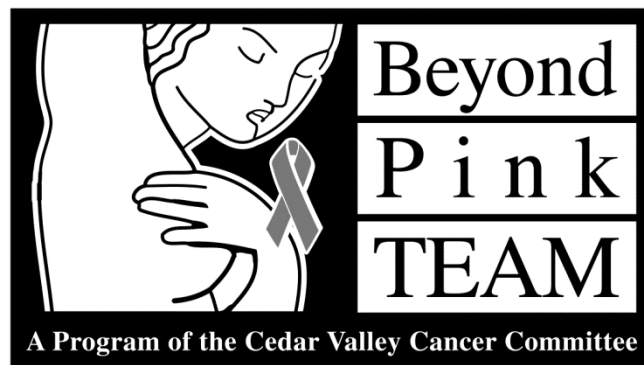


Touch of Courage

. . . Connection

July 2019



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Advocacy - Why And Its Effects

By Christine Carpenter, BPT Advocate, Member of National Breast Cancer Coalition

During and following my treatment for breast cancer I became aware of what really mattered and I discovered an intriguing combination of fragility and inner strength. I was fragile because I realized what I had lost and feared the obstacles that lay ahead. My strength came from determining to do everything possible to make the most out of whatever time I had left. I also started to consider how many women were going through the same thing I was going through and thought of all the women who will go through this - but don't even know it yet. And I thought about my own daughter, and realized that I must channel my fear, anger, and new-found strength into doing what really mattered: ending deaths from this disease.

I joined Beyond Pink TEAM and the National Breast Cancer Coalition (NBCC). Because NBCC is smart, bold, evidence-based, passionate, and systems-oriented in their mission to end breast cancer, they ignited the breast cancer conversations I wanted to have!

Knowing very little about advocacy, influencing Congress, passing

legislation, or creating grassroots networks, I began attending NBCC's annual Leadership Summits and Lobby Day, which take place in Washington, DC in early May.

It wasn't long before NBCC asked Beyond Pink TEAM to do something that really mattered and helped save the lives of many diagnosed with breast cancer. In 1998, 7 members of Beyond Pink TEAM, met with Iowa U.S. Senator Chuck Grassley in his local office, and we asked him to provide leadership to help pass the Breast and Cervical Cancer Treatment Act. Senator Grassley said "yes" and became its champion. It was signed into law in January 2001. Individuals are now Medicaid eligible to receive treatment for breast and cervical cancer even when they don't qualify for a standard Medicaid program, thanks to the efforts of the Beyond Pink TEAM, the National Breast Cancer Coalition, and advocates across the U.S. So Beyond Pink TEAM advocates have made a huge difference in access to care.

Advocacy, continued on page 7, col 1

A Survivor Shares . . . Survivor or Warrior

A survivor's story by Ann Whittemore

When I was asked to write a survivor's story I was honored, however I didn't realize the feelings and reflection it would provoke. The word survivor evokes thoughts of those who have given everything to overcome unimaginable obstacles – in our case, cancer.

I was diagnosed after noticing a lump one Sunday morning in a very conspicuous place. It seemed to have just grown overnight. I surely would have felt it before now: but I hadn't and could only wait and hope. The results would come a week later and it was, in fact, a malignant tumor. I had tried to prepare myself but having lost my parents to cancer and being a mother myself, I realized there is no preparing for the reality of it.

I did have a slow growing cancer which allowed me the time to weigh my options and decide the best course of action for me. I had a mastectomy with reconstruction. My choice was based on two things: to eliminate radiation and the chance of my breast producing another tumor. I felt very fortunate to be able to decide my path. I know that many cancer patients don't get to choose. My post operatory results showed no signs of any cells spreading beyond my breast and that chemotherapy was not needed.

I was blessed in so many ways. I was guided through the countless tests, appointments, and surgeries with the help of some of the most amazing medical professionals. They guided me through this maze when I could barely focus and did it seamlessly. They are the ones I am most grateful

for through all of this. I was given prayers, hugs, smiles, kind words, warm hands to hold, and their reassurance when I needed it most. I will be forever grateful.

I did have the opportunity to sign the breast cancer survivor wall. In some ways I did not feel worthy of it. Yes, I did survive but I know there are so many others who went and are going through so much more to earn the title of SURVIVOR. I have also seen firsthand those who have fought an incredibly noble and difficult battle and did not get to share this celebration of life. I remember them as WARRIORS.

I continue to pray for all the very special people who hold our hands and guide us through the medical mazes, for the survivors who can appreciate every new day of life, and for those who valiantly fought for every minute of new breath. I also pray that a cure will be something I see in my lifetime so that we will not need to be survivors or lost warriors.

Breast Implants

The Food and Drug Administration recently is reviewing the safety of breast implants, which may cause potential health effects and possible cancer.

It is crucial that patients considering reconstruction after a mastectomy to advocate for themselves, ask questions, research and ask more questions.



Living Green

By Patty Wandschneider

NATURAL CLEANERS FOR THE HOUSE

Spring didn't really arrive this year and our homes were shut up with all the rain. So are you ready to do some "Spring/Summer" cleaning? Here are a few recipes for some natural cleaning supplies for your home.

All-purpose Cleaner –

1 quart of warm water
¼ cup baking soda
1 teaspoon vinegar

Wood Polish –

2 parts vegetable or olive oil
1 part lemon juice.
Must refrigerate for storing

Heavy Duty Cleaning (for those tough jobs) –

1 teaspoon baking soda
2 teaspoons of liquid soap (like Castille)
1 gallon of hot water.

If it's a particularly stubborn job, add 1-2 teaspoons of Borax.

Mix all ingredients in a large container and stir. (Do not breathe in the dust.)

Spring Cleaning

When a Parent has Cancer – *Cancer affects not only the patient and their caregiver, but their children.*

When Gynger Ellis was diagnosed with cancer in April 2017, her son, John, a 4th grader, expressed his emotions through the following writing. This was taken just as he wrote it at that time.

Never Stop Believing by John Ellis

Tears fall from my eyes, nothing can comfort me, the whole light of day goes out, a stress in my already stressful life, a thing I never thought would happen, never in a 1,000,000,000 years, the hard truth my mom has CANCER.

"John, Michael, can you come in here," our mom and dad say from the kitchen. Me and Michael rush in and sit at the table, where our mom and dad are sitting.

Then they say it "cancer." As they say that I realize my life and my family's life would be different. I felt sad, my body felt sad, too. My heart sank, I fell off my seat, I was shocked, I never thought.

My mom would have cancer, never in an effort not to cry, I asked, "Is it bad?"

Our mom response with a sigh, "Yes, its bad. Its been growing undetected for maybe 9 months." After hearing that in a mess of tears I ran to my dad and cried into his shoulder and Michael cried into my mom's shoulder. They tried to comfort us, but it was no use. I knew cancer was a BAD thing, a REALLY BAD thing. A thing that makes cells in a person's body go rogue, a thing I hated to see my mom go through. Cancer. Evil Cancer was a thought I had as I left the room trying not to cry.

"Why?" I say as I'm sitting on our back porch with my mom and brother, Michael. "Why? . . . now when we have all these other stresses to deal with." My mom hugged me. I knew she could see the hatred in my eyes of cancer but also sadness dwelling in me that she had it. We sat silent for a while listening to the cool breeze whistling in the wind.

Then Michael piped up, "How did you find out you had cancer?"

Our mom replies with a frown, "A test. A cancer test and it came back positive." With that tears fell from my eyes. Me and Michael hugged our mom. We knew everything would be okay, but how long would it take.

I'm in bed, my mom is beside me. I can't sleep. All I can think about is Cancer, EVIL CANCER. The struggle it's brought to my mom, the sadness it's brought to our family, tears start to slip down my face. I try to go to sleep but I can't. I lean over and hug my mom, she hugs back. I still couldn't sleep. Who could when their mom has cancer? I stayed awake for maybe 20 more minutes. Then fell asleep with one thought in mind, I knew everything would be okay, but would it ever get better.

From crying to hugging. You have to believe the bad will turn good. Even if your having a so so so bad day and it feels like you want to destroy everything or a day where you want to cry a waterfall. But never, I mean never stop believing.

Parents needing support with telling children about a cancer diagnosis can check out the following resources:

www.cancer.org – How to tell children a parent has cancer

www.cancer.net – How a child understands cancer

www.cancercare.org – Helping children when a family member has cancer

Activities - Events - Fundraisers

Supporting the Beyond Pink TEAM



Get your running shoes ready for the **13th Annual Pink Ribbon Run on Saturday, October 5!** For the 5th year, University of Iowa Community Credit Union and Oakridge Realtors 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.

Registration is \$30 with on-line registration beginning mid-July on Beyond Pink TEAM website, www.beyondpinkteam.org. Registrations on or prior to September 20 will include a t-shirt.

Watch Facebook for more details.

September 19 – Single Speed's Pint Night Ride benefiting Beyond Pink TEAM.

Waterloo Start: Registration begins at 5:00 p.m. at Waterloo Bicycle Works (316 W 3rd) with departure at 5:30 p.m. to Bike Tech, Cedar Falls.

Cedar Falls Start: Registration begins at 5:30 p.m. at Bike Tech (217 Washington St) with departure ride to SingleSpeed, Waterloo at 6:15 p.m.

Food, Fun, & Drink: 6:45-8:30 p.m. with 10% of all food & beverage sales at Waterloo taproom (4-10 p.m.) donated to Beyond Pink TEAM.

Mark your calendar for **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 and the October **Touch of Courage** newsletter.

Thank You Donors!!!

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

Tamra Bartlet
Black Hawk County Gaming
Association
Gale Carlson
Cedar Falls Tourism Bureau
Jane Clark

Fredsville Lutheran Church
Gerry Lehne
LSB Foundation
Helen Steffen
Merna Stemmerman
Janet Szklennik

UNI Volleyball
Veridian Credit Union Employee
Satisfaction
Waterloo Black Hawks Hockey LLC
Darren & Sandra Witwer

Beyond Pink TEAM Turned 30!

This is the final article of our three-part series featuring highlights of the Beyond Pink TEAM's work over the last 30 years. If you missed previous pieces, you can view them on our website, www.beyondpinkteam.org.

The first decade of the Beyond Pink TEAM was about the birth and gradual growth of a new organization. The second decade was our teens with lots of exciting changes and growth. Our third decade we came of age.

After awarding financial assistance with the first Beyond Pink Fund grant in 2008, the demand has grown every year. In 2018, we helped 81 individuals with \$67,000.00 for medical and/or essential living expenses during treatment. In the last 7 years we have provided \$382,339.39 for 515 individuals.

The October Pink Ribbon Run has grown each of the 13 years it has been held. This is a major contributor to the Beyond Pink Fund. The Run has led to many other groups raising funds for the Beyond Pink TEAM. The community support has been amazing.

Advocacy work to end breast cancer became a greater focus. We continued to send members to Washington DC each spring for the National Breast Cancer Coalition's (NBCC) Leadership Summit to learn about cutting edge research, legislative issues and prevention of the disease plus visiting with each of our state's representatives and senators.

Our advocacy works. Each year during the past decade, all of Iowa's U.S. House Representatives (both Democrat and Republican) have supported appropriating funds for

the Department of Defense (DOD) Breast Cancer Research Program (BCRP).

We work with Senator Grassley to retain the Breast and Cervical Treatment Act he worked so hard to have signed into law in 2000. This allows the underserved, uninsured to receive treatment when diagnosed.

After many years of supporting the legislative agenda of the National Breast Cancer Coalition, the Beyond Pink TEAM was asked to be a member of their Board of Directors. January 2012 our first three-year term began. We are now serving a third consecutive term.

The 2015 NBCC Advocacy Summit triggered the idea of igniting the cancer conversation in our community. After a year of planning, the first *Ignite the Cancer Conversation* event was held in April 2016. Over 200 interested individuals attended, followed up by a similar event in 2017 and a book club edition in 2018. We are continuing to find new ways to continue this conversation.

Thirty years from now we hope the Beyond Pink TEAM is no longer needed because breast cancer is no longer a health issue. For now we continue to work towards ending the disease yet provide support, education and financial support to those diagnosed until that day comes.

Support Group Dates

July 1, 1:30 p.m.

Touch of Courage

Breast Cancer Support Group

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

July 2, 1:30 p.m.

Care & Share Cancer Support Group

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

August 5, 1:30 p.m.

Touch of Courage

Breast Cancer Support Group

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

August 6, 1:30 p.m.

Care & Share Cancer Support Group

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

August 8

Splash of Color – Women of Color

Breast Cancer Support Group

Cathy – 319-504-2703 for details

September 3, 1:30 p.m.

Care & Share Cancer Support Group

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

September 6, 1:30 p.m.

Touch of Courage

Breast Cancer Support Group

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

September 17, 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

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

Beyond Pink TEAM Advocates SHINE at NBCC Leadership Summit and Washington, D.C.

Six Beyond Pink TEAM (BPT) advocates attended the National Breast Cancer Coalition (NBCC) Leadership Summit and lobby day in Washington, D.C. These ladies are all breast cancer survivors and are dedicated to helping end breast cancer.



Attending the NBCC Leadership Summit were: (L-R) Christine Carpenter, Kristin Teig Torres, Beth Drelich, Lori Seawel, Sarah Corkery, and Traci McCausland.

Traci McCausland received the Sue Witwer Scholarship. She invited Sarah Corkery to share this grant so they both could attend the summit.

The Summit had several days of education and research updates for attendees. BPT advocates were a huge part of the Summit.

Christine has been the Iowa Field Coordinator for the National Breast Cancer Coalition for 25 years. She was asked to be a part of a national plenary panel on *The Politics of Healthcare*.

Assisting with the orientation for new leaders, Kristin was a part of the session, *Finding Your Niche: A Welcome Orientation for New Leaders*.



Lori (R) and Kristin (L) led a workshop

Several workshops were held with one led by Lori and Kristin on *Grassroots Advocacy- Building, Engaging, and Mobilizing Your Network*, sharing how Beyond Pink TEAM is educating and engaging our community about preventing cancer.

The final day of the Summit is "Lobby Day". This is an opportunity for attendees (advocates) to visit offices of our four Representatives and both Senators asking them to support quality health care for all and innovative research through the Department of Defense Breast Cancer Research Program.



BPT members visit with Abby Finkenauer.

The Beyond Pink TEAM advocates work tirelessly to make sure women and men have access to the quality care they need and deserve during their breast cancer treatments. They contact our legislators regularly so they retain the Breast and Cervical Cancer Treatment Act, which Senator Chuck Grassley led through the Finance Committee. It was signed into law in 2000. Beyond Pink TEAM advocates began *Ignite the Cancer Conversation* in 2016 in order to educate and involve our community in efforts to end breast (and all) cancers.



BPT advocates visited Senator Grassley's office.

Follow BPT and Ignite the Cancer Conversation on Facebook for the latest research, updates on legislation and how YOU can advocate.

Advocacy, continued from page 1

Over time, Beyond Pink TEAM members have continued to develop relationships with the members of the Iowa Congressional delegation, and we are proud that most of them have a 100% voting record on National Breast Cancer Coalition priorities.

Why is Advocacy so Important?

You ask why is Advocacy 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 advocacy is so important to ending breast cancer.

My take is that the optimal approach to ending the breast cancer epidemic is problem-solving research. But just throwing money at the current system is taking too long. Much research is based on what will get published or funded, not about solving big overarching problems. So a large-scale impact requires us, patients/caregivers/those touched by breast cancer to be Advocates, because **our** only agenda is to end breast cancer. At NBCC it is not about "my" breast cancer. It is about ending breast cancer for all. As Advocates we have no conflict of interest. The newest drug, the latest early detection device, a particular lab are not my bread and butter. Advocates provide an outside perspective. At NBCC the Advocates' role is to:

- ♦ Challenge: by asking the hard questions
- ♦ Question: everything
- ♦ Collaborate: on meaningful issues
- ♦ Explain: the advocate perspective
- ♦ Report: to our constituencies; and
- ♦ Oversight: to call it "like it is"

So I hope you will join me. You can

start small by joining the Beyond Pink TEAM and the National Breast Cancer Coalition. Start reading Beyond Pink TEAM and NBCC newsletters, explore our websites, and join the Iowa Breast Cancer Deadline 2020 Advocacy Network Facebook Group so, from the comfort of your own home, you can email and/or call Iowa's Senators Grassley and Ernst and Iowa's Representatives Finkenauer, Loeb sack, Axne, and King. Then, if you want to do more, join the Beyond Pink TEAM Advocates currently working to influence the next president of the United States.

NBCC has made informing and influencing the presidential candidates on breast cancer policy a high priority in every presidential campaign since inception. That effort continues for the 2020 election. Beyond Pink TEAM advocates are speaking with the Presidential Candidates as they come to the area. We ask them to show their support for ending breast cancer by signing the NBCC Policy Platform that addresses three important issues:

* **Research:** The federal government must:-

Appropriate sufficient funds annually to support meaningful breast cancer research and develop policies that guarantee transparency, oversight and accountability.

Appropriate \$150 million for FY 2020 and again in 2021 for the DOD peer-reviewed Breast Cancer Research Program.

* **Access:** Health care is a basic human right. The federal government must guarantee that all individuals have access to patient centered, evidence based, high quality and affordable health care.

* **Influence:** The federal government must ensure that trained and educated advocates have a seat at all tables where breast cancer research,

health care and policy decisions are made and implemented.

I recognize that everyone reading this leads busy lives, with what I am sure is an already jam-packed schedule of work, family, church or volunteering commitments—let alone trying to squeeze in a little time for yourself! The thought of one more commitment—or one more meeting—might seem intimidating. Yet your health, and the health of all of our daughters and granddaughters, is at risk. We must do what we can with the time that we have to **End. This. Disease.**

I challenge you to take a bigger role in this movement: take **action**. Little or big, everyone can take action.

- ♦ Join the Iowa Breast Cancer Deadline 2020 Action Network Facebook Group and the National Breast Cancer Coalition's National Action Network.
- ♦ Send an email, post on social media or make a call when an advocacy alert is issued.
- ♦ Schedule a meeting with our senators or Representatives.
- ♦ Gather your friends to attend an NBCC Leadership Summit in Washington, D.C.

Now is the time to become an **advocate** to end breast cancer.

I began telling you about my breast cancer diagnosis, my fear, my anger, and my need as a mom to end this disease. That was 26 years ago, and I am thrilled I've lived to see our daughter graduate from high school and go on to become a physical therapist, marry, and have two of the cutest grandchildren.

My grandchildren provide me with even more motivation. I want to end this disease so my grandchildren can grow up with a dad AND their mother because every child deserves a mother. Will you join me?



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.cancer.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.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

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

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
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Waterloo, IA 50701
www.beyondpinkteam.org