And if you are reading this, it is likely that you or someone you love has found themselves off and running the same race I continue to compete in. Bilateral mastectomy two weeks after the diagnosis. Six months of chemotherapy. A year of 'no hair' days. Two years of occupational therapy due to lymphedema in my hand and arm. Continued daily compression apparel. Frequent follow-up appointments with doctors. Regular decisions about long term treatment and prevention. Constant coping with the effects and side effects of these decisions and experiences. Yes, this marathon was unexpected. Yes, this marathon was unwanted. Yes, this marathon seems unending. But despite all the physical and emotional fatigue, the slow and climbing hills, the frequent detours, the painful sores, the pounding exhaustion, and the stressful potholes along this racecourse, I can honestly say that I am truly grateful to still be running!

Every mile has taught me valuable life lessons that I might not have ever experienced had I not started running. The race has changed me and allowed me to truly see and value the important things in life. It has deepened my faith and allowed me to trust God to guide my steps no matter where they lead. I have heard His words speak to me through Scripture and the uplifting music

ministry of Life 101.9 on the radio. I have experienced the peace that passes understanding and been encouraged by the unexplainable power of prayer. The race has strengthened my marriage and has allowed me to feel the joy and outpouring of love and support from my family, friends, co-workers, neighbors, and my church family. And I continue to feel privileged to have run alongside some of the world's finest "athletes."

The journey has taught me more than I could ever describe in this article, but whether you are starting the race or you have been running it for a while, I hope you will allow me to share a HIGH FIVE with you that other runners have shared with me as I have forged ahead!

1. Keep your eyes fixed on the One who feels your pain and ask Him to run with you! He can and will open your eyes to see His presence and power all along the course.
2. Receive any assistance that you are offered. Just like when the race workers and volunteers offer marathon runners refreshing cups of water and potassium-filled bananas at each mile marker, be willing to accept the help of others! The most successful runners have a supportive team caring for their needs and cheering them on!
3. Train yourself to take one day at a time! The journey can and will seem daunting if you look too far ahead or if you do not pace yourself. Give

yourself permission to stop and walk along the way!

4. Allow yourself to look back at the distance you have traveled! Yes, it may remind you of your pain, your weaknesses, and your failures, but it will also remind you of all the obstacles you have overcome and all the blessings you have encountered. If you need help remembering, keep a running log! It will help you remember the journey and may someday offer hope or inspiration for any new runners entering the race.

5. Be encouraged to ask the advice of veteran runners. Even professional runners need coaching advice and a shoulder to lean on. This is especially important if you start to feel that you are the only runner in the race! We are all in this together! You can do it! Just keep putting one foot in front of the other! That's called progress!

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### Look Good...Feel Better will be back in January!

The Look Good...Feel Better program will be offering 4 sessions next year. The first session will be in January. Call Jessica at 319-272-2816 for dates and how to register.

The sessions are taught by professional cosmetologists and offer cancer patients the opportunity to learn how to overcome hair loss, eyebrow and eyelash loss, and skin changes. Yes! You will look good and feel better about yourself during your cancer journey.

BRCA, continued from page 1

The Genetic testing companies may also offer genetic counseling via phone with a certified genetic counselor.

- A negative result is reassuring, but it doesn't mean the patient is "off the hook" for developing any of the cancers affiliated with the genes tested, but it does mean the patient does not have a genetic predisposition to that cancer development.
- VUS – variant of uncertain significance is essentially a negative report. These variants are not actionable. VUS are followed by the genetic testing companies and over time, some of these will be upgraded to a positive/pathogenic variant, others may be downgraded to negative. When there are changes to a VUS, the ordering physician is notified. That provider's office will notify the patient of the change.

Inheriting a positive/pathogenic variant, for many of the common cancer genes, is a 50/50 chance. If a patient is negative, her children are negative. If a patient is positive, her children would have a 50% chance of also having the same gene mutation.

Costs have decreased dramatically as well. \$4,000 was a commonly billed amount in the past. Some companies will provide testing for \$250 or possibly less. There is significant market share competition with the various testing companies, each have their own offers.

Health insurance providers are

prohibited by law from discriminating against patients with a pathologic genetic variant. This same protection is not available for life, disability and long-term care insurance. When a patient is seeking genetic testing and has not had a cancer diagnosis, it is recommended they have these insurance policies in place before testing. Not disclosing genetic testing results on applications is fraud, a criminal offense.

There are reports of Medicare fraud, where patients are contacted unsolicited, usually by phone, telling them because they have had breast cancer, they can be tested from home. These fraudulent callers already have the patient's Medicare number and other demographic information. If the patient agrees, a kit is sent to them, once returned, some do get a report. But there are instances of Medicare paying for the testing, but the patient never receiving a report. The Office of Inspector General (OIG) has open cases regarding this fraudulent activity, including locally.

The recommendation is to always have your testing with a medical provider. Do not accept phone calls offering testing. The genetic/ancestry testing that is commercially available is also not recommended as those labs are not accredited with Clinical Laboratory Improvement Amendments (CLIA).

To read the complete consensus statement of the American Society of Breast Surgeons (ASBS) issued this spring can be found at <https://www.breastsurgeons.org/docs/statements/Consensus-Guideline-on-Genetic-Testing-for-Hereditary-Breast-Cancer.pdf>

## Root Honors Breast Cancer Awareness Month

Eco beauty company, Root, raises awareness for breast cancer with a donation of 1% of sales in October to Beyond Pink TEAM. In addition, a new breast cancer inspired collection, "The Beyond Pink" collection will be launched.

Root was founded in 2013 to provide eco-friendly beauty and lifestyle products at an affordable price. They are located at 100 E Bremer Avenue, Waverly.



Attend an area Health & Wellness Fair and check out the Beyond Pink TEAM table. See what is new in research, learn about various support groups, and test your knowledge about breast cancer.

### October 9 – UNI Wellness Fair

11:30 a.m.-2:30 p.m.

Maucker Union, UNI Campus  
Cedar Falls

### October 30 – Hawkeye Community College Health Fair

11:00 a.m.-1:00 p.m.

Health Education & Services Center  
Hawkeye Campus



**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](http://www.beyondpinkTEAM.org)

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

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

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

**American Cancer Society** offers cancer information and services. [www.cancer.org](http://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.breastcancerdeadline2020.org](http://www.breastcancerdeadline2020.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. [www.cancer-network.org](http://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](http://www.cancer.gov)

**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. |                                       |
| <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 – Deadline 2020/Ignite the Cancer Conversation   |                                       |
| <input type="checkbox"/> Events (Fundraisers, Projects and More)  |  |                                       |
| <input type="checkbox"/> Make a donation. 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  
1753 W Ridgeway Ave, Suite 104  
Waterloo, IA 50701  
[www.beyondpinkteam.org](http://www.beyondpinkteam.org)