



# Touch of Courage . . . Connection

## July 2014

TAKING ACTION – EDUCATING – ADVOCATING – MAKING A DIFFERENCE

IN THIS ISSUE

## Cancer Risk and Genetic Testing

Kim Maxfield, RN, *Clinical Research Coordinator Covenant Clinic*

Both men and women are capable of having a mutation in the BRCA1 or BRCA2 genes.

BRCA 1 and BRCA 2 are human genes that produce tumor suppressor proteins. When either of these genes is mutated or altered, the cells are more likely to develop additional genetic alterations that can lead to cancer. Both men and women have an increased risk of breast cancer if they have this mutation and each have an increased risk of additional types of cancer.

BRCA 1 and BRCA2 mutations account for about 20 to 25 percent of hereditary breast cancers and about 5 to 10 percent of all breast cancers. They also account for about 15 percent of ovarian cancers. These mutations can be inherited from a person's mother or father. Each child of a parent that carries the gene mutation has a 50 percent chance of inheriting the same mutation. Women also have a higher risk of developing fallopian tube cancer and peritoneal cancer if they have the mutation. Men who have the mutation are at an increased risk of breast cancer and also have a higher risk of prostate cancer. Both men and women have a higher risk of pancreatic cancer.

These mutations are relatively rare in the general population so testing should only be done when a person's family history suggests the possibility of a genetic mutation. Some things that are assessed include:

- Breast cancer diagnosed before age 50
- Cancer in both breasts
- Both breast and ovarian cancers
- Multiple breast cancers
- Two or more primary types of BRCA1 or BRCA2 related cancers in a single family member
- Cases of male breast cancer
- Ashkenazi Jewish ethnicity

It is generally recommended that a person talks to a health care professional that is experienced in cancer genetics to discuss risks, medical implications of test results, psychological risks and benefits, the risk of passing a mutation to children and an explanation of the specific tests that may be used. Testing is done by collecting blood or saliva for a DNA sample. This sample is sent to a laboratory and takes about a month to receive results.

*Continued on page 2, column 3*

### A Survivor . . . That's Me!

A survivor's story - page 2

### Healthy Eating

Page 2

### BPT Annual Celebration

Page 3

### Local Breast Cancer Advocates Push Forward for Deadline 2020

Pages 3

### Upcoming BPT Events

Page 3

### Support Group Meeting Dates

July – August – September – October

Page 4

### Community Fundraisers Support BPT

Page 4

### Go Green!

Page 5

### A Gift

Page 5

### Resources

Organizations for support and education

Page 6

### Volunteer Opportunities

Page 6

# Survivor . . . It's Me!

JoAnne VanCleave

My cancer came as a complete surprise. And, as with so many things in my life, the Lord was there to help with the discovery! I had broken my back in three places, the back brace I was wearing was complicated and heavy and instead of being therapeutic it caused pain in my left breast. Had it NOT hurt I may still be unaware that I had breast cancer. I had a mammogram 3 years before my back injury which was negative, and I had not felt any lumps. More amazing the tumor was estimated to be at least 8 years old after its removal. So, yes. I was surprised.

I had a caring dedicated staff, who did all they could with dedication and smiles, and a loving supportive family, and I had treatments. Never-the-less 3 years later, it returned and I had to have both breasts removed. So it was the same old, same old, and more treatments.

Even the word cancer can zap your strength and erase your faith if you let it. It's a hard word to hear and to bear. And I think for all the courage and bravery we try to show others, it is just a good front. We easily slide into an uncomfortable state of mind that is so negative and overwhelming, our minds won't allow us to grasp the fact we can beat this or even work around the condition. It is a distressing, depressing, devastating, discouraging disease and it is always in the back of our mind, hardly ever forgettable.

It took awhile for me to adjust to having cancer. But, life helps too, the days go by and we are not alone in this. There are all kinds of organizations, volunteers, different groups that want to help. You can decide to fight, determination is as good as medicine sometimes. We find new friends we can help, we have our old friends that help us, we find new therapies, new treatments, we find our faith again and health after that. Our spirits become stronger.

In my case I have found a stronger person inside than I thought I could be.. I found you can go out of the house without hair or eyebrows or breasts!!!! and not feel any the less a woman. There are beautiful things to see and lovely people to meet. There is always someone that needs a smile. It is so

important to give a kind word or just listen. The start of the disease is the hardest part, the acceptance, if I can let others know there is a future, sometimes a more fulfilling one than we could imagine I feel maybe I have helped just a little bit. We all need support and I can remember another patient telling me about their day and how grateful they seemed to be able to live it, just that sentence made a difference to me.

So, once again, I am a three year survivor. A survivor is one who **outlasts** a situation, **endures**, **hangs on**, **persists**, **pulls thru** and **LIVES. That's ME!!**

## Healthy Eating

### Fruit Pizza

*Iowa State University Extension & Outreach*

For the cookie crust:

- 1 large egg white
- ¼ cup vegetable oil
- ¼ cup brown sugar, firmly packed
- 1/3 cup all-purpose flour
- ¼ teaspoon ground cinnamon
- ¼ teaspoon baking soda
- 1 cup uncooked quick-cooking oatmeal
- Cooking spray

For the topping;

- 3 ounces fat-free cream cheese, softened
- ½ (6-ounce) container nonfat vanilla yogurt
- Fruit for topping

Instructions:

- Preheat oven to 375 degrees F.
- Beat egg white until foamy, all oil and sugar, beat until smooth.
- In separate bowl, stir together the flour, cinnamon and baking soda. Add to the sugar mixture. Stir in oatmeal.
- Line a baking sheet with aluminum foil and spray with cooking spray. Spread dough in a 9-inch circle.
- Bake about 12 minutes. Crust will begin to puff but does not look done. Remove from oven and cool about 20 minutes. (Crust continues to cook while cooling.)
- In a small bowl blend until smooth the cream cheese and yogurt. Cover and refrigerate until cold.
- Transfer crust to serving plate, spread cream cheese mixture and top with fruit. Cut into wedges and serve, or refrigerate up to 2 hours covered and uncut.

*Continued from page 1*

For people with positive test results, there are many options available for managing their cancer risk.

-Enhanced screening which includes clinical breast examinations beginning at age 25 along with yearly mammograms and possibly breast MRI. Transvaginal ultrasounds and blood tests to help detect ovarian cancer. Men may also benefit from regular mammography and testing for prostate cancer.

-Prophylactic risk-reducing surgery. This may involve having both breasts removed in women and also surgery to have the ovaries and fallopian tubes removed.

-Chemoprevention is the use of drugs, vitamins or other agents to reduce the risk of or delay the recurrence of cancer. There are two drugs that have been approved by the FDA to reduce the risk of breast cancer in women at increased risk of cancer but the effect on women with the mutated gene is not yet clear.

Studies are currently being conducted to fine new and better ways to detect, treat and prevent cancer in people who carry the gene mutation. Knowledge in these areas are growing rapidly are constantly evolving.

For any questions or concerns about your risk please discuss with a healthcare professional.

## Annual Celebration of Beyond Pink TEAM Accomplishments



Each year, the Beyond Pink TEAM (BPT) honors breast cancer survivors, BPT volunteers and recognizes the various community groups, organizations, businesses and individuals who have generously supported the BPT. This year's celebration will be Thursday, November 6 from 5:00-6:30 p.m. at Sunnyside Country Club.



## Local Breast Cancer Advocates Push Forward for Breast Cancer Deadline 2020

How can one person influence the decisions made by members of Congress? How can one person make a difference in the battle against breast cancer? The answer to both questions is, "Become part of something bigger than yourself." That is exactly what four Beyond Pink TEAM members did in early May. Christine Carpenter, Cathy Ketton, Kristin Teig Torres, and Lori Seawel attended the Breast Cancer Deadline 2020 Advocate Leadership Summit in Washington, D.C.

At the Advocate Leadership Summit, attendees from across the country and across the ocean gathered together to:

- Network with the most highly-committed and motivated group of leaders ever assembled in the world of breast cancer.
- Interact with scientists, thought leaders, innovators and visionaries in small, intimate groups.
- Get dynamic world class, advanced leadership training.
- Hear about research on prevention and breast cancer metastasis as well as on cutting edge topics in the areas of systems change and health care delivery.
- Understand our country's Administration and Congress in preparation for Lobby Day.
- Learn best practices from other leaders who are implementing their state and individual action plans.
- And develop NBCC's grassroots strategic planning for year five of Breast Cancer Deadline 2020.

On Day 1, advocates participated in an innovative exercise on creativity designed to stimulate, challenge and inspire their thinking as they shared their thoughts on key areas of focus to be implemented in NBCC's strategic plan for year five of Breast Cancer Deadline 2020.

Day 2 sessions provided advocates with an insider's view of the research taking place on prevention and breast cancer metastasis through the Artemis Project as well as NBCC's progress on its public policy agenda. Participants heard directly from the researchers who are driving crucial scientific projects to advance our knowledge about breast cancer so we will know how to end the disease by January 1, 2020.

Day 3 included a special focus on public policy—understanding the Administration and Congress with dynamic political discussions, mobilization training workshops, and state delegation meetings.

The advocates' fourth and final day in Washington, D.C. was spent on Capitol Hill. Along with other Breast Cancer Deadline 2020 advocates, representing most of the states in the Union, these Beyond Pink TEAM members took their grassroots advocacy efforts to the doors of the nation's decision makers, providing an update on Breast Cancer Deadline 2020 and other public policy priorities of the National Breast Cancer Coalition of which the Beyond Pink TEAM is an organizational member. Advocates asked their senators and representatives to support The Accelerating the End of Breast Cancer Act and the Department of Defense Breast Cancer Research Program. Since Iowa's congressmen have been very supportive of these priorities, the team asked them to reach out to their colleagues. In addition, advocates were very active in tweeting about and to members of Congress to spread the news and encourage others to get on board.

You can play a role in bringing an end to breast cancer. Join the Iowa Breast Cancer Deadline 2020 Action Network. The purpose of this group is to engage all interested Iowans in advancing the mission of knowing how to end breast cancer by January 1, 2020. The National Breast Cancer Coalition (NBCC) has a strategic plan to achieve this mission. The Beyond Pink TEAM and the Iowa Breast Cancer Deadline 2020 Action Network have teamed with NBCC in this mission. Are you with us?

Visit [www.facebook.com/groups/217433641780809](http://www.facebook.com/groups/217433641780809) and click the "Join Group" button.

For more information about:

**The Artemis Project:**  
<http://www.breastcancerdeadline2020.org/about-the-deadline/artemis-project.html>

**DOD BCRP:**  
<http://cdmrp.army.mil/bcrp>

## The Accelerating the End of Breast Cancer Act:

[www.breastcancerdeadline2020.org/get-involved/public-policy/legislative-and-pp-priorities/priority-1.html](http://www.breastcancerdeadline2020.org/get-involved/public-policy/legislative-and-pp-priorities/priority-1.html)

**Breast Cancer Deadline 2020 and the National Breast Cancer Coalition:**  
[www.BreastCancerDeadline2020.org](http://www.BreastCancerDeadline2020.org)



*Beyond Pink TEAM members attending the Advocate Leadership Summit in Washington, DC this past May – Lori Seawel, Cathy Ketton, Christine Carpenter, and Kristen Teig-Torres.*

## Upcoming Events . . . . .

Join in the fun and support these upcoming fundraisers to benefit the Beyond Pink TEAM.

**Saturday, August 23 – 1<sup>st</sup> Annual Kathy Bunger Memorial Benefit Ride** – 10:00 a.m.-10:00 p.m., NCC Pavilion

**Saturday, October 4 – Pink Ribbon Run** – Cedar Falls Community Center, 8:00 a.m., registration at [www.trekmanracing.com](http://www.trekmanracing.com)

**Saturday, October 11 – Splash of Color Walk** – Sullivan Park, Waterloo, 7:30 a.m., registration info at [www.beyondpinkteam.org](http://www.beyondpinkteam.org)

## Support Group Meeting Dates

**July 1, 1:30 p.m.****Care & Share Cancer Support Group**

Covenant Cancer Treatment Center  
200 E Ridgeway, Waterloo  
Jeanne – 319-272-2816

**July 7, 1:30 p.m.****Touch of Courage****Breast Cancer Support Group**

2101 Kimball Ave, Waterloo  
Pat – 319-232-8691

**August 4, 1:30 p.m.****Touch of Courage****Breast Cancer Support Group**

2101 Kimball Ave, Waterloo  
Pat – 319-232-8691

**August 4, 4:45-6:45 p.m.****Grundy Area Cancer Support Group****Support for ALL cancers**

Grundy County Hospital – Grundy Center  
Kristi – 319-824-4129

**August 5, 1:30 p.m.****Care & Share Cancer Support Group**

Covenant Cancer Treatment Center  
200 E Ridgeway, Waterloo  
Jeanne – 319-272-2816

**August 11, 1:30-3:30 p.m.****Look Good...Feel Better****Hair-Make-up-Nails-Skin**

Covenant Cancer Treatment Center  
200 E Ridgeway, Waterloo  
RSVP – ACS at 319-234-0990

**August 14, 5:00-7:00 p.m.****Splash of Color – Women of Color****Breast Cancer Support Group**

Waterloo Public Library, Waterloo  
Cathy – 319-493-8857

**September 2, 1:30 p.m.****Care & Share Cancer Support Group**

Covenant Cancer Treatment Center  
200 E Ridgeway, Waterloo  
Jeanne – 319-272-2816

**September 8, 1:30 p.m.****Touch of Courage****Breast Cancer Support Group**

2101 Kimball Ave, Waterloo  
Pat – 319-232-8691

**September 16, 4:30-7:00 p.m.****Young Cancer Survivors****Meet – Mingle – and Learn**

Unitarian Universalist Church  
3912 Cedar Heights Dr., Cedar Falls  
Gabbi – 319-292-225

**November 13, 5:00-7:00 p.m.****Splash of Color – Women of Color Support Group**

Waterloo Public Library, Waterloo  
Cathy – 319-493-8857

**Looking for a Speaker . . .**

If you are interested in having a Beyond Pink TEAM representative speak at your Church, organization or group, please contact Lori Seawel at [lori.seawel@uni.edu](mailto:lori.seawel@uni.edu).

**Want to do a Fundraiser for BPT. . .**

If you would like to host a fundraiser to benefit the Beyond Pink TEAM, please contact Marty Mullnix at [mapanix@cfu.net](mailto:mapanix@cfu.net)

**Volunteer for BPT . . .**

If you are interest in volunteering for the Beyond Pink TEAM, please visit our website at [beyondpinkteam.org](http://beyondpinkteam.org) or contact Jessica Miller at [jmiller1321@gmail.com](mailto:jmiller1321@gmail.com)

**Breast Cancer Awareness at the Ballpark – July 20th**

The Buck's Organization held its first Breast Cancer Awareness Night at the Ballpark with rain stopping the game. Even though the game was made up the next night, the Bucks will be hosting a 2<sup>nd</sup> Night for the BPT on Sunday, July 20, with first pitch at 3:35 p.m. The team will be wearing PINK game jerseys which will be auctioned off after the game. Proceeds will go to BPT. Join in the fun at this "Family Fun" Day at the Ballpark.

**COMMUNITY SUPPORT OF BPT MISSION CONTINUES WITH FUNDRAISERS**

The Allen Student Radiology Organization (ASRO) recently donated to the Beyond Pink TEAM with proceeds from the t-shirts fundraiser they held during the past school year. Students pictured are: (L/R) Sue Robinson (ASRO advisor), Jennifer Apple, Dee Hughes (BPT representative), Chelsea Gilbert, Stephanie Boecenstedt.



Emily Parks (pictured) and the North East Iowa Saddle Club Association (NEISCA) held their "Pretty In Pink" Horse Show in June. Proceeds from their auction will benefit BPT. Emily is a breast cancer survivor and wanted to give back to the community. Hats Off to her!



Jackie Morgan and her Go Getters held a garage sale in June with proceeds benefiting the BPT. Jackie has seen the need for support and likes that the funds she raised will stay right here in the Cedar Valley helping breast cancer survivors.

# Go GREEN !

By Cindy Harris, a Survivor



## Sunscreen Dangers!

The concept of sunscreen sounds good but with all of the chemicals in most sunscreens you realize these sunscreens should be avoided. One way to do this is to wear light weight cotton long sleeved shirts. They are light and airy and can protect skin from sun damage. This type of clothing is common in countries closer to the equator.

In the United States, we use more sunscreen and do a lot more artificial tanning with beds and spraying than other countries, but the United States still has one of the highest skin cancer rates? Since our government does not require all ingredients to be listed on our health and beauty products, you usually don't even realize some of the harmful chemicals in sunscreen. What's the answer? Make your own. This is not waterproof so it needs to be reapplied after sweating a lot or swimming.

### Sun Screen -

1/3 cup coconut oil, (externally good for you as well as internally)

6 teaspoons zinc oxide

1 Tablespoon natural aloe vera gel

7 large lettuce leaves

3 capsules vitamin E oil

Unscented lotion (best to make your own)

Heat the coconut oil, zinc oxide & aloe gel in small sauce pan. Place over stove medium temp until mixture begins to simmer. Remove & stir or whisk. Combine heated mixture with lettuce leaves & vitamin E oil into a blender or food processor. Chop contents so the lettuce breaks apart in smaller pieces & blend on high to liquify or puree. Thicken sunscreen by adding unscented lotion, continue to blend. Add a little bit of the lotion at a time to avoid making the sunscreen too thick. Pour into plastic bottle for storage.

To use rub into your skin. The sunscreen will have a greenish tint from the lettuce, especially if you use a dark leafy lettuce instead of iceberg or romaine.

Store in refrigerator since it contains natural food products. This lengthens the freshness & prevents premature spoiling. Keep in cooler if taking with you.

NOTE: The more zinc oxide the higher the SPF. Above amount is about 25 to 30.

Zinc oxide should not be directly inhaled as perfume and new studies have found that zinc oxide does not penetrate into the skin.

Remember . . . spray tans and tinted lotions have chemicals in them to tint the skin.

## Did You Know?



In the United States, a woman has a **1 in 8** chance of developing invasive breast cancer in her lifetime – nearly 50% more likely than in 1975.

NBCC has a plan – through research, access and influence, by January 1, 2020, we will know two key things we do not know today:

1 – **HOW TO PREVENT BREAST CANCER:** Women (men, too) will no longer get the disease (*Think vaccine*).

2 – **HOW TO PREVENT METASTASIS:** Women (Men, too) will no longer die of the disease.

## A Gift

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I was given a gift, wrapped shabbily.  
It was non-returnable, non-refundable!  
Reluctantly I accepted it.

In it I found courage I never knew existed  
And a patience far beyond anything ever experienced.

I was given the ability to trust a stranger with that most dear to me,  
And an endurance for the unknown.

I was given unconditional love of family and friends,  
Always there, never stopping, never faltering.

I was given many prayers from far and wide,  
And the warmth of knowing I am truly cared about.

I was given a fond farewell of my modesty and vanity,  
And the acceptance and love of an imperfect body.

I was given many new friends,  
Wonderful, courageous women I am so very proud to know.

I was given warm sunshine and beautiful green grass,  
Blue skies, and sparkling city lights.

I was given things to see,  
That once before were ignored.

I was given the chance to wake up,  
Instead of sleepwalking through life.

I was given every glorious day to enjoy,  
Every month to savor, every year to rejoice.

I was given the gift of life.  
I was given breast cancer.

**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.cancercares.org](http://www.cancercares.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). Local office: 319-234-0990 – 2709 University Ave, Waterloo

**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](http://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](http://NCCN.org/patients)

**M.D. Anderson Cancer Center**, University of Texas offers patient and cancer information. [www.mdanderson.org](http://www.mdanderson.org)

**Susan G. Komen for the Cure** website offers cancer and social networking information and a newsletter on their website. [www.komen.org](http://www.komen.org)

# Touch of Courage • • • Connection

Cedar Valley Cancer  
Committee  
4756 Charolais Dr  
Waterloo, IA 50701  
[www.beyondpinkTEAM.org](http://www.beyondpinkTEAM.org)

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 address listed.

Name \_\_\_\_\_

Address \_\_\_\_\_

City State Zip

Phone \_\_\_\_\_ E-mail \_\_\_\_\_

I would like to participate with the Beyond Pink TEAM by:

- Willing to write a survivor story for the newsletter
- Volunteer: *(Check all that apply)*
  - Assist with Support Groups
  - Education (Health Fairs/Presentations)
  - Development (Publicity)
  - Advocacy – Deadline 2020
  - Events (Fundraisers, Annual Luncheon, Projects and more)
- Willing to write letters or make phone calls to legislators for breast cancer issues, through the Iowa Breast Cancer Advocacy Network.
- Interested in making a donation. Make checks payable to: Beyond Pink TEAM *(all donations are tax deductible)*
  - BPT Fund
  - NBBC Scholarship Fund
  - Area of Need